5

Encounters with Bioinformation: Three Examples

5.1 Introduction

At this point in the discussion, I want to step back from theory a little, to examine how the proposition offered in the last chapter – that personal bioinformation has potentially important epistemic and hermeneutic roles to play in embodied narrative self-constitution – stands up when considered in light of people's experiences of encountering bioinformation about themselves. To this end, in this chapter I will examine findings from empirical studies that have gathered data on people's expectations of and reactions to receiving – or, in some cases, not receiving – information relating to their health, bodies, and biological relationships.

To be clear, the objective here is not one of *proving* my hypothesis about the roles played by bioinformation in our self-constituting narratives, much less proving that a narrative conception of identity is an appropriate one. It is not clear that empirical proof of a conceptual and normative picture such as this would be possible. Furthermore, the empirical findings I will draw upon have not been selected in a theory-neutral way, so cannot provide a non-question-begging verification of my hypothesis. Having said this, if the account offered in this book is to make a useful contribution to practical, ethical frameworks that can guide information governance, it must be responsive to, and plausible in light of, the available evidence of how people respond to and use personal bioinformation. So, although this project does not itself use empirical methods, it shares some of the concerns motivating the so-called empirical turn in bioethics. That is, if bioethical arguments are to be relevant and of concrete value in informing disclosure practices, policy, and law, they need to engage with findings from the empirical social sciences about the realities of people's experiences and practices.[1]

[1] For further discussion of approaches to empirical bioethics, see Borry et al. (2004); Hedgecoe (2004).

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The aims of this chapter reflect aspects of what has been termed a 'theorist approach' to empirical bioethics, in which the locus of normative authority lies in the theoretical premises of the enquiry, while empirical evidence is used to sense-check and refine factually based elements of the normative argument.[2]

My first aim in this chapter is to demonstrate that my theory-based position is, at the very least, congruent with people's lived experiences. It is to check that what we know of these experiences supports, or at least does not undermine, the cogency and credibility of the arguments presented in the previous chapter. In order to do so, it must indicate that people do indeed use personal bioinformation to construct or make sense of who they are in ways that are not trivial, wildly anomalous, or vanishingly rare. My second objective is to bring to life and illustrate my central claims about the critical instrumental roles of bioinformation in building our accounts of who we are. Examples from the empirical literature will add texture and detail, moving these claims beyond abstractions. Third, I will use evidence from empirical studies to refine the proposals I have made so far, with the aim of arriving at a more nuanced picture of the extent and nature of impacts of different kinds of information, on different people, and under different circumstances. This, in turn, will also allow me to move beyond discussing personal bioinformation in general terms as a single undifferentiated class, which it plainly is not, by looking at how different kinds and instances of bioinformation may vary in the ways and degrees to which they affect our identities. This will not only allow for greater specificity in what can be said about the narrative roles of personal bioinformation and the normative significance of these roles but also offer insights into reasons for these differences. Each will be key when considering, in the coming chapters, how identity impacts might be addressed in practice.

As introduced in Chapter 1, I will explore findings relating to three categories of bioinformation. These are: information conveying the fact of having been conceived using donor gametes; results from tests for genetic susceptibility to common complex disorders; and neuroimaging findings that purport to provide predictive, diagnostic, or prognostic insights into mental illness. I have selected these examples for a number of reasons. First, on purely pragmatic grounds, these choices have been influenced by the availability of high-quality empirical studies that provide insights into information subjects' attitudes and reactions. Second, these three

[2] Molewijk et al. (2004).

examples are not confined to one kind of information, and each kind differs in the extent to which it conveys reliable or meaningful insights into subjects' health, bodies, or minds. Third, they represent information encountered in different contexts – some are generated in healthcare, some may be available to information subjects in research or commercial contexts, and others may not yet be readily accessible. Finally, each kind of bioinformation has been subject to diverse assertions or repudiations of identity significance. For example, claims about the identity relevance of genetic relatedness and genetic test results have attracted significant scholarly attention in recent years. And, although the potential identity value of knowledge of donor conception is now reflected to some extent in UK law, the reality and nature of this value remain a disputed topic. In contrast, findings derived from psychiatric neuroimaging have attracted markedly fewer discussions of identity impacts. This variety of examples will help us understand not only the possible ways identity impacts may vary but also where all three share common features that may then be generalisable beyond these particular examples.

The findings discussed below are sourced from published empirical social science research. This includes qualitative and quantitative studies, of various sizes and methodologies, encompassing, for example, large multiphased longitudinal studies and small ethnographic projects, as well as systematic reviews. The unifying feature is that they report individuals' expectations of and reactions to receiving, or being denied, bioinformation that pertains to them. In some cases, these studies report the views of other parties, for example, clinicians or parents, where their views reflect or anticipate how information subjects might react. The studies discussed exhibit some limitations and are not representative of all possible information recipients. They are chiefly conducted in the UK, Western Europe, North America, and Australasia, and white and more highly educated participants are often over-represented. And further issues arise from self-selection in some studies, where participants with a particular interest in, for example, undergoing genetic testing are over-represented. These limitations are flagged further below and must be taken into account when considering the generalisability of the findings.

What follows here is not a comprehensive or systematic review and it does not need to be in order to serve the purposes described above. I have drawn upon findings that plausibly speak to the possible impacts of receiving bioinformation – or, in some cases, lacking or being denied it – on individuals' self-narratives. In some studies, though by no means all, investigators have collected or interpreted these findings with the

express research aim of examining effects on recipients' identities. My approach here will be neither to unquestioningly adopt these existing analyses nor to limit my focus to those impacts that investigators or research participants explicitly characterise as identity-significant. Doing so risks tying this inquiry to narrower, or simply different, senses of identity than the narratively-constituted conception with which I am concerned – a conception that, I am suggesting, offers distinct advantages in terms of normative and conceptual robustness and practical applicability. According to the picture outlined in the preceding chapters, our identity narratives are woven from many diverse experiences, characteristics, and activities. Casting the net to include a range of reported reactions, unrestricted by researchers' and – to a lesser extent – participants' different conceptions of what 'identity' means, makes space for a more holistic picture of identity and allows for consideration of the ways that our identities may be significantly affected by shifts in diverse constituent threads. However, I have not taken this as a licence to include every reported fleeting impression or to play fast and loose with participants' own depictions of their experiences. To count as having a potential narrative impact, and thus be included in the illustrative examples below, participants' accounts must imply effects with a degree of stickiness and weight, such that it is reasonable to consider that the information encounter somehow alters, contributes to, or detracts from their account of who they are. As this suggests, the approach taken here to identifying relevant studies and findings is theory-led and purposive, involving the strategic selection of illustrative material, and my analysis of the findings is inferential and interpretive.[3] While this approach entails some circularity, it reflects the reflexive and mutually informing nature of the relationship between what is inferred from evidence of people's responses and the theoretical framing of these in this inquiry.[4]

The remainder of this chapter is divided into four parts. The first three will present findings relating to each of the three different categories of bioinformation in turn and explore each through the lens of a narrative conception of identity. The fourth will draw these analyses together to take stock of what may be gleaned about the diverse ways that different personal bioinformation may contribute to or impact upon our stories of who we are, the variety of roles it may play, and how these observations might lend weight to or require refinement of the picture I have offered so

[3] Bryman 2016.
[4] Chan et al. 2020.

far. The first category of bioinformation to which I will turn is the one that sparked my curiosity and initiated the central enquiry of this book – information about donor conception.

5.2 Illustrative Example I: Encounters with Donor Origins

What Kind of Bioinformation?

The empirical findings to be explored in this section are those reporting people's experiences of learning of and living with the knowledge that they were conceived using donated gametes – that is, sperm or eggs from someone other than one or both of their parents.[5] The personal bioinformation under scrutiny here chiefly concerns the fact of donor-conception, rather than details about the donor.[6] As noted in the opening chapters, donor-conceived individuals' interests – particularly their identity-related interests – in knowing about their 'genetic parentage' has been a topic that has animated academic, legal, policy, and public debates in recent decades.[7] The view that it is in the interests of donor-conceived individuals to be told of their donor origins is now widely, if not universally, held.[8] Nevertheless, as observed in Chapter 2, despite the fact that UK law reflects some recognition of these interests by requiring donor identifiability, scholarly debate continues about the nature and extent of the benefits of knowing to donor-conceived individuals' identities, whether not knowing really leads to harm, and what such harm might amount to.[9]

Before turning to look at the experiences of those who have learned that they were conceived using donor gametes, it will be useful to expand a little on what was said in Chapter 2 about when and how donor-conceived individuals conceived in the UK are currently able to come

[5] Information about donor conception counts as 'personal bioinformation' under the definition set out in Chapter 1 because it is interpreted as being about the origins of an individual's biological existence and their genetic relationships (it has a biological 'interpretive pedigree'), rather than because it is necessarily derived from analysis of biological material or processes.

[6] In various sources, 'information about donor origins' may be used to refer to information about the sheer fact of donor-assisted conception or to descriptive and identifying information about gamete donors themselves. Here, I will concentrate on research relating to the former.

[7] Nuffield Council on Bioethics 2013.

[8] Nuffield Council on Bioethics 2013.

[9] For a dissenting view, see Pennings 2017, and for responses to this view, see Letters to the Editor (2017) *Human Reproduction* 32 (7), 1532–1536.

by this knowledge. As previously mentioned, the identities of donors of gametes used in licensed treatment in the UK are required by law to be recorded and accessible to donor-conceived individuals on request once they turn eighteen.[10] However, making such a request clearly requires knowing, or suspecting, that one was donor conceived. Parents in the UK are not legally obliged to tell their children about their conception, and there is no indication of donor conception on birth certificates as required in some other jurisdictions.[11] Licensed fertility clinics are, however, required by law to advise parents of the importance of telling children early in their lives and to offer parents support in doing so.[12] This follows recommendations of many leading researchers in the field that it is in the interests of children's psychosocial well-being and family relationships if parents begin to talk to children about their donor conception at a preschool age.[13] Public and professional attitudes about the benefits of openness are changing, in line with emerging evidence from social research and social trends towards investing significance in genetic heritage.[14] Nevertheless, it is ultimately left to parents to decide whether and when to tell, and while they are increasingly telling their children, the majority of parents still do not do so.[15] Not all share the view that disclosure is in their children's interests.[16] Many parents report finding it difficult to do so.[17] And stigma associated with infertility and donor conception, as well as concerns about damaging family relationships, are cited as reasons why some families do not disclose.[18] Same-sex and single parents are more likely to tell than heterosexual couples.[19]

Parents are of course not the only possible source of this information. People may find out from other family members or friends, or reach their own inferences, for example by observing differing family traits or when

[10] Human Fertilisation and Embryology Act 1990 (as amended)
[11] Blyth and Frith 2009. In the Australian State of Victoria, birth certificates indicate that further information is held on the register.
[12] Human Fertilisation and Embryology Act 1990 (as amended) s.13(6) and (6c). *HFEA Code of Practice (9th Edition)* (Human Fertilisation and Embryology Authority).
[13] Ilioi et al. 2017; Nuffield Council on Bioethics 2013.
[14] Freeman 2014.
[15] Nuffield Council on Bioethics 2013. As an indication of the proportion of families that disclose, one 2014 study found that by the time children in the participating families were seven, only 29 per cent who had used sperm donors and 41 per cent who had used egg donors had started the process of disclosure (Blake et al. 2014).
[16] Readings et al. 2011.
[17] Readings et al. 2011.
[18] Crawshaw and Daniels 2019; Nuffield Council on Bioethics 2013.
[19] Beeson et al. 2011.

asked for their family medical history.[20] Events such as divorce or bereavement can prompt revelations, and late and unplanned disclosures are not uncommon.[21] Increasingly, unsuspecting individuals are discovering they are donor-conceived accidentally through their own or close relatives' uses of DTC genomic testing services, many of which offer the means to ascertain genetic relatedness or connect with genetic relatives.[22] Individuals with suspicions can also take matters into their own hands by using these DTC services. And the UK Donor Conceived Register provides a route for people to undergo voluntary genetic testing for the purposes of connecting with donors or donor-siblings.[23] Once they reach eighteen, people are entitled to apply to the HFEA to find out if they are donor-conceived.[24] However, for those conceived outwith licensed UK clinics, for example via private arrangements or treatment in other countries, the HFEA will not hold these records. Research and surveys indicate that most donor-conceived people do not know about their donor origins.[25]

Though many of the findings considered below are from studies conducted in the UK, and thus in the disclosure context outlined above, some predate 2005 changes in UK law that required donor identifiability and encouraged parental openness. And some of the studies took place in other jurisdictions with different disclosure policies, including the USA and Australia. Many of the findings are from two prominent longitudinal projects, the European Study of Assisted Reproduction Families and the UK Longitudinal Study of Assisted Reproduction Families, both led by the Centre for Family Research at the University of Cambridge.[26] These studies investigate children's psychological well-being and quality of family relationships at intervals between infancy and adolescence, offering insights into how experiences change with age. Other studies drawn on below include smaller ethnographies, some of which expressly set out to explore identity-related

[20] Frith et al. 2018b.
[21] Daniels et al. 2011; Kirkman 2003.
[22] Harper et al. 2016.
[23] Donor Conceived Register website, www.donorconceivedregister.co.uk/ (accessed 18 July 2021).
[24] Human Fertilisation and Embryology Act 1990 (as amended) s.31.
[25] Tallandini et al. 2016; '2020 We Are Donor Conceived Survey Report' www.wearedonorconceived.com/2020-survey-top/2020-we-are-donor-conceived-survey/ (accessed 18 July 2021).
[26] University of Cambridge Centre for Family Research website 'New Families Research Group', www.cfr.cam.ac.uk/groups/ntf (accessed 18 July 2021).

impacts. Rich though these findings are, they exhibit two limitations relevant to the present inquiry. First, there are inevitable practical and ethical obstacles to capturing the experiences of individuals who are unaware they are donor-conceived. Second, studies in this field often draw participants from networks that facilitate contact between donor-relatives, meaning those particularly invested in understanding their origins may be over-represented.[27]

Information Subjects' Experiences

The following sections highlight findings from the empirical research literature that potentially speak to the roles played by knowledge of their conception in donor-conceived individuals' identity narratives. In order to tease apart potentially different impacts of *discovering* and *knowing* that one is donor-conceived, I will divide these findings according to three epistemic states: those of *not* knowing about one's donor origins; discovering one's donor origins; and living with this knowledge.

What Is It Like Not to Know?

Despite the inherent methodological difficulties of ascertaining the effects of 'not knowing' on donor-conceived individuals, observational studies comparing disclosing and non-disclosing families offer one possible source of insights, and individuals' reflections on their experiences prior to learning of their donor conception are another. The two longitudinal studies mentioned above have, at the time of writing, followed children up to fourteen years old and have found no significant differences in children's psychological well-being or quality of family relationships between disclosing and non-disclosing families.[28] When it comes to retrospective reflections from those who now know, it is not uncommon for participants to report that, before they found out, they felt 'different' from other family members in appearance or character traits or as if their parents were hiding something.[29] For example, one individual reports, 'I'd always known that something wasn't quite right that there was something different about me but I just didn't know what.'[30] Another

[27] Those conceived using donor eggs or embryos may be less well represented in current research. Freeman 2015.
[28] Ilioi and Golombok 2015; Ilioi et al. 2017.
[29] Frith et al. 2018, p. 177; Kirkman 2003; Schrijvers et al. 2019.
[30] Nuffield Council on Bioethics 2013, p. 87.

recalls 'huge parts of my life which seemed somehow wrong but I had no idea why'.[31]

It has been posited that concealing donor conception can itself cause family tensions or affect parents' behaviours in ways that are palpable to their children.[32] For example, one donor-conceived individual reports that this 'created a "shroud of secrecy" and a "sense of shame" something I could sense, but of what I had no real knowledge'.[33]And another reports, 'I sensed that my social father wasn't my biological father and I began asking questions'.[34] Some describe a sense of disconnection blighting their lives or damaging their self-esteem.[35] Others report having experienced a 'disjointed' sense of self.[36] It is possible that some of these recollections are coloured by hindsight or by difficult experiences of discovery.[37] However, these kinds of findings appear consistent across a number of studies, and they cannot be easily dismissed.

What Is It Like to Find Out?

Even if not knowing is not itself experienced as problematic, it leaves open the likelihood of late or unplanned discovery. Reactions to discovery tend to vary markedly by the age at which this happens and the ways in which people find out.[38] The two are often linked, with earlier telling generally managed by parents in planned and incremental ways, while later disclosures are often accidental, revealed by third parties, or precipitated by family crises.[39]

It is not uncommon for parents to report fearing that disclosure will confuse young children or cause psychological problems, but the most common reactions observed amongst those told before reaching school-age are indifference, pleasure, or curiosity.[40] For many, the experience is one of 'always having known'.[41] One teenager remembering being told says, 'I don't think I really minded . . . to be honest . . .

[31] Frith et al. 2018a, p. 176.
[32] Golombok et al. 2002.
[33] Turner and Coyle 2000.
[34] Hewitt 2002, p. 3.
[35] Frith et al. 2018a.
[36] Frith et al. 2018a, p. 176.
[37] Nuffield Council on Bioethics 2013.
[38] Ilioi and Golombok 2015.
[39] Nuffield Council on Bioethics 2013.
[40] Ilioi et al. 2017.
[41] Freeman 2015.

I still don't really care'.[42] Research indicates that, generally speaking, the older someone is, the more difficult the experience of discovery tends to be, and that discovery later in life may cause psychological harm.[43] Those who find out during adolescence or adulthood are more likely to react with shock, anger, distress, or confusion.[44] Participants in several studies report a sense of betrayal that they had been lied to by those close to them, as illustrated by the words of one interviewee who recalls '[s]hock, absolute disbelief, felt I'd been betrayed and lied to all my life'.[45] While another recalls feeling that their 'entire life [had been] based on a lie'.[46]

Sometimes, this shock is related to a perceived loss of family relationships. For example, one participant, who found out when she was forty, says, '[i]t rocked my foundation, it was completely unbelievable. Couldn't believe how naive I'd been for so long. Suddenly I have a void where I used to have a family history and relatives.'[47] Another reports being forced, abruptly and involuntarily, to relinquish her self-conception as the 'biological product of both her parents'.[48] And others describe revelations during medical consultations when it transpired family medical histories did not apply to them.[49] Some describe their experiences explicitly in the language of identity. One individual recalls being 'shocked and surprised. The knowledge presented a whole new way of viewing myself in terms of identity.'[50] Some describe becoming depressed having 'discovered' they were no longer 'the person I thought I was'[51] or being angry because they no longer knew who they were.[52] Others talk of challenges in making sense of their own characteristics. For example, one person expresses the regret, 'I don't know who my dad is, who I am when I look in the mirror, where my son got his cleft chin from'.[53]

[42] Zadeh et al. 2018, p. 1101.
[43] Golombok 2017. Cf. Mahlstedt et al. 2010 found no straightforward correlation between age and experience of discovery. Lucy Frith and her co-authors have also suggested that early disclosure does not necessarily eradicate all difficulties people have in adjusting to the knowledge (Frith et al. 2018a).
[44] Beeson et al. 2011; Turner and Coyle 2000.
[45] Frith et al. 2018b, p. 194.
[46] Turner and Coyle 2000, p. 2045.
[47] Frith et al. 2018a, p. 177.
[48] Turner and Coyle 2000, p. 2045.
[49] Frith et al. 2018b.
[50] Frith et al. 2018a, p. 177.
[51] Kirkman 2003, p. 2229.
[52] Hewitt 2002, p. 3.
[53] Frith et al. 2018a, p. 177.

Not all experiences of disclosure in adolescence or adulthood are negative. Some individuals report curiosity or joy upon learning of their donor conception.[54] Some are excited to gain a new living 'parent'.[55] And, many welcome what they see as explanations for differences in familial characteristics, feelings of non-belonging, or family tensions – of the kinds described above.[56] For example, one individual says that it 'explained so many unanswered questions I had [and] resolved a fog of confusion'.[57] Another one recalls that '[t]he shock made me extremely emotional and I cried a lot. I also felt relief in knowing that I was not imagining things when I felt as though I were different from my parents.'[58] As this illustrates, it is not uncommon for those who learn of their donor origins in their teens or adulthood to describe a mixture of positive and negative reactions – often shock and disorientation upon discovery, followed by feeling 'liberated' or 'relieved'.[59] Here too, participants frequently talk in terms of identity. Several participants in one study describe having to 'reappraise' their identities, framing this as a positive opportunity.[60] A participant in another study describes '[t]he sense of relief of finally having an answer to questions I hadn't vocalised was very welcome'.[61] As we will see in the next subsection, it is often necessary to distinguish between the initial experiences and impacts of learning new information and subsequent experiences of living with the knowledge.

What Is It Like to Live with the Knowledge?

As already noted, longitudinal studies have found no differences in psychological well-being or adjustment between children and young adolescents in disclosing and non-disclosing families, leading researchers to conclude that sheer fact of being, and knowing about being, donor-conceived 'does not create significant difficulties' in these age groups.[62] However, some 'consistent and meaningful' differences emerge when comparisons are made by age of discovery.[63] Disclosure during

[54] Hewitt 2002; Nuffield Council on Bioethics 2013.
[55] Jadva et al. 2009; Kirkman 2003.
[56] Blyth 2012.
[57] Kirkman 2003, p. 2229.
[58] Frith et al. 2018a, p. 177.
[59] Kirkman 2003; Turner and Coyle 2000, pp. 2044, 2045.
[60] Turner and Coyle 2000, p. 2045.
[61] Frith et al. 2018a, pp. 176–7.
[62] Freeman and Golombok 2012, p. 202; Ilioi et al. 2017.
[63] Ilioi et al. 2017, p. 322.

childhood is generally followed by unproblematic accommodation of the knowledge.[64] Parents report children being 'comfortable' or 'unfazed'.[65] Those told before they were seven display higher levels of well-being, often associated with better family relationships.[66] And most adolescents in the UK Longitudinal Study of Assisted Reproduction Families reported feeling indifferent about being donor-conceived, though some found it 'cool' or 'interesting'.[67]

For those that learn of their donor origins for the first time in adolescence or adulthood, anger or confusion may persist, even after any initial shock has passed.[68] For some, this involves negative feelings about *being* donor-conceived.[69] For example, one participant refers to it as a 'shameful secret', albeit one they have come to terms with.[70] And another says that they 'felt like a commodity that has been commissioned ... I genuinely felt that I am different to other people'.[71] For some, their donor conception is central to how they define themselves, marking them out in positive ways, or making them feel 'special'.[72] As one research participant who 'always knew' her origins explains, '[m]y conception is who I am, it is who I will always be, it will never change. ... My hair is black, my parents divorced when I was three, I am an only child, and I was conceived through DI [donor insemination].'[73] However, donor conception sometimes plays no part in someone's self-characterisation, as is the case for the individual who reports, 'I am no different than any other person. How we are born does not make us who we are. I do not define myself by that trait.'[74]

Some kinds of reported identity impacts may be distinguished from the bald adoption or loss of particular labels. Several studies observe that later discovery can precipitate a kind of 'identity crisis', challenging or replacing someone's existing sense of themselves or leaving them feeling as if their identities are incomplete or now contain irreconcilable

[64] Ilioi et al. 2017.
[65] Nuffield Council on Bioethics 2013, p. 56.
[66] Ilioi et al. 2017.
[67] Zadeh et al. 2018, p. 1101.
[68] Beeson et al. 2011.
[69] Jadva et al. 2009.
[70] Frith et al. 2018b, p. 194.
[71] Hewitt 2002, p. 4.
[72] Hewitt 2002, p. 3; Nuffield Council on Bioethics 2013.
[73] Kirkman 2003, p. 2238.
[74] Jadva et al. 2009, p. 1913.

elements.[75] Maggie Kirkman notes that some participants in her study report difficulties reconstructing a satisfying sense of who they are.[76] Lucy Frith and her co-authors encounter similar findings, with participants recalling that they 'found it very hard to come to terms with. It's like a whole half of who I am and my history is just missing', or that '[t]he knowledge presented a whole new way of viewing myself in terms of identity, now having to incorporate the fact that one half of my genetic background was unknown to me'.[77]

However, Frith and colleagues also report a contrasting experience of discovering donor-conception, in which participants describe this knowledge as bringing together disparate parts of their biographies, 'enabling a more coherent narrative to be formed'.[78] Even when discovery is disruptive or distressing, many individuals nevertheless report welcoming the information because it provides a 'better sense' of who they are or explains disparities in appearances or family tensions.[79] This is illustrated by one respondent who explains, '[i]t made sense of my life so far. I was aware that things had not always made sense before I was told. So decisions my parents had made became understandable. It hugely impacted my sense of my own identity and my feelings of self-worth.'[80] And another says, 'I feel that this explained huge parts of my life which seemed somehow wrong but I had no idea why ... [it was] a huge adjustment in my personal feeling of identity, overall positive'.[81]

For many, the significance of knowing about their donor conception lies in the impact it has on their family relationships. Reconfigured family relationships are experienced in both positive and negative ways. For some, knowing about their conception helps them locate their own beginnings in the circumstances and choices of their parents and gamete donors and understand how their own story began. This is illustrated by a Donor Sibling Registry member who says, 'who wants to start a book on Chapter 2? I want Chapter 1, the Introduction and the Prologue as well!'[82]

Several studies have observed that openness about donor conception can enhance relationships, for example, by cementing trust or by

[75] Frith et al. 2018b, p. 194; Turner and Coyle 2000.
[76] Kirkman 2003.
[77] Frith et al. 2018a, p. 177.
[78] Frith et al. 2018a, p. 176.
[79] Blyth 2012; Frith et al. 2018a, pp. 176, 178; Kirkman 2003.
[80] Frith et al. 2018a, p. 176.
[81] Frith et al. 2018a, pp. 176–8.
[82] Ravelingien et al. 2013, p. 259.

providing a 'special bond' in ways that bring a family closer together.[83] In contrast, enduring anger amongst individuals who learn they are donor-conceived in their later teens or adulthood is sometimes directed at parents who are regarded as having lied or prioritised other family members' needs.[84] Some describe their relationships with their parents as permanently damaged.[85] Trust between parents and offspring may be a casualty of later disclosure.[86] Mothers attract a considerable proportion of blame and mistrust, often being viewed, perhaps unfairly, as being chiefly responsible for concealing, disclosing, and discussing this information.[87]

Several studies report participants' feelings of loss and grief at having to relinquish previously assumed relationships or heritage,[88] as illustrated by the respondent quoted above who talks of 'a void' where family connections had once been.[89] However, others describe relief upon learning that they are not genetically related to a parent towards whom they feel antipathy or disconnection.[90] For example, one individual recalls, '[m]y father and I never had a bond really ... In some ways I got some closure from learning the truth because I could finally see that we didn't have a bond for a reason and not because of something I had done wrong.'[91]

Relationships with extended family may also suffer for a number of reasons, including donor-conceived individuals' fears of rejection.[92] Some also inherit the burden of concealing their conception, as illustrated by a research participant who says, '[i]t made me feel distanced from my father's family as I wasn't sure if they would still think of me in the same way if they knew that we weren't genetically related'.[93] These dilemmas and concerns may have intergenerational reverberations – as one respondent reports, 'I feel sorry for my children because they are deprived of a grandparent. I'm also reluctant to discuss my genetic background with them and that perpetuates the secrecy of my

[83] Hewitt 2002, p. 3; Ilioi et al. 2017; Scheib et al. 2003.
[84] Frith et al. 2018b.
[85] Hewitt 2002; Kirkman 2003.
[86] Blyth 2012; Turner and Coyle 2000.
[87] Frith et al. 2018b.
[88] Beeson et al. 2011; Blyth 2012.
[89] Blyth 2012; Frith et al. 2018, p. 177.
[90] Beeson et al. 2011; Jadva et al. 2009; Turner and Coyle 2000.
[91] Frith et al. 2018a, p. 180.
[92] Frith et al. 2018a, p. 180.
[93] Frith et al. 2018a, pp. 180, 181.

origins.'[94] Individuals' views about family secrets may offer glimpses of their own feelings about what donor conception means for their identity, as with the respondent who says, 'I think they should know the truth (then they can care about me for me and not just the person they think I am)'.[95]

Knowing that one is donor-conceived also opens up the possibility of identifying donor relations. Some do not wish to take up this opportunity. But many donor-conceived individuals express excitement at the prospect of meeting, learning more about, or building relationships with their gamete donors or donor siblings.[96] For some, donors may be imagined as 'fantasy parents'; one individual recalls, 'I also felt excited, because it meant I might have a living "father" (my social father died when I was quite young), and half-siblings as well'.[97] Some report positive contact experiences, such as the participant who says, 'I now understand myself a lot better and I feel my four daughters have also gained a great deal from finding members of their biological grandfather's family'.[98]

The ways that individuals interpret and respond to knowledge of donor conception are themselves influenced – for better and worse – by new and changed relationships that follow discovery. Kirkman observes that parents can be important collaborators in helping donor-conceived individuals make sense of what their conception might mean for their identities.[99] However, loss of trust, damaged relationships, fears of rejection, and parents' further unwillingness to talk following disclosure may close-off precisely these kinds of collaborative opportunities.[100] It has also been suggested that having a chance to meet donors or to learn more about them can be a factor in how well donor-conceived individuals are able to reconcile knowledge of their conception with their identities.[101] Similarly, people report valuing opportunities to share experiences with donor siblings.[102] However, for regulatory, practical, or personal reasons, hopes of contacting donors or donor siblings may not always be realisable. And contact is not always a positive experience.[103]

[94] Frith et al. 2018a, pp. 180, 181, 198.
[95] Frith et al. 2018b, p. 196.
[96] Zadeh et al. 2018.
[97] Jadva et al. 2009, p. 1913.
[98] Frith et al. 2018a, p. 182.
[99] Kirkman 2003.
[100] Kirkman 2003.
[101] Blyth 2012; Ravelingien et al. 2013.
[102] Kirkman 2004.
[103] Freeman 2015.

Despite the varied, deeply personal, and sometimes distressing nature of the experiences described above, one finding is particularly striking – several studies indicate a widespread *preference for knowing* that is not straightforwardly correlated with positive experiences of disclosure. For example, in one relatively large study, only 1 per cent of participants said that they wished that they had not found out.[104] Another smaller study found that '[w]ithout exception participants who are adult offspring of donor-assisted conception argued the necessity of developing an identity that accurately reflected their conception'.[105] One such participant reports that despite having to 'redevelop' her sense of identity, she is glad to have found out because 'truth is always better'.[106] And participants in several studies conducted with people who found out in their teens or adult years say they wish they had found our earlier.[107] The widespread importance of knowing – and the specific relevance of this knowledge to identity – is borne out by the Nuffield Council on Bioethics' observation from their 2013 review of evidence and testimony of donor-conceived people that,

> [S]ome have expressed very strongly the view that knowledge of their biological origins, in the sense both of the truth about the circumstances of their conception and of the knowledge of their donor, is essential to both their sense of self and to their social identity: their understanding of 'who they are' and of where they fit in the world.[108]

Through the Lens of Narrative Self-constitution

What inferences can be drawn from these diverse and complex experiences to the possible roles that knowledge of donor conception might play in individuals' narratives of who they are? And what light might this shed on debates about the identity-significance of this particular kind of personal bioinformation? Over the next few paragraphs, I will start to investigate these questions, before bringing them together with lessons from two further illustrative examples at the end of this chapter.

The views reported above indicate that for many donor-conceived individuals, knowledge of their conception has marked impacts on

[104] Jadva et al. 2009. This study had 164 participants, recruited from a network facilitating donor and sibling contact, so those invested in knowing may be overrepresented.
[105] Kirkman 2003, p. 2238.
[106] Kirkman 2003, pp. 2229, 2230, 2238.
[107] Frith et al. 2018a; Hewitt 2002.
[108] Nuffield Council on Bioethics 2013, p. 89.

their understanding of who they are. However, they also demonstrate that these impacts are not inevitable and are not always positive. If we then look closer to examine the specific nature of these impacts, there are some signs that learning of donor-conception can instigate the acquisition or loss of particular *labels* – for example, where recipients come to think of themselves as 'being donor-conceived'. However, perhaps contrary to what one might assume, reports of straightforwad (re)labelling are not prominent amongst participants' recollections. Instead, two of the strongest themes are, first, the ways in which learning of and living with the knowledge of donor conception offers new explanatory or interpretive contexts for experiences of family life, relationships, and traits; and second, the ways that disclosure affects the relational aspects of people's accounts of who they are.

When it comes to the second of these themes, knowledge of donor conception is widely experienced as unpicking or adding new threads to the stories that individuals tell about who they are – for example, with respect to their family heritage, who they are related to, and the qualities of their relationships to others, as well as shifting the range of supporting actors and contributing editors that feature in these stories. Altered relationships are experienced as significant in their own right – as when lost heritage is mourned – but often also play a role in making recipients identity stories more or less intelligible and comfortable to inhabit and enact – for example, by explaining difficult family relationships or by making their own past appear founded on untruths. Changing relationships, such as loss of trust in parents or subsequent contact with donor siblings, are experienced as having consequent effects upon individuals' abilities to make sense of who they are, by removing or introducing opportunities to discuss and reconcile their feelings with significant others. This then often plays into their onward relational and dialogical construction of comfortable, coherent self-narratives in which the fact of their donor-conception may variously play a significant part, or little or no part.

These indications of the relational construction of more – or less – intelligible and comfortable self-narratives point to the wider (re)interpretive and explanatory roles that knowledge of donor conception can play. Here, we may recall the cluster of claims about the narrative importance of knowing about one's genetic parentage introduced in Chapter 2. Several of the personal experiences cited above, particularly with respect to explanations of anomalous traits or feelings of not-belonging, lend weight to Sarah Wilson's suggestion that information

about genetic parentage is valuable when it helps with 'alleviation of uncertainty with respect to the past'.[109] However, the empirical findings indicate that this knowledge does not only fulfil retrospective interpretive roles but can also help make sense of contemporary occurrences and relationships. As Jamie Nelson says, understanding the 'earlier chapters of our lives' can help us 'read well what is going on in the part occurring now'.[110] The empirical findings described above similarly lend some support to David Velleman's claim that recognising similarities between ourselves and close genetic relatives can be valuable for making sense of aspects of our physical embodiment.[111] However, here again, the experiences reported indicate a wider case can be made that it is not only *acquaintance* with donor relatives that can be helpful. Simply knowing about donor conception can sometimes allow individuals to locate themselves in their embodied and relational history. For example, knowledge of donor origins can be useful when it helps fill in the beginnings of recipients' biographies as biological beings and as members of their families, thus helping them (re)conceptualise where they stand within relationships, parental decisions about family-making, and wider family narratives. The empirical literature also provides illustrations of the roles that knowledge of donor origins can play in helping individuals align their own self-narratives with those of their parents and with their families' view of them, and to understand why these accounts have diverged. In other cases, however, these new insights may instead hinder mutual understanding and shared perspectives.

Where these explanatory, grounding, and aligning roles contribute to the internal and external coherence, comfort, and sustainability of recipients' stories of who they are, this may equip recipients better to understand and navigate their embodied lives and relationships and to engage in continued relational self-constitution. As Nelson says, seeing how our lives connect with those of others can bring 'depth and richness to the continuing story in which we participate'.[112] However, it is equally clear that for many donor-conceived individuals – particularly those who discover after childhood – knowledge of donor conception has the opposite effect. Rather than bringing coherence or richness, it upends previously valued and relatively settled or intelligible self-conceptions, resulting in what Eric Blyth calls 'disjunctions in [recipients']

[109] Wilson 1997, p. 285.
[110] Nelson 1992, p. 81.
[111] Velleman 2008.
[112] Nelson 1992, p. 81.

biographies'.[113] As Frith and her co-authors observe of some of their participants, 'the knowledge they were donor-conceived came as a complete surprise and did not fit any previous sense of biography and therefore challenged their sense of identity'.[114] The 'challenge' here may take a number of forms including loss of previously valued threads of self-characterisation, or the introduction of a 'competing' narrative in which central beliefs have been replaced with new, unfamiliar, or unwelcome ones.[115] The above recollections also indicate the particular distress that can arise from occupying a self-narrative that is at odds with others' views of who one is – for example, family members who do not know about one's conception. Thinking about these harms in narrative terms – as arising from disjunction and external incoherence – is consistent with indications that disclosure is less likely to cause distress when it occurs in early childhood, when individuals have the opportunity to develop identity narratives consistent with their donor origins from the start and in ways that are also in harmony with wider family narratives.[116]

It is apparent that the disruptive impacts of late disclosure can have serious and enduring impacts, with some individuals reporting that they have been unable to reconstruct a satisfying account of who they are.[117] These negative consequences must be taken seriously. We cannot assume that personal bioinformation is always beneficial to our self-narratives. However, the experiences reported in the empirical literature, coupled with a narrative analysis, also offer a valuable insight into the possibility that distressing identity *disruption* and identity *detriment* are not necessarily synonymous or coextensive. Freeman, who has herself conducted research with donor-conceived individuals, cautions that '[a]n absence of evidence of psychological "harm" should not be equated with an absence of evidence of psychological "wrong". Conversely, a negative outcome cannot necessarily be equated with a "wrong".'[118] We could substitute 'identity' for 'psychological' here while also further characterising the nature of the wrong involved. When identity is seen as constituted by a responsive, evolving, diachronic narrative, we can understand how the possibilities for identity impacts extend beyond the bald options of preservation or destruction. We can also appreciate why it is important

[113] Blyth 2012, p. 10.
[114] Frith et al. 2018a, p. 177.
[115] Frith et al. 2018a, p.177.
[116] Freeman 2014.
[117] Kirkman 2003.
[118] Freeman 2015, p. 60.

to distinguish between experiences of *discovery* and those of living with or without the information. A narrative perspective allows us to recognise that initial disruption, even of a profound and painful kind, may sometimes be resolved into – or even serve – a longer-term identity benefit in terms of narrative intelligibility and resilience. For example, this may be the case where, despite initial distress, someone comes to value the opportunity to re-evaluate and adjust their account of who they are, now equipped with fresh insights into their parents' choices or inherited traits. Conversely, we can understand how non-disclosure could place the *future* comfort and coherence of someone's self-narrative in a vulnerable position of probable, non-trivial jeopardy from late discovery, even when the prior state of 'not knowing' is not itself distressing.

I want to suggest that the kind of latent harm characterised in this last scenario lies in the construction of what Kirkman terms a 'misleading identity', based on ignorance of donor origins.[119] It might reasonably be objected that there are infinite facts about our lives of which we are unaware without being *misled* about who we are.[120] However, in this respect, ignorance of donor conception differs – not because this knowledge is intrinsically essential to our identities but because, where it is the norm for one's social parents also to be one's genetic ones, and in the absence of information to the contrary, most people would assume this is true of their family.[121] In the case of donor-conceived individuals, this assumption would be, at least partly, false. And, as noted in the previous chapter, it is the risk of building one's identity around an unrecognised false belief, rather than the omission of particular facts, that is the relevant potential source of identity harm here.[122] The ethical dimension of this difference comes into sharp focus when we think of our identity narratives as the interpretive frameworks on which we depend for making sense of and navigating our practical lives, frameworks that could serve us poorly if premised on falsehoods.

Before closing this exploration of reported experiences through the lens of narrativity, I want briefly to return to respond to worries that the kind of identity significance I am positing here is after all synonymous with an essentialised view of identity. My intention here is not to claim that knowledge of our genetic parentage is essential to a 'complete' or

[119] Kirkman 2003, p. 2238.
[120] de Melo-Martín 2014.
[121] Shaw 2006.
[122] Lillehammer 2014.

'true' identity. As the Nuffield Council is careful to point out, when donor-conceived individuals invest knowledge of their conception with identity significance, this cannot automatically be read in geneticised terms, '[i]t should be understood, rather, much more broadly in terms of their own story, including their biography, background and family connections'.[123] This highlights an important and subtle point – that a useful and necessary distinction can be drawn between identity-significance that *tracks* genetic connections and identity-significance that is *reducible* to genetic heritage. For example, when research participants report welcoming knowledge of their conception because it allows them to make sense of discrepancies between family traits, this does not necessarily mean that they take inherited characteristics as wholly defining who they are. Rather, it may signal that they welcome the opportunity to understand how these traits fit into a story that starts in a particular way and incorporates various kinds of relationships to and commonalities with others. They value the fresh perspective, on their lives and characteristics, provided by this knowledge and the ways in which, in Velleman's terms, this 'encode[s] one's appreciation of meaning in the events of one's life'.[124] As Maggie Kirkman observes, in applying a narrative framing to the findings from her own empirical research, '[f]amily stories of birth and conception, stories of "how our family came to be", are fundamental to the idea of narrative identity'.[125]

As to the many expressions of a desire to know 'the truth' – some participants might indeed mean the truth about 'who they really are', with all the genetic essentialism this implies. However, again, such a desire need not be intended or interpreted in this way, but rather as a wish to understand the circumstances in which their life and family relationships came to be, or the wish not be left in the dark – much less deceived – about these aspects of their biography. Interpretation of donor-conceived individuals' experiences through the lens of narrative self-constitution can help us make sense of this significance without recourse to essentialism. We need neither assume essentialism is present in the attitudes of donor-conceived individuals nor utilise this as an explanatory tool ourselves. Before I can attempt to draw wider conclusions about the generalisability of the analysis offered here to other categories of personal bioinformation, or consider which refinements

[123] Nuffield Council on Bioethics 2013, p. 14.
[124] Velleman 2005, p. 375.
[125] Kirkman 2003, p. 2231.

might be required to the conceptual and normative picture drawn in the previous chapter, I want to look to two further illustrative examples.

5.3 Illustrative Example II: Encounters with Genetic Risk

What Kind of Bioinformation?

This second illustrative example looks at findings from empirical studies reporting individuals' expectations of and reactions to receiving results from genetic testing for susceptibility to serious, complex disorders. The two kinds of tests to be looked at here are those for variants of the Apolipoprotein E (*APOE*) gene associated with an elevated risk of late-onset Alzheimer's disease and tests for genetic mutations on the *BRCA1* and *BRCA2* genes associated with higher risks of breast and ovarian cancers. The E4 variant of the *APOE* gene is believed to be a 'robust risk factor' for late-onset Alzheimer's disease in some populations.[126] The *BRCA* mutations are responsible for significantly elevated lifetime risk of developing hereditary forms of breast and ovarian cancer in female carriers and breast and prostate cancer in men.[127] Both late-onset Alzheimer's disease and breast and ovarian cancers are multifactorial disorders, meaning they are not caused by a single gene but by interactions between multiple genetic and environmental factors. They may also occur in the absence of the genetic variants in question. So a 'positive' result – indicating that the person tested is a carrier of the variant associated with higher susceptibility – provides an estimate of an individual's predisposition to the disease, rather than being straightforwardly predictive.[128] And a negative test result does not rule out risk. As in the previous example, before turning to people's experiences, I will review the current availability of *APOE* and *BRCA* testing in the UK, bearing in mind that this sits within the wider landscape of access entitlements reviewed in Chapter 2.

[126] Having one copy ε4 variant of the *APOE* gene is thought to increase the risk of Alzheimer's disease to about three times that of the general population, while two copies increase the risk between eight and thirty times. There is variation in the association between the ε4 allele and late-onset Alzheimer's in different ethnic groups (Farrer et al., 1997).

[127] A previously unaffected woman testing positive as a carrier of the *BRCA1* mutation has a 60–90 per cent lifetime risk of developing breast cancer and a 40–60 per cent lifetime risk of developing ovarian cancer, compared with a general population risk of 12.5 per cent for breast and 2 per cent for ovarian cancer (The Royal Marsden NHS Foundation Trust, 2016).

[128] A *BRCA*-positive result is more strongly predictive than one for relevant *APOE* variants.

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There are ongoing clinical and ethical debates about the relative harms and benefits of – and thus justifications for – offering genetic testing for serious multifactorial conditions, particularly if there are no effective preventative or therapeutic options or where there are risks of over-diagnosis. These debates have traditionally focused on clinical actionability as the chief desideratum. And there are long-standing assumptions that uncertainty – for example, arising from probabilistic findings or unclear prognoses – is likely to cause psychological distress, which may be both greater and harder to justify in the absence of therapeutic options.[129] A central aim of this project is to demonstrate that treating the ethical considerations relevant to such decisions solely in terms of a balance between clinical utility, physical harm, and psychological distress is to work with an incomplete ethical palette. This second illustrative example offers an opportunity to explore whether identity should be part of the picture when instituting genetic screening policies – not only part of subsequent approaches in genetic counselling – and also to contribute to the conceptual and ethical debates about the identity-related impacts of genetic testing introduced in Chapter 2.

In accordance with National Institute for Health and Care Excellence (NICE) guidelines, *BRCA* screening in the UK is offered only to adults with a family history of breast or ovarian cancer and a genetic relative who has tested positive for a *BRCA* mutation.[130] These cancers are sometimes treatable, and surveillance and preventative interventions, such as prophylactic surgery, may be available to those testing positive.[131] By comparison, *APOE* testing has relatively low predictive strength, and there are no effective preventative measures or treatments available for Alzheimer's disease.[132] Clinicians and Alzheimer's advocacy groups, therefore, recommend against provision of *APOE* testing altogether.[133] However, as noted

[129] Parens and Appelbaum 2019.

[130] *Guidelines: Familial Breast Cancer: Classification and Care of People at Risk of Familial Breast Cancer and Management of Breast Cancer and Related Risks in People with a Family History of Breast Cancer (Cg164)* (National Institute for Health and Care Excellence, 2013, updated 2019).

[131] *Guidelines: Familial Breast Cancer: Classification and Care of People at Risk of Familial Breast Cancer and Management of Breast Cancer and Related Risks in People with a Family History of Breast Cancer (Cg164)* (National Institute for Health and Care Excellence, 2013, updated 2019).

[132] Atkins and Panegyres 2011.

[133] Alzheimer's Research UK, 'Genes and Dementia' (2014); Alzheimer's Society website, 'Genetic Testing', www.alzheimers.org.uk/info/20091/what_we_think/153/genetic_testing (accessed 18 July 2021).

in Chapter 2, tests for both *APOE* and *BRCA* mutations are available, without restriction, through DTC genomic services.[134] Two further key routes by which someone might find out their carrier status for particular genetic variants are through individual findings from genomic research or from the status of close genetic relatives. Clinical actionability and the seriousness of the condition are likely to be key to professional and legal decisions about the requirement to communicate risk findings in each of these circumstances. So, while it is not possible to say definitively, it is somewhat more likely that someone might learn of *BRCA*-positive status than of *APOE*-related Alzheimer's risk in research contexts or from family members. Of course those tested may share their results with family members without this being a legal obligation or on the advice of a clinician.

The views discussed below are drawn from published social science studies that used a range of methodologies to investigate the attitudes and reactions of individuals to the prospect or experience of receiving susceptibility estimates based on genetic testing. Most of these studies collected data on some combination of psychological, social, and behavioural effects. The views of *APOE* testing for Alzheimer's susceptibility discussed below are chiefly drawn from the US-based REVEAL study.[135] The phases of this large, longitudinal study discussed here comprised a series of randomised clinical trials involving asymptomatic adults with first-degree relatives with late-onset Alzheimer's disease.[136] The study aimed, inter alia, to investigate the psychological and behavioural effects of receiving genetics-based risk estimates for Alzheimer's from tests conducted as part of the study and the effectiveness of different genetic counselling approaches.[137] The findings relating to *BRCA* testing for susceptibility to breast and ovarian cancer discussed here come from a wider range of, often smaller, studies and from systematic reviews. All the participants were women, some with prior cancer diagnoses, who had undergone *BRCA* testing in clinical settings. Most of these studies did not set out to investigate identity-related effects directly. Limitations of these sources for my current purposes include over-representation amongst participants of people willing to undergo testing and a lack of socio-economic and ethnic diversity.[138] There are also possible pitfalls in

[134] See, for example, '23andMe Genetic Health Risk Reports: What you should know' www.23andme.com/en-gb/test-info/genetic-health (accessed 18 July 2021).
[135] Roberts et al. 2005.
[136] Roberts 2012.
[137] Roberts et al. 2011.
[138] Roberts et al. 2011.

attempting to generalise from findings relating to particular tests for susceptibility to conditions with particular characteristics.[139] The inclusion of views about both *APOE* and *BRCA* testing will go some way to mapping possible points of commonality and divergence.

Information Subjects' Experiences

In the following sections, I bring together findings that plausibly speak to the impacts of test results on recipients' identity narratives, dividing the findings into two parts. The first will look at the expectations and motivations of participants who have not yet received test results or are recalling their feelings prior to receipt. The second will review reactions to encounters with test results and subsequent experiences and behaviours. This division will allow reflection on the extent to which actual impacts of tests results match people's expectations. I will return in the next chapter to consider the reasons behind divergences in people's attitudes and reactions to different types of testing.

Motivations and Expectations

Many participants in REVEAL report that their motivation for taking part in the study was a bald desire to know their risk status and many felt broadly positive about this prospect.[140] All REVEAL participants had a family history of Alzheimer's.[141] Several report that because of their family history, they were 'scared to death' that they were 'already doomed' to a future with the disease or feared they were already exhibiting signs of impaired memory.[142] Many view genetic testing as a possible means of coping with or taking control of a suspected, though unquantified, risk of inherited disease by confirming or dispelling such fears.[143] One motive commonly cited is to 'put my mind at ease'.[144] Others report the hope that knowledge will equip them with a kind of power, even in the absence of effective preventative or treatment options.[145] For some, the sheer act of participating in the REVEAL study offers a sense of purpose and way of dealing with

[139] Wade2019.
[140] Hurley et al. 2005.
[141] Roberts et al. 2005.
[142] Hurley et al. 2005, p. 379.
[143] Lock 2008.
[144] Christensen et al. 2011, p. 412.
[145] Gooding et al. 2006.

uncertainty.[146] Mitigating uncertainty similarly emerges as a common theme amongst motivations for *BRCA* testing, with participants in one study reporting that 'knowing gives you more control', and 'the more I know, the more I can help myself'.[147] A participant in another study, who had a history of breast cancer but had not had prophylactic surgery, explains that 'obviously I hope I'm negative. But I'd much rather live with the knowledge of knowing that I'm positive and that I'm doing everything I can to give myself the best chance, than to live with uncertainty.'[148] It has been suggested that even when someone knows they have a family history of cancer or Alzheimer's, they may nevertheless look to genetic testing for a source of 'credible' information, with the authority to overturn or confirm their assumptions.[149] However, as we will see below, reality may be more complicated than this.

Many participants in REVEAL anticipate that their personal risk estimates will be of practical use.[150] Some of this anticipated utility is directly health-related, for example where it was hoped that test results will open avenues to specialist health advice or act as incentives to take up behaviours purported to be protective.[151] And some want to be prepared in case genuinely effective preventive or therapeutic interventions for Alzheimer's become available.[152] Practical motivations also extend beyond health protection. REVEAL participants talk in terms of 'getting things in order', where these 'things' include personal and financial affairs, for example purchasing long-term care insurance.[153] Holly Gooding and her co-authors report that the most common reason given by participants for pursuing genetic testing was to 'better plan for other problem-focused coping efforts, like financial planning and completing advance directives. This focus on taking concrete actions may help people exert some sense of control over an uncontrollable disease like AD.'[154]

Some REVEAL participants cite less specific, but nonetheless future-focused, reasons. One participant says if she was to learn that she was at high risk of Alzheimer's, '[t]here are some things that I haven't done that

[146] Hurley et al. 2005; Lynch et al. 2006.
[147] d'Agincourt-Canning 2006, pp. 104–105.
[148] Hallowell et al. 2004, p. 558.
[149] Roberts and Uhlmann 2013, p. 1225.
[150] Hurley et al. 2005.
[151] Hurley et al. 2005.
[152] Roberts et al. 2003.
[153] Gooding et al. 2006, p. 264; Hurley et al. 2005.
[154] Gooding et al. 2006, p. 265. AD refers here to Alzheimer's disease.

I might want to start doing'.[155] Meanwhile, others are motivated by opportunities for reflection or reprioritisation. For example, one participant reports that the information could be useful for 'see[ing] where I am at', and another wonders, 'maybe it will make me look at my life in a different way'.[156] Nina Hallowell and her co-authors observe, that for the most part, participants in their study with existing cancer diagnoses were less motivated by planning for their future health than understanding their past.[157] A substantial number report seeking testing to obtain 'an explanation for why they had developed cancer'.[158]

Another prominent theme amongst participants' motivations is obtaining susceptibility information for the direct benefit of others or to inform their own other-affecting decisions. Many in the REVEAL study report seeking *APOE* testing because of their feelings of responsibility for or commonality with family members who had experienced Alzheimer's or who could be at risk.[159] The desire to prepare family members for future caring responsibilities and financial burdens was another significant motivator amongst REVEAL participants.[160] It has been suggested that female participants were more likely to want to know their susceptibility because of their experiences of caring for affected relatives.[161]

Similar altruistic or relational aims were evident in the context of *BRCA* testing, where individuals talk about seeking testing to help close relatives or to contribute to research.[162] Lori d'Agincourt-Canning notes that participants in her own study 'did not view their decision to seek [*BRCA*] testing in isolation from everyone else. Rather, obtaining genetic information allowed them to express their identity as embodied selves as well as selves-in-relation.'[163] Hallowell and her co-authors observe that all thirty participants in their study said that they sought testing to provide family members with information to help plan their futures. Enactment of relational roles and concerns is also indicated by the age at which *BRCA* testing is sought, with one study finding that participants were more likely to seek testing around the age their mothers were

[155] Hurley et al. 2005, p. 378.
[156] Hurley et al. 2005, p. 378.
[157] Hallowell et al. 2004.
[158] Hallowell et al. 2004, p. 558.
[159] Lock 2008.
[160] Chilibeck et al. 2011.
[161] Roberts et al. 2003.
[162] Foster et al. 2009; Hallowell et al. 2003.
[163] d'Agincourt-Canning 2006, p. 113.

diagnosed.[164] This study also found that being a parent was associated with earlier testing.[165] Responsibility for relatives is similarly present in choices *not* to be tested, with participants worried that their own positive result might make their family members feel, in one participant's words, 'almost like a person who's been diagnosed'.[166]

A wish to contribute to Alzheimer's research emerges strongly amongst REVEAL interviewees, with many citing the desire to reciprocate indirectly for the care that their relatives had received or to express solidarity with other affected families as their reasons for participating.[167] Similar motivations have been observed in those undergoing *BRCA* testing. D'Agincourt Canning argues that decisions about being tested are not motivated by solipsistic concerns but rather call upon the individual to exercise the moral aspects of their identity.[168] These observations echo findings about motivations for taking part in medical research more generally, in which individuals may characterise participation as an expression of their moral values, where the values expressed might include, for example, concern for the wellbeing of specific family members or the desire to support scientific knowledge as a broader, public good.[169]

The nature of the studies reviewed here means that they disproportionately represent the views of those willing, even keen, to be tested. However, less enthusiastic attitudes do also emerge. Some REVEAL participants declined to be tested on the grounds they believed they would not benefit from or cope well with the findings. For example, one participant worries that the test results would drive them 'crazy' and that 'sometimes a little knowledge is too much'.[170] While another says, 'I don't want any more bad information. This is all I can handle. And I'm healthy, so I'm all set.'[171] Similar reasons for declining testing are also evident in *BRCA*-focused studies.[172] For example, one participant worries 'cancer [would then become] this consuming thing in your life'.[173] In

[164] Hesse-Biber and An 2016.
[165] Hesse-Biber and An 2016.
[166] d'Agincourt-Canning 2006, p.111.
[167] Christensen et al. 2011; Hurley et al. 2005.
[168] d'Agincourt-Canning 2006.
[169] See Hallowell et al. 2010.
[170] Gooding et al. 2006, p. 264.
[171] Gooding et al. 2006, p. 264.
[172] d'Agincourt-Canning 2006.
[173] d'Agincourt-Canning 2006, p. 110.

another study, participants were sceptical that available clinical options would compensate for the anxiety of being tested.[174]

Reactions and Responses

Between being asked about their motivations and receiving their test results, REVEAL participants underwent counselling and education about *APOE* testing that highlighted the weak predictive strength of the tests and the multifactorial nature of Alzheimer's risk.[175] This may partially explain a prominent finding of a 'slight discordance' between how participants expected they would respond to learning of their risk of Alzheimer's and how they actually reacted.[176] The most noted aspect of this discrepancy is that in many cases – contrary to participants' expectations – test results failed to supplant their prior perceptions of their inherited risk or to provide an end to uncertainty.[177] Some participants discounted the evidence of their low risk estimates. For example, one interviewee is reported as saying, '[s]o technically I should feel better. But I don't believe it.'[178] Some who had received high risk estimates reacted with equanimity, viewing their results as 'nothing new' to worry about.[179] Accurate recall of results was also patchy. Even where participants could recall which *APOE* variant they carried, many could not explain its risk significance.[180] The educational materials and counselling received by REVEAL participants are thought to have contributed to tempering reactions to results.[181] In addition, Gillian Chilibeck and colleagues suggest recipients' lay beliefs about the causes and nature of Alzheimer's were often 'actively mobilized' to help make sense of the science.[182] As Margaret Lock describes it, '[r]isk estimates provided in the REVEAL study rarely displace "lay knowledge" that participants bring with them . . .. Rather this "scientific" information is either nested into pre-existing knowledge, simply forgotten, or even actively rejected.'[183]

[174] Esplen et al. 2009.
[175] Christensen et al. 2011. Participants were divided into groups, each of which received counselling and education materials of varying degrees of detail.
[176] Christensen et al. 2011, p. 413.
[177] Lock et al. 2006.
[178] Lock et al. 2006, p. 292.
[179] Lock et al. 2006, p. 292.
[180] Eckert et al. 2006. For example, only around half of the participants remembered the general gist of their risk estimate after a year.
[181] Christensen et al. 2011.
[182] Chilibeck et al. 2011, p. 1771.
[183] Lock 2008, p. 75.

The personal significance of the *APOE*-based risk estimates was not, however, totally obviated, as discussed below.[184]

There are similar indications that existing beliefs about cancer risk can prove resistant to new information. For example, some recipients' presumptions of being at high risk persisted despite negative *BRCA* results.[185] And others continued to feel vulnerable in their liminal 'lower risk' status – neither eligible for follow-up screening nor wholly free from risk.[186] Hallowell and her co-authors report that amongst most of their participants, all of whom had existing diagnoses, *BRCA* test results had little impact on perception of their risk or existing sense of fatalism about future health.[187] These authors also observe that 'the majority of women in [our] study were able to accommodate the information that they are/may be at genetic risk of cancer into their biography and maintain their forward trajectory'.[188]

When it comes to practical and behavioural responses to receiving test results, REVEAL participants again described making fewer changes than they had anticipated.[189] Results indicating elevated risk did prompt some to purchase or change their long-term care insurance or adopt what they perceived to be protective health behaviours.[190] In contrast – perhaps unsurprisingly, given greater availability of risk-reducing interventions – receipt of positive *BRCA* tests often led to behavioural changes including increased uptake of prophylactic surgery and screening or lifestyle adjustments, such as changed diet or smoking cessation.[191] Perhaps more surprisingly, these changes were not limited to those found to be *BRCA*-positive.[192] One study found that variability amongst women choosing to pursue screening or surgery depended more on personal circumstances, such as feelings of guilt or vulnerability and availability of social support, than on sheer facts about their health.[193]

One of the headline conclusions from the REVEAL study is that the long-held assumption that probabilistic susceptibility testing will cause distress and anxiety, particularly in the absence of clinical options, was

[184] Christensen et al. 2011.
[185] Roberts 2012.
[186] Scott et al. 2005.
[187] Hallowell et al. 2004.
[188] Hallowell et al. 2004, p. 560.
[189] Christensen et al. 2011.
[190] Gooding et al. 2006; Roberts 2012.
[191] Lim et al. 2004; Lynch et al. 2006.
[192] Heshka et al. 2008.
[193] Hesse-Biber and An 2016, p. 987.

not substantiated by the findings.[194] Many participants – not only those at low risk of Alzheimer's – reported relief and reduced distress.[195] Studies looking at *BRCA* testing have reported similar findings. For example, one found 'a generally low level of potential distress' and an 'overwhelming positive attitude toward genetic testing'.[196] Perhaps surprisingly, several studies have noted a lack of straightforward correlations between positive test results for *BRCA* and distress, or negative results and relief.[197] Though increased levels of distress or anxiety and 'turmoil' were commonly observed at the time of *APOE* and *BRCA* testing itself, this was seen to dissipate, with few suffering enduring psychological harm.[198] One large review looking at the psychological impacts of receiving genetic information about diverse kinds of disease risk concludes that negative reactions are, on the whole, minor and transient, while nevertheless cautioning that more serious negative psychological reactions, though rare, should not be ignored.[199]

It would be a mistake to assume that all notable reactions to test results can be reduced solely to either practical risk management or distress. Many report broader changes in attitude or outlook, and often positive ones. For example, mutation-positive *BRCA* tests are described by some as 'life-changing' or leading to a 're-evaluation of priorities'.[200] Some participants are glad to know so that they can undertake 'important and positive life changes' or prepare emotionally for future changes in their health.[201] Several studies report participants who received negative *BRCA* results as experiencing relief or a 'renewed appreciation for life', or as feeling like they were finally being 'part of the normal population'.[202] Similarly, *APOE* testing was often found to facilitate what REVEAL researchers refer to as 'emotion-focused coping strategies', helping participants address uncertainty and make plans in awareness of possible risk.[203] Echoing the views expressed by donor-conceived individuals, genetic test results are frequently welcomed for the sheer knowledge they convey or are perceived as conveying. For example, one

[194] Roberts 2012.
[195] Christensen et al. 2020; Lock et al. 2007.
[196] Lynch et al. 2006, p. 95.
[197] Hallowell et al. 2004; Mella et al. 2017.
[198] Bemelmans et al. 2016; Lim et al. 2004, p. 129.
[199] Wade 2019.
[200] Esplen et al. 2009, p. 1217.
[201] Esplen et al. 2009, p. 1217; Lim et al. 2004, p. 129.
[202] Butow et al. 2003; Esplen et al. 2009, p. 1217; Lim et al. 2004, p. 122.
[203] Gooding et al. 2006, p. 265.

individual undergoing *BRCA* testing reported simply wanting to know 'what's going on with my body'.[204] Meanwhile, a REVEAL participant expresses the view, '[k]nowledge is power . . . I don't think you can necessarily change your destiny, but certainly to go through life with your eyes only half open doesn't help you at all'.[205]

However, more negative reactions are also seen. Some receiving negative *BRCA* results report feeling numb, dislocated, or guilty about having 'escaped' a threat faced by family members.[206] Meanwhile, others who had not previously considered a genetic dimension to their cancer react to positive results as if receiving a new diagnosis, finding it hard to imagine their future or come to terms with their risk status.[207] One such participant regretfully reports, 'I would much rather not know that I had the gene . . .. It's part of your life all the time with the gene.'[208] The researchers suggest that in these cases, 'the risks of unknown cancers are perceived as presenting an explicit threat to self'.[209] One participant in another study reports, '[s]ometimes I think of myself as *healthy, but doomed*. I don't think of myself as sick, or as a mutant, but as healthy, but on the edge, *healthy, but with a curse*. . . .. It's unpleasant. It doesn't enter into everything I do – all of my functioning or everyday life – but just sort of hangs there.'[210] This kind of reaction takes on a notably concrete dimension in the context of *APOE* testing. In one study, researchers observed that despite being informed of the predictive limitations of *APOE* testing, participants who knew they had tested positive for the *APOE* genotype associated with increased risk of Alzheimer's not only underestimated their performance in memory tests but actually performed worse in them.[211]

Amongst the long-recognised, detrimental effects of receiving a positive *BRCA* test result are negative self-perceptions and stigma.[212] Some carriers report feelings of alienation or of being 'different' as a result of learning they had 'a defective or altered gene'.[213] A participant on one study describes how they feel as if '[t]here's something wrong with me that's not even physical – it's like my body or the

[204] d'Agincourt-Canning 2006, p. 106.
[205] Lock et al. 2006, p. 290.
[206] Esplen et al. 2009; Lim et al. 2004.
[207] Hallowell et al. 2004.
[208] Hallowell et al. 2004, p. 561.
[209] Hallowell et al. 2004, p. 561.
[210] Klitzman 2009, p. 884 (italics in source).
[211] Lineweaver et al. 2014.
[212] Vodermaier et al. 2010.
[213] Vodermaier et al. 2010, p. 10.

blueprints of my body don't work well'.[214] These feelings can extend to recipients' body image by, for example, undermining their confidence and trust in their bodies, causing them to see themselves as 'mutants', 'damaged goods', or reproductively 'impaired'.[215] Stigma and fatalism are not, however, universal amongst those who learn they are *BRCA* positive. For example, one research participant says, 'I don't feel I'm a "sick person". I feel I'm very healthy. I know women who say, "I have cancer". I never thought like that. I don't look at myself as being sick. I go for my check-ups, but it definitely doesn't affect my everyday life.'[216]

Recognition of the need to capture the kinds of impacts just described led one group of Canadian researchers to develop 'The *BRCA* Self-Concept Scale', a validated, evidence-based tool to be used in counselling and research that measures effects of *BRCA* testing across a number of dimensions, including self-esteem and stigma.[217] Studies using this scale are able to go beyond observations of distress amongst those testing positive to deliver more nuanced findings. For example, one study found that higher existing levels of 'self-esteem' and 'self-mastery' were associated with less anxiety upon receiving results, and that feelings of stigma were closely correlated with distress, with younger carriers experiencing higher levels of both.[218] The authors speculate this finding may be attributable to younger recipients experiencing a positive test result as derailing unrealised life goals.

Impacts on familial roles and responsibilities emerge strongly in the *BRCA*-related research, as do the parts played by familial roles in shaping the personal significance of test results. As noted above, for many, seeking testing represents a way of enacting care and responsibility for close relatives. However, for others, positive results are experienced as undermining precisely these roles.[219] For example, because of the risk of passing on the mutation, some parents felt guilt upon testing positive or as though they had failed to fulfil the role of a parent as protector of their children's well-being.[220] The effects of surgery and feelings of 'impairment' following a positive result can also impact negatively on people's feelings about parenting and reproductive choices.[221] In some contrast, researchers on

[214] Klitzman 2009, p. 885.
[215] Esplen et al. 2009, p. 1217; Klitzman 2009, p. 886.
[216] Klitzman 2009, p. 883.
[217] Esplen et al. 2009.
[218] Vodermaier et al. 2010.
[219] Underhill et al. 2012.
[220] Lynch et al. 2006; McConkie-Rosell and DeVellis 2000.
[221] Vodermaier et al. 2010.

the REVEAL study have suggested that genetic tests with relatively low predictive power, such as *APOE* testing, can reinforce family connections.[222] For example, some participants found it helpful to gain what they felt was an explanation of their parents' dementia.[223] And several reported being pleased that they and their children now knew 'where they stood'.[224] Others were concerned about what their future illness could mean for the caring responsibilities of family members.[225]

The contribution of positive test results to feelings of commonality with others beyond immediate family has been observed in relation to *BRCA* testing. For example, Robert Klitzman reports one participant in his study as saying, '[h]aving this gene makes me feel more female. Women have to deal with special things: having this biological clock, bleeding every month, menopause. It's not a self-pity thing, but an added female thing.'[226] Meanwhile, another says, 'I do hotline work. I don't do the Walk-a-thon, but do cancer runs – for cancer research in general, not just BC [breast cancer]. I don't look at myself as "gene-positive person". I always say "I'm a BrCa-1 carrier". I would say I'm outgoing, athletic, enjoy people, and am sensitive.'[227] Several of the participants in Klitzman's study were clear that their risk status is only 'a piece of who I am'.[228] Indeed, the reactions cited above illustrate how recipients' varied responses to their results join a constellation of interwoven characteristics which extend far beyond their health.

I will now turn to take stock of what inferences might be drawn from the attitudes and experiences described above to the possible roles played by this category of personal bioinformation in recipients' narrative accounts of who they are.

Through the Lens of Narrative Identity

Due to the nature of genetic disease, experiences of living through family illness and awareness or expectations of their own disease risk already feature prominently in the stories many of the above participants tell

[222] Chilibeck et al. 2011. Monica Konrad (2005) has noted that where family members learn they do not share the same risk of developing the highly penetrative, monogenic condition Huntington's disease, this can be a new source of familial divisions.
[223] Lock et al. 2006.
[224] Lock et al. 2005, p. 59.
[225] Ashida et al. 2010.
[226] Klitzman 2009, p. 886.
[227] Klitzman 2009, pp. 884, 886.
[228] Klitzman 2009, pp. 884, 886, 887.

about themselves. This means that the effects of new susceptibility information on their identities are not always immediately obvious or dramatic. That is, they do not generally involve wholesale revision of narrative contents or direction, or the imposition of specific new labels or self-descriptors. However, there are clear indications of the ways in which learning of risk status serves to cast both past and anticipated future chapters of recipients' narratives in a new interpretive light. Even when results are probabilistic and uncertain, they can help recipients make sense of their past experiences – for example, of their own illness or of caring for affected family members. And even when test results do not remove uncertainty in the ways recipients hoped they would, they often still provide recipients with impetus and assistance in thinking about how their future self-narratives might look and how they might exercise some degree of control over this. This control might involve taking steps to protect their health or their material security, preparing for health challenges to come, or rethinking their plans, priorities, and outlook.

It is clear that the impacts of test results on identity-constituting narratives are not always welcome or constructive. For some, positive test results disrupt their sense of themselves as healthy, or how they envisioned their stories would unfold. The risk of genetic disease may be experienced as threatening self-defining projects, roles, or relationships, or exacerbating uncertainty about their futures and future health. Learning they are a carrier can also change recipients' relationships with their bodies, making them feel alien or unreliable, sometimes leading to stigmatised self-conceptions or loss of a sense of agency. However, as with knowledge of donor conception, there are also indications that we should not assume that initial distress or disruption of self-perceptions always translates into longer-term identity harms. Some recipients come to accommodate their risk status in, or exclude it from, their accounts of who they are. It is also notable that it is not possible to draw a neat correlation between the ostensibly bad news of a positive test result and negative impacts on the recipients' sense of who they are. The value of susceptibility estimates often appears to lie in the explanatory power and sense of, albeit limited, control that they offer, the changes in outlook and priorities that they make possible, and their influence on the tone and comfort of recipients' self-conceptions.

As the above examples indicate, the ethically significant effects of test results on people's lives are not necessarily tied to clinical actionability or practical planning. However, it is also a mistake to think of practical undertakings as wholly separate from the business of identity

development. Practical activities – for example, planning for the future security of our families – are often themselves identity-constituting, particularly where these are expressive of the values, plans, and commitments by which we characterise ourselves. Our stories of who we are constructed by what we do, not just by how we think of ourselves.

As with the discovery of donor conception, genetic susceptibility test results often affect the narrative threads comprising recipients' relationships to and concern for others. Unwelcome or unexpected results can be sources of family tensions or bonds. And familial and social responsibilities provide motivations for seeking testing. More specifically, testing and test results appear to play important parts in constituting the particular familial or social roles that make up people's stories of who they are. For example, being tested may be a way of enacting care and concern for relatives. And learning of shared, inherited genetic risk can affect the recipients' feelings about their abilities to meet behavioural and moral norms associated with fulfilling the roles of a loving parent or a responsible member of an at-risk family or community. As d'Agincourt Canning observes, 'within genetics, people might see their selves inscribed onto the lives of others'.[229]

The responses cited above also hint at the role of positive risk status in engagement with self-constituting 'biosocial' activities – those centred on biological connections and experiences of embodied commonality with others.[230] Sahra Gibbon has noted that hereditary breast cancer and being a *BRCA* carrier are particularly associated with biosociality and patient activism, such as fundraising for research or seeking to increase awareness of the disease.[231] *BRCA* activism may also intersect with other shared modes of self-definition, for example gender or ethnic identifiers. *BRCA*-related cancers occur with particular frequency in Ashkenazi Jewish populations.[232] It has been suggested that being a carrier – and what this is taken to imply about a shared history of oppression and migration – may be experienced as connecting members of Ashkenazi communities and as a 'reiteration of Jewish identity'.[233] It is not uncommon for *BRCA* campaign groups to link awareness-raising activities to shared community identity.[234]

[229] d'Agincourt-Canning 2006, p. 111.
[230] Rabinow 2010.
[231] Gibbon 2007.
[232] Levy-Lahad et al. 1997.
[233] Mozersky and Joseph 2010.
[234] See, for example, the Sharsheret campaign in the US https://sharsheret.org/who-we-are/ (accessed 18 July 2021).

The analysis offered over the preceding paragraphs stands in contrast to the sceptical perspective that probabilistic susceptibility testing – when contrasted with strongly predictive tests for single-gene disorders – has few, if any, noteworthy impacts on individuals' identities. This kind of view is emphatically expressed by Margaret Lock and her co-authors in their analysis of the REVEAL findings. They conclude that REVEAL participants did not experience 'anything remotely approaching a profound personal or identity change based on the test results'[235] and that 'little if any significant changes take place with respect to [their] sense of identity'.[236] I wish to suggest that these claims are not wholly borne out by findings relating to *APOE* testing, much less *BRCA* testing.

The studies discussed above do indeed indicate that distress – particularly of a clinically significant kind – is much less in evidence than it has long been assumed. It is also apparent that receipt of genetic risk information – whether positive or negative – does not necessarily lead recipients to make wholesale revisions to their prior beliefs about their susceptibility.[237] And while there are some examples of recipients adopting their risk status as a specific self-descriptor, there is little evidence that this is universal, or that it necessarily involves adoption of the kind of encompassing, illness-vigilant, responsibilised selfhood that Carlos Novas and Nikolas Rose have termed a 'risk identity'.[238] So, while it is perhaps true that those tested rarely experience seismic or wholesale changes in how they describe and present themselves, I would argue that we absolutely cannot conclude from this that genetic susceptibility testing has *no* significant identity impacts. To do so would be to adopt too narrow a conception of identity and of the kinds of identity changes that might make a difference to our lives and well-being. One of the conclusions from the REVEAL study is that information about Alzheimer's risk informed by *APOE* testing can have 'personal value' for those tested.[239] And a recent overview of systematic reviews of impacts of genetic susceptibility testing concludes that 'there are enough data showing that people are influenced by such testing, even if more subtly than is detected with many general, validated measures',[240] and that 'qualitative findings clearly demonstrate that genetic and genomic testing results can

[235] Lock et al. 2005, p. 58. See also, Parry 2013.
[236] Lock 2008, p. 72.
[237] Lock 2008, p. 72.
[238] Novas and Rose 2001.
[239] Roberts 2012, p. 142.
[240] Wade 2019, p. S95.

change peoples' inner lives'.[241] My suggestion is that some of this 'personal value', 'influence', and 'change' – and not only to recipients' *inner* lives but also to their *practical*, *moral*, and *relational* lives – can be understood in terms of the contribution of test results to recipients' identity narratives. These contributions include enhancing the coherence and depth of meaning of these narratives, for example by better equipping recipients to make sense of prior experiences of family illness or to deal with the prospect of personal, relational, and health challenges, or by leading them to feel solidarity with others similarly affected. These narrative contributions do not involve wholesale revisions or adoption of brand new social identities. Rather, they exemplify precisely the kind of interpretive and selective digestion of information that is integral to the narrative-building endeavour. And when these kinds of assimilation, adjustment, and perspectival shifts change how the recipient understands themselves, interprets the world, weighs up what matters to them, and projects themselves into their own future, they are far from trivial.

A number of researchers, working both on REVEAL and *BRCA*-related studies, note that the personal meaning and significance of test results to recipients are shaped by their family history, existing diagnoses and illness experiences, and their familial roles.[242] These observations highlight the ways in which identity development is neither linear nor monadic. It involves the weaving and reweaving of multiple threads – some of which are contributed by existing experiences and characteristics, and others of which are contributed by externally sourced information about our bodies. The reconciliation and mutual interpretation of these threads are no less important to the business of identity construction, and our interests in being able to develop and inhabit the identities we construct, than dramatic reinvention.

It should be clear that the picture of the identity significance of genetic test results offered here in no way rests upon the premise that our genetic inheritance defines who we 'really' are. As with knowledge of donor conception, we might wonder, however, whether any identity significance invested by *recipients themselves* depends on their holding geneticised beliefs about what constitutes their identities. Commentators are divided on the extent to which essentialist attitudes are evident in research participants' responses.[243] Discussing *BRCA* testing, d'Agincourt-Canning suggests that

[241] Wade 2019, pp. S93, S95.
[242] Chilibeck et al. 2011; d'Agincourt-Canning 2006; Hallowell et al. 2004.
[243] Parens and Appelbaum 2019.

many people's views sit somewhere between belief in the unassailable authority of genetic tests and a more 'pragmatic' perspective that recognises the limitations of these tests but also sees them as their best hope for taking control of their epistemic insecurity in the face of risk.[244] The experiences discussed above reflect this mixed picture. Some degree of deterministic thinking may be signalled by participants who report feeling doomed or like 'mutants'. However, many reject determinism – for example, by refusing to be defined by their risk or by embracing measures to take some control of their health and futures. This signals that biologically essentialist assumptions are neither prerequisite for nor a necessary consequence of experiencing test results as having identity-significance. I will return in the next chapter to consider the kinds of factors that do affect differential attributions of identity-significance. Before doing so, I will turn to my third and final illustrative example.

5.4 Illustrative Example III: Encounters with Psychiatric Neuroimaging

What Kind of Bioinformation?

With this third and final illustrative example, I move beyond genetic information to look at research participants' actual and anticipated reactions to findings derived from neuroimaging data about functional and structural features of their brains. These are findings that purport to provide insights into information subjects' mental health status. The kinds of mental health status in question here include probabilistic future risk of developing conditions such as major depressive disorder (MDD), bipolar disorder, psychosis, and schizophrenia, diagnosis of these conditions, and likely responsiveness to particular treatments or interventions.

The attitudes and experiences explored below relate chiefly to uses, or prospective uses, of data about regions of metabolic activity in the brain – treated as a proxy for brain function – obtained from functional magnetic resonance imaging (fMRI) or, in some cases, positron emission tomography or single-photon emission computed tomography. Some of the studies also relate to uses of MRI to examine subjects' brain structures. The following discussion will refer to findings generated 'from neuroimaging'. However, in many cases, conclusions drawn about individuals' mental health status will be the product of algorithmic analyses of their

[244] d'Agincourt-Canning 2006, p. 113.

neuroimaging data in combination with other data gathered from them – for example, about family disease history – and compared with data collected from large groups of research participants with and without mental health diagnoses.[245]

At the time of writing, neuroimaging is only used for limited purposes in clinical psychiatric and mental healthcare, chiefly to identify targets for surgery and to rule out structural anomalies as causes of psychiatric symptoms.[246] These uses are not my focus here. Instead, I will examine attitudes to predictive, diagnostic, or prognostic applications that are currently chiefly restricted to research contexts, research that is often aimed at clinical translation.[247] There is enthusiasm in some quarters about the prospects of this field of inquiry delivering ways of identifying pre-symptomatic risk, more precise and robust diagnoses than those that currently rely substantially on clinicians' judgements, and better targeted treatments.[248] However, there is also widespread scepticism about the value of neuroimaging-based techniques over existing practices for three key reasons.[249] First, at the time of writing, several aspects of the methodologies used – particularly in fMRI studies – are insufficiently standardised or well-developed to deliver reliable and sensitive results at an individual patient level.[250] Second, the equipment, expertise, and resources needed to conduct fMRI scanning in routine clinical practice are currently prohibitive.[251] These two practical limitations may be resoluble as methods and technologies develop.[252] However, a third, concern arises from more fundamental disagreement about the validity of biological models of mental illness and may not be so readily overcome. It is not necessary to adopt a wholly anti-biological view of mental illness to recognise that neural biomarkers are rarely unique to or neatly aligned with existing psychiatric diagnostic categories, or to be concerned that neurobiological methodologies may lead to embodied, social, or environmental causes of and therapies for mental illness being sidelined.[253] For these reasons, there remains doubt about whether neuroimaging could ever provide suitable predictive, diagnostic, or

[245] Kellmeyer 2021.
[246] Staudt et al. 2019.
[247] Cooper et al. 2013.
[248] Farah and Gillihan 2012; Rose et al. 2015.
[249] For further discussion, see Etkin 2019.
[250] Lawrie et al. 2019.
[251] Lawrie et al. 2019.
[252] Kellmeyer 2017.
[253] Pickersgill 2011; Ramos 2012.

prognostic methods in mental healthcare.[254] Despite these limitations, there are two reasons for selecting this as my third illustrative example. First, I want to take steps to make sure that any conclusions I draw are not only applicable to genetic information. Second, brain data represent a category of bioinformation about which questions of identity significance seem likely to become more ubiquitous and pressing as neuroscience and data-driven healthcare advance.

As with the previous examples, it will be helpful to review the current availability of this kind of bioinformation to information subjects. For the reasons given above, patients are currently very unlikely to receive diagnostic or prognostic neuroimaging-based findings in mental healthcare. And because of the questionable reliability of individual research findings, it also remains unlikely that participants would receive findings about their mental health as part of the feedback policies of research studies.[255] If patients or participants were to receive such findings, these would not necessarily take the form of literal brain *images*. They would perhaps be more likely to receive verbal advice about diagnoses, percentage risk estimates of susceptibility to a particular illness, or guidance on more effective treatment regimes. It is not, however, impossible that they could receive images. In one ethnographic study, discussed further below, psychiatric patients were given structural MRI scan images of their brains, as hard copies or digital files, by investigators as an 'enticement' or 'thank you' for taking part in neurological research.[256] This was despite the neurologists describing these images as 'mere window dressing', displaying no visible markers of the participant's illness, when discussing them with the researcher.[257] At present, the most likely – though still not widespread – source of purported mental health 'diagnoses' using neuroimaging are probably DTC imaging services and consumer devices that are marketed with the promise of allowing users to monitor their own states of, for example, focus, anxiety, or relaxation.[258] Concerns noted above about

[254] Giordano 2012.

[255] Lawrie et al. 2019. Depending on the research protocol, participants might receive feedback on incidental findings raising serious clinical concerns. Considerations informing feedback policies are discussed in Chapter 2.

[256] Cohn 2010, pp. 67, 74. A further route by which participants may obtain images is if serious incidental findings are observed and image files are sent to their NHS patient record – in which case the participant could submit a request to view these (see Littlejohns et al. 2020).

[257] Cohn 2010, p. 74.

[258] Alpert 2012; Hickey et al. 2021.

methodological reliability are magnified considerably in the context of DTC neuroimaging.[259]

The following discussion draws on findings from the empirical literature that provide insights into information subjects' attitudes to receiving various kinds of neuroimaging-based information relating to their mental health. As with the previous two examples, these studies broadly investigate psychosocial effects, though several set out explicitly to explore potential identity impacts in some form.[260] Unsurprising, given the current state of the art, there are very few studies involving participants who have actually received neuroimaging-based mental health information. The majority of those discussed below report instead how participants – many with existing mental health diagnoses, some without – anticipate how they would react to hypothetical receipt of neuroimaging findings. Some of the studies report clinicians', researchers', and parents' views about how patients would be likely to react. The few exceptions to these hypothetical enquiries are those that report of experiences of those who have used DTC imaging services[261] or who have received neuroimaging findings through participating in research.[262] This means that the limitations to note with respect to these findings include the caveat that attitudes and expectations reported are often speculative or based on third-person assumptions and they are usually predicated on the hypothetical counterfactual that neuroimaging would deliver robust and reliable mental health insights.[263] In addition to this many of the studies are relatively small, with several comprising part of interconnected projects with overlapping groups of participants.

Information Subjects' Experiences

Perhaps the most immediately striking indication from the studies looked at here is that the majority of participants are enthusiastic – sometimes cautiously, sometimes more fulsomely – about what neuroimaging results could offer in terms of their own treatment, care, self-perceptions, and

[259] Thom and Farrell 2019.
[260] Buchman et al. 2013; Dumit 2003, 2004.
[261] Anderson et al. 2013.
[262] Cohn 2010; Dumit 2003.
[263] As indicated by attitudes to genetic susceptibility testing above, expectations and hypothetical reactions may diverge from what people actually feel or do once they receive the information. I discuss the possible implications of the epistemic limitations of this information below.

wider lives. For example, in one survey of the general public – none of whom had psychiatric diagnoses – the vast majority said they would be prepared to have a brain scan if it could safely and reliably predict an illness such as depression or schizophrenia.[264] Amenability to predictive scanning extends also to those with known diagnoses or risk factors.[265] Not all patients or members of the public have such positive expectations or experiences, though, as described further below.

One of the reasons many participants with existing psychiatric diagnoses give for their enthusiasm is that they see neuroimaging as potentially providing authoritative and reliable insights into the nature or cause of their mental illness – implicitly more dependable than subjective clinical judgements of mental health professionals. Participants in several studies said that neuroimaging-based assessment would provide, or had provided them with a more 'clear and objective', 'certain', or 'concrete' diagnosis.[266] Another study found that the majority of participants believed neuroimaging results would help them accept their condition and understand its biology.[267]

Several studies note beliefs amongst patients and healthcare professionals that – because of their perceived objectivity and authority – neuroimaging-based diagnoses would deliver therapeutic benefits by encouraging improved access to, uptake of, or compliance with health-protective behaviours and treatment.[268] However, in counterpoint to these hopes, some clinicians and commentators voiced concerns that biologised, brain-based explanations of mental illness might encourage patients to be pessimistic about treatment or recovery or to rely more heavily on psychopharmaceuticals to the exclusion of other therapeutic strategies.[269] While some patients expressed concerns that neuroimaging-based diagnoses could increase their worry about their illness, for the most part, professionals' concerns about fatalism or 'prognostic pessimism' are not borne out by patients' own responses.[270] Indeed, the majority of participants in one study – who had diagnoses of MDD – reported that a neuroimaging-based diagnosis would make them more likely to undertake psychotherapy.[271] Participants with

[264] Lawrie et al. 2019.
[265] Anderson et al. 2013; Illes et al. 2008; Lawrie et al. 2019.
[266] Anderson et al. 2013, p. 7; Buchman et al. 2013, p. 74.
[267] Illes et al. 2008
[268] Anderson et al. 2013; Borgelt et al. 2011; Buchman et al. 2013.
[269] Borgelt et al. 2011; Lebowitz 2014.
[270] Buchman et al. 2013; Illes et al. 2008.
[271] Illes et al. 2008.

schizophrenia in another study welcomed the prospect of neuroimaging if it could help tailor individual treatment more effectively.[272] And amongst a group who had used commercial neuroimaging services, most said they felt more positive and in control of their health, with only a few reporting decreased hope.[273]

Another common reason given by those with existing diagnoses for welcoming neuroimaging-based diagnoses is that these could help explain or legitimise their experiences of mental illness.[274] For example, Daniel Buchman and colleagues describe one participant's hope that neuroimaging will offer a way to 'reconfigure the meaning of his experience [of illness]'.[275] While another reports that he would welcome neuroimaging as 'acknowledgement of what I am going through' and proof that he is not 'just crazy'.[276] Meanwhile a participant in Simon Cohn's study recalls, 'I did think to myself, "would it show up on the scan? Which part of the brain is it that is causing the depression?" You know, can you just point to something and say, "That's your depression?"'[277] This optimism is echoed by some participating mental healthcare professionals, who hope that neuroimaging could provide their patients with 'existential relief' by offering biological reasons, 'a physical basis', and 'meaningful explanation' for their suffering.[278] Cohn, whose participants had been gifted brain images after taking part in neurological research, observes that some found these images 'comforting', carrying them in their wallets or displaying them in their homes.[279] Joseph Dumit similarly notes that, in contrast to the hostile ways patients with genetic disease have been observed to respond to gene images, in his experience patients with mental illness often react to neuroimages with care and concern, indicating that they see these images as representing their suffering, rather than its external cause.[280]

Several studies report patients' hopes that neuroimaging-based findings would also legitimise their experiences of mental illness in others' eyes – including family and friends – by communicating the illness's 'reality'. Dumit observes that putatively diagnostic neuroimages carry

[272] Rose et al. 2015.
[273] Anderson et al. 2013.
[274] Illes et al. 2008.
[275] Buchman et al. 2013, p. 74.
[276] Buchman et al. 2013, p. 74.
[277] Cohn 2010, p. 75.
[278] Borgelt et al. 2011, pp. 9–10; Cohn 2010, p. 74.
[279] Cohn 2010, p. 77.
[280] Dumit 2003.

medical and scientific authority that makes them a valued resource for accounting for oneself in social contexts and a basis for finding commonality with others and for engagement in patient activism.[281] Cohn notes the particular importance of the material, portable nature of the printed brain image in communicating illness experiences.[282] He suggests that physical images offer a means for patients to engage others and 'convey private subjective suffering within the social world'.[283] For example, one individual with schizophrenia describes such an image as providing 'proof now about my schizophrenia .... It's there on the scan, no one needs question it any more.'[284]

Cohn's findings, however, also highlight the risk that friends and family will not always interpret neuroimages in the ways that participants hope, for example by failing to be persuaded that the images convey evidence of an 'ordinary' physical illness.[285] Indeed, neuroimaging researchers and health professionals participating in another study raised concerns that neurobiological explanations of psychosis might lead to conflict or paternalistic behaviour within families.[286] Not all participants living with mental illness invested neuroimaging findings with the authority or insight to explain or legitimise their experiences. Dumit quotes an individual with a diagnosis of bipolar disorder, who sees images representing their brain function as 'genuinely exciting' but then goes on to say, these 'do not explain my madness nor do they guide me in what I can do about it'.[287] Similarly, others regard neuroimaging as a 'crude limitation' of what their illness means for them.[288]

The optimistic expectations for explanation, validation, and health benefits noted above must be viewed in light of the current limitations in the reliability, accuracy, and appropriateness of neuroimaging-based psychiatric diagnosis and risk estimates, as well as misplaced assumptions about their objectivity. Images representing functional brain data look like cross-sections of a human brain and are often vividly coloured to indicate areas of greater or less activity. A number of authors note the compelling but potentially misleading nature of their seductive visual

[281] Dumit 2003.
[282] Cohn 2010.
[283] Cohn 2010, p. 79.
[284] Cohn 2010, p. 76.
[285] Cohn 2010, p. 76.
[286] Corsico 2021.
[287] Dumit 2003, p. 43.
[288] Cohn 2010, p. 77.

form and the apparent simplicity and objectivity of the insights they are taken to convey about the brain and mental health.[289] For example, Dumit describes neuroimages as 'potent objects'.[290] Neuroimages are not, however, literal photographs of the brain but graphical representations of statistical analyses of highly processed data sets and the product of researchers' choices and machine learning processes.[291] Cohn suggests that by giving scan images as 'thanks', the neuroscientists in his study may be – albeit inadvertently – colluding in patients' interpretations of these as literal pictures of disease and in their need for these images to validate their illness.[292] In contrast to patients and the public, healthcare professionals and neuroscience researchers are more cautious or sceptical about the current clinical or personal value of psychiatric neuroimaging to individual patients.[293] Many of the anticipated therapeutic and personal benefits discussed here would be undermined, or even commuted into harms, if neuroimaging technologies were to provide misdiagnoses and false reassurance or to misdirect care pathways.[294] I will return below to discuss how a parallel risk may play out with respect to anticipated identity benefits.

When it comes to explicit discussion of the relationship between mental illness and identity, a number of studies report that people living with psychiatric disorders hoped that neuroimaging findings would help them to attribute their disorder to faults or features of their brains rather than part of 'who they are'; in some cases this was reflected in people's experiences.[295] Cohn observes that amongst his participants, 'the scans are frequently used to endorse a categorical separation from their disease' and offer a means by which patients cease to regard themselves as 'intrinsically ill'.[296] As he describes it, seeing – or imagining that they see – the location of their disease in a brain scan image allows some living with serious psychiatric illness to view their disease as an external, physical 'thing', 'something particular, bounded', or 'an alien pathological entity', separate from the self.[297] Dumit too suggests that some people may use neuroimaging findings as a source of impartial facts from which to

[289] Dumit 2004; Joyce 2005.
[290] Dumit 2004, p. 133; see also Roskies 2008.
[291] Kellmeyer 2017. For further discussion, see Farah 2014.
[292] Cohn 2010.
[293] Anderson and Illes 2012; Borgelt et al. 2012.
[294] Kellmeyer 2017.
[295] Buchman et al. 2013; Dumit 2004; Illes et al. 2008.
[296] Cohn 2010, pp. 74, 79.
[297] Cohn 2010, pp. 74, 75, 79.

construct what he calls an 'objective self' – a mere biological object-in-the-world.[298] So, for example, someone may talk of their 'depressed self' as separable from their 'true self' and distance themselves from particular behaviours, as expressed in disavowals such as 'the illness is speaking not me'.[299] A further, hoped-for benefit of this kind of separation – cited by both patients and clinicians alike – is that by demonstrating that mental illness is a 'banal physical disease' like any other, neuroimaging could help alleviate feelings of self-blame for illness and moral responsibility for recovery.[300] Judy Illes and her co-authors report that the majority of their participants who reported feeling self-blame for their depression expected that a diagnostic brain scan would significantly mitigate these feelings.[301] Similarly, in another study, participants with diagnoses of MDD echoed hopes commonly voiced by mental health advocates that neuroimaging-based diagnoses could reduce the stigma and fear often associated with mental illness.[302]

Some participating health professionals, however, worry that rather than facilitating a separation between identity and illness, neuroimaging-derived information about mental health could have the opposite effect, leading patients to see their disorder as an intrinsic, permanent brain 'defect' or 'an error in them' as a person.[303] These concerns may not be without foundation. For example, some studies suggest that receipt of neuroimaging findings could lead recipients to define themselves as 'a depressed person' or someone with 'defective brain chemistry'.[304] Dumit cites a biographical account of living with depression in which the author questions the very possibility of disassociating *who* she is from her 'sick brain', given its role in her experience and agency.[305] And Cohn's observation – that friends or family members may fail to invest neuroimages with the explanatory or exculpatory power that patients hope for – also indicates that stigma may be recalcitrant.[306] Indeed, researchers have observed that invoking *genetic* causal factors in psychiatric disorders can

[298] Dumit 2003, p. 35.
[299] Dumit 2003, pp. 35, 45.
[300] Buchman et al. 2013; Cohn 2010, p. 67; Dumit 2004, p. 37.
[301] Illes et al. 2008.
[302] Buchman et al. 2013.
[303] Buchman et al. 2013; Borgelt et al. 2011, p. 6.
[304] Buchman et al. 2013; Dumit 2004.
[305] Here, Dumit cites the experiences of depression described by journalist Tracy Thompson in her memoir of illness *The Beast: A Reckoning with Depression* (New York: G. P. Putnam's Sons, 1995) discussed in Dumit 2004.
[306] Cohn 2010.

actually increase associated fear and prejudice.[307] Insofar as this is attributable to perceptions that biological causes make these disorders more serious or intractable, similarly negative attitudes might extend to evidence of neurobiological factors.

As these diverse findings indicate, the perceptions of the relationship between brain, mental illness, and identity – and the ways that these then shape or are shaped by real or hypothetical encounters with neuroimaging-based risk estimates or diagnoses – are far from straightforward. Neuroscience researchers and health professionals in one study report that perceptions of the connection between mental illness and the self varied widely amongst patients and that neuroessentialist views are not as widespread as might be assumed.[308] Patients themselves hold ambivalent views about the connection between brain and self. For example, Cohn observes that his participants ascribed 'complex and multiple' meanings to their scan images.[309] Dumit too suggests that seeing oneself as having a depressed 'brain-type' may be experienced in simultaneously objective *and* subjective ways, 'lived by the person as well as against the person'.[310] Similarly, Buchman and his co-authors note that their empirical findings reflect 'the complex and sometimes contradictory ways in which people integrate notions of a disordered brain into a concept of self that at once *has* a brain and *is* a brain'.[311] This tension or vacillation has also been observed in empirical studies addressing the wider relationship between neuroscience and self-conceptions.[312] For example, Martyn Pickersgill and his co-authors conclude that while people are drawn to neuroscientific accounts of the self, they also often continue to view their brains not as a 'magnificent epicentre of subjectivity' but as 'an object of mundane significance'.[313]

Through the Lens of Narrative Identity

The findings discussed above indicate that neuroimaging-derived information purporting to provide insights into mental health status often do feed into the ways individuals characterise themselves. And

[307] Read 2007.
[308] Corsico 2021.
[309] Cohn 2010.
[310] Dumit 2004, p. 45.
[311] Buchman et al. 2013, p. 73 (emphasis in source).
[312] Martin 2010.
[313] Pickersgill et al. 2011, p. 361.

it seems likely that it might do so more widely if this kind of bioinformation were to become generally available in care or consumer settings. Citing a view prominent amongst the research and clinical professionals that he interviewed, Paolo Corsico concludes that 'information around genomic and brain correlates of psychosis, as well as information around psychosis risk status and illness susceptibility is a powerful tool in the process through which research participants and care recipients define their identity'.[314] As with the two previous illustrative examples, the ways and extent to which this category of personal bioinformation is likely to affect recipients' identity narratives will vary between individuals and circumstances and these effects may manifest in negative as well as positive ways.

Given that many of the views described above are voiced by people with existing mental health diagnoses or family histories of mental illness, it is perhaps unsurprising that – much as with genetic susceptibility testing – there are no widespread indications that neuroimaging-derived information would introduce wholly new categories of contents to information subjects' accounts of who they are. Instead, for many, this information is seen as offering opportunities to adjust the self-descriptors that already contribute to their self-narratives – for example, by confirming a diagnosis or by allowing them to think of themselves as having a disease rather than being 'crazy'. And the most notable anticipated impacts lie in the potential for neuroimaging findings to provide fresh interpretive tools with which people are able to reframe their lived experiences, reinterpret the meaning of mental illness, and find a place for it within – or outwith – their accounts of who they are. If, however, neuroimaging were to be used to identify the pre-symptomatic risk of serious disease in those without a known family history of mental illness, we might perhaps anticipate different reactions – perhaps ones more akin to the narrative disruption experienced upon late discovery of donor-conception.

The (re)interpretive opportunities offered by neuroimaging-based information are often welcomed, as exemplified by people's relief, or anticipated relief, at having authoritative, external verification of their subjective experiences of illness or at acquiring grounds for seeing themselves as having a real, concrete disease. The specifically narrative advantage of this kind of interpretative facility may be seen in the opportunity to make sense of distressing experiences resulting from mental illness and

[314] Corsico 2021, p. 10.

to construct a more intelligible or resilient self-narrative around understanding that these experiences are symptoms of a disorder. Serious mental illness can itself have profound impacts on sufferers' identities. Psychiatric diagnoses may be viewed as markers of difference and otherness and are often sources of stigma.[315] And where distress, confusion, or delusions are amongst the symptoms, illness may be experienced as disruption to identity or loss of self.[316] It is not uncommon for accounts of these kinds of identity impacts to be characterised in narrative terms. For example, David Roe and Larry Davidson describe the onset of a serious mental illness such as schizophrenia as a bifurcation of the individual's self-narrative.[317] And – as discussed in Chapter 3 – Catriona Mackenzie and Jacqui Poltera characterise Elyn Saks's experiences of living with schizophrenia as a fragmentation of self and inability to construct a narrative that hangs together in any intelligible way.[318] Mackenzie and Poltera suggest that by 'appropriating her illness as part of herself', Saks has been able to understand the fragmenting effects of psychosis on her sense of identity, pursue treatment, and bring some coherence to her self-narrative in ways that 'enable her to be the self she wants to be'.[319] This reflects psychological research that suggests that those living with psychosis may benefit from constructing 'recovery narratives', incorporating acknowledgement of their illness into rebuilding their sense of who they are.[320] Neither Saks's experience nor the literature on recovery narratives relate to neuroimaging specifically. Nevertheless, the empirical findings outlined above offer some ways of imagining how the perceived reliability and objectivity of neuroimaging-based findings might support (re)construction of intelligible narratives. Meanwhile self-narratives incorporating illness insights may, in turn, support individuals in accounting for and weathering distressing experiences and periods of 'loss of self' that accompany some forms of mental illness.

As highlighted in the previous illustrative example, it is important not to reduce all significant effects of encountering bioinformation solely to the information's clinical utility or its emotional impacts. However, it is equally important not to assume that clinical utility is

[315] Read 2007.
[316] Wisdom et al. 2008.
[317] Roe and Davidson 2005.
[318] Mackenzie and Poltera 2010.
[319] Mackenzie and Poltera 2010, p. 40.
[320] Ben-David and Kealy 2020; Roe and Davidson 2005.

unrelated to identity development. If hopes that neuroimaging-based insights could open doors to more effective therapies and treatment compliance were to be vindicated, these insights could contribute to patients' identities insofar as they help patients to manage symptoms that interfere with their capacities to make sense of their experiences and identities. And some of the therapeutic approaches adopted, such as talking therapies, might be precisely the kinds of practices that deal in storytelling and self-understanding. Beyond this, it is clear that psychiatric neuroimaging could offer new ways of thinking about the origins and nature of the mental illness, potentially – provided that disclosure is appropriately managed – recasting it in a less stigmatising light and helping alleviate shame and self-blame. If neuroimaging findings were able to reliably fill these practical and reinterpretive roles, they could make positive contributions to information subjects' identities to the extent that they could support the development of self-narratives that are more intelligible and comfortable to inhabit.

If our identity narratives are to be inhabitable and sustainable and allow us to function in the world, however, it is not enough that they are rendered intelligible in our own eyes. They also need to be recognised and respected as such – at least to some degree – by the people we live amongst. The findings above indicate that, for some people, psychiatric neuroimaging findings could be of considerable value in bearing witness to their suffering and the reality of their disease and thus – they hope – in persuading those around them of the veracity of their self-characterisations and the role of mental illness in – or separate from – their identity. Having said this, the experiences recounted above indicate that this hoped-for recognition could be elusive or fragile. It is at the mercy of what others understand neuroimages to convey and the extent to which these match information subjects' own interpretations. Findings from the empirical literature also illustrate ways in which neuroimaging-derived risk estimates or diagnoses could encourage stigma or fatalism, rather than supporting resilience. This could, in turn, engender self-narratives that are experienced as oppressive or limiting. Corsico notes that the neuroscientists and clinicians participating in his study are divided on whether neuroimaging-based diagnoses would exacerbate or ameliorate essentialist thinking, stigma, or prognostic pessimism.[321] Importantly, these professionals place considerable

[321] Corsico 2021.

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emphasis on the manner in which findings are disclosed in shaping whether they are received as stigmatising and whether they foster resilience or hopelessness. In the words of one participant, 'it's all about delivery!'[322] I will return in Chapter 7 to consider the ways in which delivery might be able to avert some identity harms and cultivate benefits.

As in the previous two examples, the kinds of impacts on narrative identity indicated by the views reviewed above do not depend on information subjects adopting neuroessentialist views of self. Even when participants welcome the objectivity and authority of neuroimaging findings, this does not automatically signal a biologised view of their *identities*, even if it is rooted in a biological view of mental illness. This decoupling is evidenced in a number of places. For example, it is apparent that some individuals embrace neuroimaging as a way of communicating the reality of their illness but do not seek to reduce the nature of this 'reality' to something solely biological or innate. And it is yet more explicit in instances where neuroimaging findings are valued for identity development precisely because they allow, or would allow, the individual to exclude mental illness from their story of who they are, reframing it as an 'ordinary' physical disease, rather than part of what defines them. This notwithstanding, healthcare professionals' concerns that some patients might take neuroimaging-derived risk estimates or diagnoses to mean that they are inherently defective need to be taken seriously, particularly if this could reinforce or seed oppressive or limiting neuroessentialist views of the self.

This brings me to a crucial rider to what has been said thus far about the possible narrative roles of this category of bioinformation, particularly where these carry the prospect of making self-narratives more coherent or bearable. Here, the current, potentially surmountable, practical and methodological barriers to its reliability and clinical utility, as well as less tractable concerns about reducing mental illness to brain states or functions, cannot be ignored. The most obvious potentially detrimental effects of these epistemic limitations are health-related, for example where they lead to inappropriate diagnosis or care. And, as noted above, this is not unrelated to the maintenance of a reasonably inhabitable and coherent self-narrative, insofar as maintenance may be contingent upon effective symptom management. However, more direct threats to identity detriment may also be appreciated when the roles of neuroimaging findings are viewed in narrative terms. False or misleading

[322] Corsico 2021, p. 11.

findings, including those that obscure social and environmental contributions to mental illness, could lead recipients to misinterpret or misapply the meaning of their experiences of illness in their self-narratives. As discussed in the context of donor conception, this may lead to the development of an unsustainable identity narrative that provides a poor interpretive framework for lived experience. For example, misdiagnosis might poorly prepare someone to anticipate or tackle the way that symptoms of psychosis or depression influence their sense of who they are. And a welcome 'meaningful explanation' of one's illness is no explanation at all if it is inaccurate or misleading. Indeed, it is possible that embracing such an explanation could jeopardise the current or future intelligibility of someone's sense of themselves if it comes to occupy a role in their self-narrative to the occlusion of other factors more relevant to a more meaningful and intelligible story. Although the threats of these kinds of narrative jeopardy may still be remote while neuroimaging is not yet used in clinical psychiatry, they pose more immediate challenges if and when neuroimaging findings are made available in research or supplied in DTC settings.

This concludes the third and last of my illustrative examples. My suggestion here is that as with the previous two examples, findings from empirical studies offer compelling illustrations of how this category of personal bioinformation could play a range of both welcome and unwelcome, but nonetheless non-trivial, roles in the identity narratives of those to whom it pertains. However – and this is no small caveat – many of the potential narrative roles noted above are premised on the counterfactual reliability and accuracy of psychiatric applications of neuroimaging.

Before turning, in the next chapter, to focus on the specific nature of our identity-related interests and the variables that contribute to particular kinds of bioinformation meeting these interests, I want to take stock of where all three illustrative examples taken together leave my central proposition, that personal bioinformation can play important contributory, epistemic, and hermeneutic roles in the ongoing development of our narrative identities.

5.5 Narrativity across the Three Examples

As noted at the start of this chapter, my aims in exploring the three illustrative examples are threefold: to sense-test my core proposition – that personal bioinformation can play key roles in the construction of

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embodied narratives with the qualities that constitute and support our practical identities – against accounts of people's real experiences of encountering various kinds of bioinformation; to illustrate and bring this proposition to life; and to further refine it in light of information subjects' views and experiences. In this final section of the chapter, I will take stock of where we are in respect of these aims. In doing so, I will identify common themes amongst the narrative roles of these categories of bioinformation based on my interpretation of the findings discussed above. This will provide clues to the kinds of narrative roles that might be similarly filled by categories of bioinformation other than those examined here. From this, we can begin to extrapolate beyond these examples and establish a more broadly applicable picture of the nature of identity-related interests and responsibilities in respect of bioinformation disclosure in a range of contexts. The seeds sown here will be developed further in the coming chapters.

The first, broad observation I wish to make is that the expectations and reactions described in this chapter certainly seem to indicate that information subjects' encounters with all three categories of personal bioinformation can – or could – contribute to, or otherwise alter, their accounts of who they are as particular individuals with particular characteristics, outlooks, commitments, and needs. These impacts take different forms and vary in pervasiveness and gravity. And none of these categories of personal bioinformation is universally experienced as having identity significance or value by all recipients in all circumstances. Indeed, disclosures are variously experienced as welcome, unwelcome, beneficial, and disruptive. And, sometimes, they have little or no obvious or contemporaneous effects on recipients' identities at all. This variation notwithstanding, illustrations of how encounters with these three categories of personal bioinformation affect information subjects' understanding of their own characterising traits, behaviours, and experiences are by no means anomalous. And where this occurs, the effects are often experienced as initiating non-trivial changes in both their sense of who they are and the framework through which they interpret and engage with the world. Furthermore, while variation amongst impacts is undeniable, the extent to which reactions across the three broad bioinformation types echo each other is striking. Where there are variations in the degree and nature of these impacts, these chiefly lie between different people, in different circumstances and contexts, receiving ostensibly similar kinds of bioinformation. I will return to examine what kinds of factors may account for these differences in the next chapter.

It is of course the case that narrative identity, particularly the normative, embodied conception I have set out in the preceding chapters, is not the only lens through which the experiences reviewed above could be interpreted. However, I would suggest that it is both a plausible and illuminating one. It serves to highlight that there is no single effect, mechanism, or phenomenon that is '*the* identity role of personal bioinformation'. It is also clear that recognising the identity significance of personal bioinformation does not depend on either information subjects themselves or us adopting a biologically essentialised view of identity. The distinction drawn above with respect to knowledge of donor conception – that the identity significance and narrative roles of personal bioinformation may track biology without being reducible to it – holds no less true for the effects of learning of genetic disease susceptibility or mental health status. A narrative analysis also demonstrates that identity impacts are by no means limited to adding or replacing discrete, unitary labels or identifiers. While self-labelling and classification by 'person type' may sometimes be a consequence of receiving new bioinformation, it is worth noting how infrequently this is cited as the most notable consequences of disclosure. Indeed, new labels are often expressly rejected. The lens of narrativity also draws attention to the fact that bioinformation-instigated shifts in someone's understanding of their body, mind, relationships, or health do not need to be dramatic or involve wholesale reinvention to be keenly felt and make a meaningful difference to their identities. Below, I will map what I see to be the spread and intersections of what emerge as the most substantial and widely experienced parts played by personal bioinformation on recipients' self-constituting narratives, as evidenced by the accounts above.

Diverse Narrative Roles

Perhaps most straightforwardly, the three examples illustrate ways in which diverse kinds of personal bioinformation may introduce or remove contents or plotlines of recipients' self-narratives. For example, a recipient of a positive *APOE* test may start a regime of intellectual stimulation hoping to defer the effects of dementia or plan to embark on a long-deferred personal project – commitments and activities that then become part of how they describe themselves. And while one donor-conceived individual may acquire a painful storyline of themselves as someone with a difficult relationship with their mother, another may throw themselves into a rewarding and consuming search for donor-siblings. Receipt of

bioinformation is just as likely to entail the removal or editing of existing self-descriptors as to add new ones. This is apparent in cases in which perceptions of being a strong or indomitable person are challenged by unexpected genetic susceptibility or when valued family relationships are damaged by reproductive revelations.

Another conspicuous cluster of narrative roles illustrated by all three examples relate to the introduction of fresh context or perspectives from which the recipient is able to re-evaluate or make sense of aspects of their embodied and relational memories and experiences and to interpret and adjust their self-narrative in light of these. These memories and experiences might include, for example, those of their own behaviour or that of others towards them; periods of ill health, changing mood, or impaired thinking; sensations and emotions; awareness of family illness; or manifestations of particular traits. The views related above illustrate ways in which bioinformation can cast these in a new light, change their meaning or significance, address uncertainties, or help account for tensions, anomalies, and gaps. For example, donor-conceived individuals may welcome learning of their donor conception because it helps resolve questions and confusion about family resemblances. And a neuroimaging-based diagnosis may help someone to make sense of distressing symptoms and to reconceive themselves as suffering from a disease rather than being 'crazy'.

This is not the same as suggesting that bioinformation provides the *truth* about who someone is or that it functions as a bald corrective to mistaken beliefs about what they thought or experienced.[323] Rather, the claim here is that it provides them with the opportunity, interpretive context, and perhaps impetus to reappraise the contents – and relations between the contents – of their existing self-narrative in light of fresh insights into their biological, bodily states. This may then facilitate the repositioning, weaving-in, or exclusion of threads from the individual's own account of who they are. This, in turn, offers the possibility of arriving at an account that is more intelligible, satisfying, or sustainable given wider lived experiences and other narrative threads. It is also clear, however, that bioinformation is not always useful or successful in fulfilling these kinds of reinterpretive or explanatory roles. For example, a discovery of donor conception during adulthood, which coincides with the death of a parent who could have supported them in making sense of this knowledge, may leave someone's self-narrative less readable and inhabitable than it was before. And unexpected identification of a risk

[323] Cf. Walker 2012.

of serious physical or mental illness may be experienced as disorienting and existentially threatening.

The stories we construct about who we are shaped not only by what has already happened to us but also by our anticipation of what is to come. The diachronic nature of narrativity allows us to recognise how bioinformation's explanatory and interpretive capacities can also function prospectively. Insights and knowledge gained now may support someone in making sense of, accommodating, or excluding future experiences of changing embodiment, relationships, or ill health from their accounts of who they are. While this – by the very nature of its future orientation – is less explicitly illustrated by the examples considered here than retrospective explanatory potential, it is signalled by the regret of donor-conceived individuals who wish they had been given the means to make sense of family anomalies earlier, and by those who talk of welcoming genetic susceptibility testing so that they can 'get things in order' or 'rethink their priorities'. Again, it would be a mistake to assume that personal bioinformation invariably usefully fulfils this prospective narrative role. For example, the weakly predictive nature of an *APOE* test result might fail to deliver hoped-for certainty about dementia risk, leaving the recipient's future self-narrative as foggy and unreadable as it was before.

The examples above also illustrate the role of bioinformation in initiating practical planning and behavioural changes. A narrative lens allows us to recognise that where bioinformation instigates steps such as embarking on treatment or searching for donor siblings, these activities are not necessarily distinct from identity development just because they are practical. They may themselves provide narrative contents or plotlines in their own right. They could, as previously noted, also be part of the individual's efforts to gain some understanding and control over the way their self-narrative might unfurl in the future and to adjust their current behaviours or priorities accordingly. These activities and undertakings should not automatically be assumed to separate from the business of self-constitution. According to the practical conception of identity described in the preceding chapters, the roles and traits that contribute to the self-narratives that constitute our identities are not mere inert descriptors. They supply our motives and evaluative frameworks, and they are true self-characterisations to the extent that they are expressed and enacted in appropriate circumstances. For example, sharing genetic test results with family members or undertaking financial planning in anticipation of future incapacity may be inherent to what it means to someone to be a responsible parent and a loving spouse. Conversely, a positive test result

could threaten someone's self-conception as a responsible parent when they view protection of their children's safety and well-being as integral to fulfilling this descriptor.

Having said this, it is apparent that a practical response to a diagnosis or identification of disease risk is sometimes just this – an opportunity for the recipient to undertake, for example, the appropriate preventative steps and relegate the matter to a brute fact of their biological existence, rather than something that defines them. Conversely, the experiences recounted above indicate that receipt of information does not need to result in action or behavioural changes to be experienced as making a significant difference to the recipient's sense of who they are. Findings relating to all three examples suggest that bioinformation is often experienced as adding context or explanations, precipitating changes in outlook, setting expectations, or shifting relationships and roles in ways that make meaningful, non-trivial differences to recipients' characteristics and experiences of the world, despite not being manifest in contemporaneous activity. For example, being alerted to disease susceptibility can allow someone to 'see where they stand', or knowledge of donor conception can lead to feelings of being cut adrift from a family, even – or perhaps especially – when there are few opportunities to express or discuss these feelings.

In Chapter 4, I hypothesised that personal bioinformation derives identity value from its contribution to the coherence and interpretive capacities of our *embodied* self-narratives. It is apparent that the same may be said of the *relational* nature of these narratives. The three examples examined here serve to underline the ways in which the embodied and the relational aspects of our self-narratives are often closely entwined and mutually constituting, with neither wholly reducible to the other. This is manifest in a number of ways. For example, encounters with bioinformation can reinforce or undermine particular relationships and the way these feature in people's stories of who they are. Reasons for seeking, and subsequent reactions to receiving, genetic risk information may also play a part in constituting or undermining relational roles of care and responsibility for parents, siblings, and children. And people's desires for information, and subsequent responses to it, often spring from and feed into the ways they see their self-narratives as entwined with those of particular others and with shared familial or community narratives. For example, REVEAL participants' reasons for undergoing genetic testing and their responses to their results reflect their sense of already being characterised by the membership of families marked by Alzheimer's

disease and by wanting to contribute to research that could help others in the same position. As previously noted, the intertwining of self-constitution, biology, and social connections has been observed by Sahra Gibbon in the activism coalescing around *BRCA* carrier status, and by Alondra Nelson amongst African American and Black British users of DTC ancestry tracing services hoping to find their ancestral African roots.[324] Nelson's phrase 'affiliative self-fashioning' captures the role that these kinds of biosocial activities play not only in adding plot lines but also in providing the kinds of dialogical contexts in which narrative meaning-making and construction take place.[325] Finally, it is apparent that the meaning and significance that particular personal bioinformation holds for recipients and the ways in which it affects their self-narratives are shaped by the meaning it holds for those close to them – for example, whether these people also see donor conception as a source of shame or mental illness as sufficiently explained by an image of brain functioning. I shall return in the next chapter to consider the part played by socially ascribed meanings in shaping the identity-significance of particular kinds of findings and insights.

It is critical to note here that alongside the potential for personal bioinformation to be welcome, exciting, explanatory, reassuring, or enabling lies the possibility that it is instead disruptive, stigmatising, oppressive, or uncomfortable. The conceptual picture I advanced in Chapter 4 paid too little attention to the prospect for identity harms. It is apparent that negative narrative impacts can take several forms. These may involve the introduction of unwanted or hurtful self-descriptors and narrative contents – as when genetic test results cause recipients to feel as if they are 'marked' or 'damaged goods' – or the severing of cherished narrative threads – for example where someone's self-characterisation as a future parent is threatened. It is also possible that bioinformation could be experienced as unprecedented and shattering – as in cases of a late revelation of donor conception and consequently damaged relationships – to the extent that it undermines the recipient's ability to recognise themselves or to see their self-narrative continuing in any recognisable or desirable form. This indicates the third dimension of identity harm brought to light by a narrative framing. This is the particular threat to the sustainability and future coherence of someone's narrative posed by the active or implicit communication of misleading or false information.

[324] Gibbon 2007; Nelson 2008.
[325] Nelson 2008, p. 771.

While it is crucial that we recognise that personal bioinformation is not always sought or happily received, it is also important not to lose sight of just how widespread the desire is to receive, or not to be denied, information is across all three examples. While mindful of the potentially self-selecting participation of 'information enthusiasts' in the studies reviewed above, it is still striking that where there are quantified findings, the vast majority skew towards 'wanting to know'. In the qualitative findings, this is manifest in phrases such as 'to go through life with your eyes only half open doesn't help you at all'[326] and 'truth is always better'.[327] These kinds of attitudes are present even when people know that test results could reveal susceptibility to serious disease and amongst those who have had distressing experiences of discovery. Personal testimonies indicate that many information subjects really do value the insights and explanations, the interpretive tools, and the foresight that personal bioinformation offers to them when making sense of who they are in light of their health, bodies, biology, and relationships, and when (re)building a self-conception that 'fits' their past, present, and future experiences.

These observations point towards a third important area for refinement of the conceptual picture set out in Chapter 4 – the need to explore the complex relationship between identity-related impacts that are experienced as beneficial or detrimental. The illustrative examples indicate that there may not always be straightforward dichotomies or correlations between 'beneficial' and 'harmful', 'welcome' and 'unwelcome' bioinformation – where 'beneficial' and 'harmful' refer to the relative utility and suitability of bioinformation for the development and maintenance of coherent, meaningful, and inhabitable self-narratives. As illustrated by accounts of discovery of donor origins, initially shocking and identity-disrupting revelations may eventually come to be valued when they help the individual make sense of their previous experiences of familial discord and reconstruct a fresh, satisfying account of who they are. And it is plausible that the converse may also be true – for example, eagerly sought and welcomed neuroimaging results from a DTC clinic may be so inaccurate as to provide false reassurance to the client about their mental health and constitute a precarious basis for imagining their future and navigating emerging symptoms. I will return in the next chapter to further unpick the nature of narrative identity value and detriment and the complex relationships between their various dimensions.

[326] Lock et al. 2006, p. 290.
[327] Kirkman 2003, pp. 2229–2230.

A Dynamic, Multistranded Whole

The possibility that personal bioinformation may be upsetting but also welcome, or initially comforting but ultimately treacherous, is an important reminder that our identities are not inert, with the only prospects being preservation – where this is assumed to be a virtue – or disruption – which is commonly assumed to be harmful. Characterisations of identity impacts that reduce identity value to the absence of distress or dogged retention of our existing stories are too simplistic. Our identities are perpetually evolving and responding to our experiences and circumstances, and this may go better or worse, aided or undermined by myriad factors, including encounters with personal bioinformation. Furthermore, our identities are not homogeneous or monadic but complex, multistranded wholes in which the different constitutive threads bend and colour each other and are bent and coloured by their interpretive environment. As such, ethically significant impacts on our identities extend far beyond labelling or classification. A narrative framing highlights that it is not only the bald addition or removal of contents from our self-narratives that makes a difference to our identities but also the ways these are interpreted, woven together in different permutations, and enacted. The experiences and views detailed above support the contention that, rather than using insights into our bodies to create – in Dumit's terms – 'objective selves' that are separate from our phenomenal, lived identities, our *subjective* accounts of who we are are richly embroidered by our insights into our biological characteristics and relationships.[328] Personal bioinformation provides new threads, as well as ways of reinforcing, redirecting, or unpicking old ones, and fresh lights in which to view the whole. A narrative conception allows us to appreciate that a mutually interpretive interweaving of experience and externally sourced data, which with varying degrees of success brings together the material and phenomenological, permits the construction of a lived and liveable embodied and relational identity. Recognising the diachronic, dynamic, and multistranded nature of our identities and the multiple roles that personal bioinformation may play in them is essential to grounding a robust and properly conceived picture of our identity interests in our encounters with this information. It is the precise nature of these interests and how they can be met to which I turn in the next chapter.

[328] Dumit 2003.