INDEX

Abi-Rached, Joelle, 10, 54
access to personal bioinformation. see under personal bioinformation
ADHD (attention-deficit hyperactivity disorder), 205
advisory committees, potential bioinformation disclosers and, 221
affiliative self-fashioning, 54
African Americans, ancestry tracing by, 54, 178
African ancestry tracing, 196, 206
African heritage, identity harms and, 204
Alaimo, Stacy, 92
Alzheimer’s disease, 188
desire to contribute to research concerning, 147, 177
preventive/therapeutic interventions for, 145
testing for, 44, 141–4, 156, 174, 250
ancestry tracing African Americans ancestry tracing and, 54, 178
African ancestry tracing and, 196, 206
Black British ancestry tracing and, 54, 178
anxiety, 209
APOE (Apolipoprotein E) gene, 141
APOE testing for risk of Alzheimer’s disease, 44, 141–4, 174
counselling and education about, 148
motivations for undergoing, 146, 177
reactions to receiving results from, 150–3
recommendations regarding access/disclosure, 250
Article 8 of the European Convention on Human Rights (ECHR), 33–7, 250
access to health records and, 41, 45
articulation constraint role of personal bioinformation in meeting, 103
Schechtman on, 72
Ashkenazi Jewish populations, BRCA-related cancers and, 155
Asperger’s syndrome, 101
asymptomatic disease, 85, 115
Atkins, Kim, 62, 96, 97
attention-deficit hyperactivity disorder (ADHD), 205
autonomy, 77–8, 212–17
Baylis, Françoise, 69, 95
BCIs (brain-computer interfaces), 260
biobanks (vignette concerning participation in), 1, 221, 255
biological essentialism, 48–51, 110–13
beyond biological essentialism and, 51
reactions against, 50
bioethics, 3
biography, 101, 106, 198
donor conception and, 132, 137, 140
 genetic parentage and, 58, 107
 genetic risk and, 149
bioinformation governance, 5, 247–63
bioinformation, personal. see personal bioinformation
biosocial identity-making, 54
biosociality, 54
bipolar disorder, 158
Black British, ancestry tracing by, 54, 178
Blyth, Eric, 137
bodily doubt, 92
Bortolotti, Lisa, 108
the brain, 10, 15, 20, 49
brain scans, 1, 9, 162 see also neuroimaging
brain-computer interfaces (BCIs), 260
Brandon, Priscilla, 97
BRCA genes
breast/ovarian cancer risk and, 141
the governance landscape and, 257
BRCA-related cancers, Ashkenazi Jewish populations and, 155
BRCA Self-Concept Scale, 234
BRCA testing, 44, 141–4, 191
age at which it is sought, 146
BRCA activism and, 155, 178
desire to contribute to research concerning, 147
motivations for participating in, 145, 146
reactions to receiving results from, 150–3
breast cancer, 141
Buchman, Daniel, 163, 167
cancer, breast/ovarian, 141
Carel, Havi, 92, 117
Caribbean heritage, identity harms and, 204
case studies, list of, xiv
Cassam, Quassim, 94
characterisation, identity as, 24, 25
the 'characterization question', 23
Chilibeck, Gillian, 148
choice (not) to know, 7, 27, 213
autonomy and, 213
navigating choice and, 237
Christman, John, 70, 79, 83
CIOMS (Council for International Organizations of Medical Sciences) Guidelines, disclosure of health research findings and, 43
clinical actionability, 7, 8, 142, 210
clinical utility, 142, 169, 231
coherence. see narrative coherence
Cohn, Simon, 163, 165, 166
colorectal cancer, 112
comfortable narratives, 185
communication, identity-supporting, 238–44
competing interests, disclosure and, 229–32
conceptual and normative foundations, filling gaps in, 46–60, 197–205
confidentiality, family information and, 42, 255
consent, 214, 255
constraints on self-constituting narratives, 72
constructed identity significance, 191, 196
d'Agincourt-Canning, Lori, 146, 147, 155, 157
damaging narrative contents, 202–5, 224
Data Protection Act 2018 (DPA), 41, 45, 209
data, as distinguished from information, 13
Davidson, Larry, 169
DeGrazia, David, 62, 78
de Melo-Martín, Inmaculada, 52
depression, 114, 158, 162
determinism, 48
diabetes, Type-1, 207
direct-to-consumer (DTC) genomic testing services. see DTC (direct-to-consumer) genomic testing services
disability paradox, 191
disclosure of bioinformation, 5–7, 12, 14, 16 see also under personal bioinformation
debates about, 18
identity interests in, 18
recommendations regarding, 247–63
discrimination, 55, 204
distress
  narrative disruption and, 105, 138, 250
  relationship to and distinction from
  identity interests, 209
donor conception, 15, 19, 174, 188
donor anonymity and, 38
  encounters with, 19
the governance landscape and, 252
  illustrative example concerning, 19,
  124–41
  information subjects’ experiences
  of, 127–35
  narrative impacts and, 135–41
types of information involved, 124
  information about
  discovery of, 126
  donor-conceived individuals’ legal
  entitlements to, 37–40, 126
  mitochondrial replacement
  therapy and, 40, 197, 253
  parental disclosure of, 38, 125–6
  recommendations regarding,
  252–3
  preference for/importance of
  knowing and, 135
Ravitsky on, 47
  responsibilities for disclosure
  and, 241
  social context and, 192
UK regulations and, 37–40, 124
  Donor Sibling Registry, 132
DPA (Data Protection Act 2018), 41, 45
DSD (differences in sex development),
  damaging narrative contents
  and, 203
DTC (direct-to-consumer) genomic
  testing services, 7, 9, 18, 44, 126,
  192, 257–9
ancestry tracing and, 54, 196, 206
  bioinformation governance issues
  and, 251
  genetic-essentialist assumptions
  and, 49
misleading information and, 201
  potential bioinformation disclosers
  and, 221
  recommendations regarding access/
  disclosure, 257–9
responsible communication of
  health information and, 240
  vignette concerning, 1, 2
Dumit, Joseph, 163, 165, 180
duty to help, 225–9
Edelman, Marian Wright, 197
Embodied Narratives
  case studies, list of, xiv
  guide to the chapters in this book,
  28–30
  terminology used in this book, 12–28
  embodiment, 90–4
  identity significance of, 190
  narrative identity and, 94–8
  empirical bioethics, 121
  entitlements to personal
  bioinformation in law, 31–42
epilepsy, 103, 261
  epistemic qualities of bioinformation,
  113–18, 200
ethical responsibilities for disclosure of
  bioinformation, 218–48
  ethical foundations of, 221–9
  limiting considerations and, 229–32
  shared social responsibilities
  and, 244
European (Oviedo) Convention on
  Human Rights and
  Biomedicine, 32, 33
European Convention on Human
  Rights (ECHR), Article, 8 of
  access to health records and, 41, 45
  right to identity and, 33–8, 250
European Court of Human Rights
  (ECtHR), 34, 250
European General Data Protection
  Regulation (GDPR), 41
European Study of Assisted
  Reproduction Families, 126
  exclusion, 55, 79, 82
  experiences, identity narratives and, 175
  external coherence, 103, 104
FDA (Food and Drug Administration),
  direct-to-consumer genomic
  testing services and, 44
feminist theories of self, 91
first-personal narration, 69
fMRI (functional magnetic resonance imaging), 158
Food and Drug Administration (FDA), direct-to-consumer genomic testing services and, 44
forensic genetic analysis, 204, 225
Fraassen, Bas van, 114
Freeman, Tabitha, 39, 138, 192
Frith, Lucy, 132, 138
functional magnetic resonance imaging (fMRI), 158
future challenges for access to personal bioinformation, 262
GDI (General Definition of Information), 13
GDPR (European General Data Protection Regulation), 41
General Definition of Information (GDI), 13
genetic ancestry tracing, 8, 9, 54, 206
African American ancestry tracing and, 54, 178
African ancestry tracing and, 196
Black British ancestry tracing and, 178
unreliability of, 206
genetic essentialism, 50, 140
genetic identity, 47
genetic information, 3, 8
issues of wider entitlement and, 40
‘right to know’ or ‘not to know’ and, 6
genetic parentage, 35, 46, 47, 107, 124
knowledge of, 10
Lillehammer on, 111
Velleman on, 58
genetic risk, 19
illustrative example concerning, 141–58
information subjects’ experiences of encounters with, 144–53
narrative impacts of, 153–8
type of bioinformation involved, 141–4
recommendations regarding access/disclosure and, 221
the ‘genetic self’, 48
genetic testing, 141–58, 192, 195 see also DTC (direct-to-consumer) genomic testing services
Gibbon, Sahra, 53, 54, 155, 178
Glover, Jonathan, 70, 80
Gooding, Holly, 145
governance, 5, 247–63
group identity, 26
Hacking, Ian, 53, 96
Hallowell, Nina, 146
Haraway, Donna, 191
Harris, John, 216
Haslanger, Sally, 52
Hauskeller, Christine, 46
intra-species classifications and, 53, 55
on reifying social distinctions, 9
the Havasupai people, 26
health research
bioinformation generated by, 4, 43
feedback of findings from, 6, 18, 43, 230, 253–5
identity harms and, 204
potential bioinformation disclosers and, 17, 220
health status, identity significance and, 190, 193
Healthcare Improvement Scotland, potential bioinformation disclosers and, 221
healthcare information
clinical actionability and, 210
right to access records of, 41, 45
secondary research uses of, 4, 43, 221
healthcare professionals, as potential bioinformation disclosers, 220
Hekman, Susan, 92
helpfulness, 225–9, 254
Henschke, Adam, 21
hermeneutic role of bioinformation, 113–18
HFEA (Human Fertilisation and Embryology Authority), 38, 39
applying to for donor information, 126
the governance landscape and, 253
home test kit companies, potential bioinformation disclosers and, 221
HRA (Human Rights Act 1998), 33, 38
Human Fertilisation and Embryology Act 1990 (HFE Act), 38
Human Fertilisation and Embryology Authority (HFEA), 38, 39
applying to for donor information, 126
the governance landscape and, 253
Human Rights Act 1998 (HRA), 33, 38
identity, 1–30
bioinformation impacts and, 8
constituting vs. revealing, 108
definitions of, 20–8
as a multi-stranded whole, 180
narrative theories of, 61–86
question of 'who we are' and, 3, 5
right to, under European Convention on Human Rights (ECHR), 33–7, 250
role of bioinformation in, 98–109
identity harms, 86, 199–205, 223
identity interests, 10, 181–219
ascertaining where they lie, 232–8
distinguishing from other interests, 208–17
fundamental identity interest and, 183–6
governance issues and, 247–63
information-related, 186–90
legal entitlements and, 31–40, 218
protection of, 2, 11, 12, 33–8, 45–6
relationships between structure and contents, 205–8
responsibilities for meeting, 219–46
identity narratives, 57–86, 172–80, 198
the body and, 94–8
contents of, 65, 86, 87, 99, 202–8, 224
fundamental identity interest and, 183–6
inhabitability of, 186
knowledge of genetic parentage and, 135–41
negative impacts and, 178
personal bioinformation as a tool of, 98–109
vulnerability and, 223
identity significance of bioinformation, 190–7
contexts of, 190–4
social construction of, 196
identity-supporting disclosure practices, 238–44
identity value, 43, 210
Illes, Judy, 166
illustrative examples of encounters with bioinformation, 19, 120–72
image (public persona), 21
imaging services, potential bioinformation disclosers and, 221
implanted devices, 103, 260
individual research findings, feedback of, 6, 18, 43, 230, 253–5
infertility, 103
information, as distinguished from data, 13
information-related identity interests, 186–90
information subjects, 3, 16
entitlements to access personal bioinformation and, 8, 31–42
information interests of, 5–8
informed consent, 214, 255
inhabitable narratives, 186
intelligibility, 64, 73, 75, 77, 83
harm to caused by misleading information, 201
internal, 103
internal coherence, 103, 104
International Declaration on Human Genetic Data, 32
International Human Rights Law, 32
interpretation, 13
interpretive frameworks, 14, 96, 105
Jolie, Angelina, 53
Juengst, Eric, 44, 49, 201
Kennett, Jeanette, 77
Keywood, Kirsty, 216
KH and Others v. Slovakia, 37

https://doi.org/10.1017/9781108652599.011 Published online by Cambridge University Press
Kirkman, Maggie, 59, 132
  on family stories and narrative identity, 140
  on ignorance of donor origins, 139
  on parents as key collaborators in helping donor-conceived individuals, 134
Klitzman, Robert, 57, 153
Korsgaard, Christine, 24, 87
Laurie, Graeme, 211, 257
  legal entitlements to personal bioinformation, 31–42, 45–6
Lillehammer, Hallvard, 110, 113
  the lived body, 91
Lloyd, Genevieve, 67
Lock, Margaret, 51, 148, 156
Loughlin, Michael, 116
Lupton, Deborah, 52, 116
Lynch syndrome, 100
MacIntyre, Alasdair, 62, 68, 94
Mackenzie, Catriona, 23, 24, 62
  on achievability, 84
  on biological realities, 106
  the body and, 95, 96, 98
  on capacities and capabilities, 79
  on characteristics, 116
  on coherence, 82
  on identity harms, 203
  on identity narratives, 63, 74
  on internal goods, 78
  on interpretive frameworks, 96
  on making sense of who we are, 76
  on narrative contents, 65
  on the relative integration of identity narratives, 82
  on Saks, 80, 169
  on the self over time, 64
  on Strawson, 80
magnetic resonance imaging (MRI), 158
major depressive disorder (MDD), 158, 162
MAOA gene, identity harms and, 204
Maori populations, 204
Marshall, Jill, 35, 37, 46, 51
  master narratives, 68, 87, 196
the material body, 91
Matthews, Steve, 77
MDD (major depressive disorder), 158, 162
meaningfulness, 14, 64, 87, 184
memories and experiences, identity narratives and, 175
mental health status, 158
  responsibilities for disclosure and, 241
vulnerability and, 224
Merleau-Ponty, Maurice, 91
Meyers, Diana, 81
  on achievability, 83
  emergent intelligibility and, 77
  on figurations, 196
  on intersectional identities, 81
  on self-descriptors, 194
Mikulic v. Croatia, genetic parentage and, 35
Miller, Franklin, 226, 254
misleading information, 200–2, 224
mitochondrial replacement therapy (MRT), 18, 40, 197
mobile apps
  potential bioinformation disclosers and, 221
  tracking pandemics and, 6, 260
MRI (magnetic resonance imaging), 158
MRT (mitochondrial replacement therapy), 18, 40, 197
Murdoch, Iris, 78
narrative coherence, 74
  achievability of, 82
  external, 103, 104
  harm to caused by misleading information, 201
  internal, 103, 104
  objections to, 79–86
  recapped, 183
  the value of, 79–81, 104, 205–8
narrative contents, 65, 99
  as damaging, 202–5, 224
  as meaningful, 87
  as relate to structure, 86, 205–8
narrative context, of identity significance, 193
narrative identity, theories of, 61–88
the body in, 94–8
narrative self-constitution, 61–88, 94 narratives. see identity narratives
narrativity, 58, 82, 86, 172–80
importance of according to Atkins, 97
interpretation and, 66, 100
relational, 67
requirements of, 71, 80
National Institute for Health and Care Excellence (NICE)
BRCA screening guidelines and, 142
potential bioinformation disclosers and, 221
need, vulnerability and, 222–5
Nelson, Alondra, 54, 178, 196
Nelson, Hilde Lindemann, 62, 68, 196
on counterstories, 83, 241
on the early chapters of our lives, 137
on first-personal narration, 70
on identity narratives, 74
on oppressive master narratives, 87
Nelson, Jamie, 58
on how our lives connect with those of others, 137
on the opening pages of our biographies, 107
neural activity, 9
neurobiological self, 54
neuroessentialism, 49
neuroimaging, 10, 49, 175, 195
communication context and, 193
data from, algorithmic analyses of, 159
motivations for, 162
psychiatric neuroimaging and, 20, 158–72
neuroscience, reportings of in non-specialist media, 9
neurotechnologies, 49
NICE (National Institute for Health and Care Excellence)
BRCA screening guidelines and, 142
potential bioinformation disclosers and, 221
Nordgren, Anders, 44, 49, 201
normative and conceptual foundations, filling gaps in, 46–60, 197–205
normative roles, 102–8
normativity, 60, 63, 78, 88
Novas, Carlos
biographical narration and, 57
risk identity and, 54, 56, 156
Nuffield Council on Bioethics, 47, 135, 140
numerical identity, 21
Nussbaum, Martha, 85, 87
Odièvre v. France, 36
oppressive conditions, 80, 83
oppressive master narratives, 87
origins cases, in European Court of Human Rights (ECtHR), 33–7
ovarian cancer, 141
overactive thyroid, 103
pandemics
bioinformation collection and, 4
tracking exposure/immunity via mobile apps, 6, 260
Parry, Bronwyn, 51
personal bioinformation, 5, 16
access to by information subjects, 8, 17
future challenges for, 262
information subjects’ entitlements in law and, 31–42
knowledge of genetic parentage and, 10
concerns about identity relevance and, 110–18
contexts in which encountered, 3, 16–20, 120–80
contribution to embodied narratives and, 119
defined, 13–16
epistemic qualities of, 113–18, 200
examples of encounters with, 4, 16–20, 120–72
identity significance of, 190–7
interpretive context and, 100
as a narrative tool, 98–109
normative roles and, 102–8
personal identity, 22
personal utility, 43, 210, 254
PET (positron emission
tomography), 158
phenomenology, embodiment and, 52, 91
Pickersgill, Martyn, 167
policy research, potential
bioinformation disclosers and, 221
Poltera, Jacqui, 62
on identity narratives, 74
on narrative coherence, 82, 84
on narrative scepticism, 80
on Saks, 80, 169
positron emission tomography (PET), 158
potential bioinformation disclosers, responsibilities of, 219–46
practical identity, 23
practical self-characterisation, 25
preparedness, 145, 210
principle of helpfulness, 225–9, 254
privacy, 6, 7, 45, 211
psychiatric neuroimaging encounters with, 20
illustrative example concerning, 158–72
information subjects’ experiences and, 161–7
narrative impacts of, 167–72
type of bioinformation involved, 158–61
psychological distress
narrative disruption and, 105, 138, 250
relationship to and distinction from
identity interests, 209
psychological preparedness, 145, 210
psychosis, 158, 204
public persona (image), 21
rational/ethnic profiling for forensic purposes, 204
Racine, Eric, 49
racism
misuses of genetic science and, 55
oppressive master narratives and, 87
Ravitsky, Vardit, 9, 47
reality constraint, 73
reductionism, 48
Rehmann-Sutter, Christoph, 239, 243
relational narrativity, 67–9, 240
relational roles, 28, 65, 68, 185, 189
relational self-constitution, 137
REVEAL Study, 143, 144–51
importance of interpretive context and, 188
participant counselling and, 148
rheumatoid arthritis, 101, 105
Ricoeur, Paul, 86, 97
right to identity
under European Convention on
Human Rights (ECHR), 33–7, 250
Human Rights Act (HRA) and, 33, 38
under United Nations Convention
on the Rights of the Child (UNCRC), 33
‘right to know’ or ‘not to know’, 2, 6, 217
right to respect for private and family
life, European Convention on
Human Rights (ECHR) and, 33–7, 41, 45, 250
rights, 182
risk identity, 54, 56, 156
Roberts, Scott, 258
Roe, David, 169
Rogers, Wendy, 60, 115, 117
on coherence, concerning
asymptomatic disease, 85
on narrative identity and
asymptomatic disease, 208
on vulnerability, 223, 228
Rose v. Secretary of State for Health, 38
Rose, Nikolas
narratives and, 57
risk identity and, 54, 56, 156
on self-characterisation, 10
Saks, Elyn, 80, 169
Scanlon, Thomas, 222, 225
Schechtman, Marya, 76, 77, 86
articulation constraint and, 103
the body and, 94, 99
on capacities, 85
on coherence, 84
on constraints on self-constituting narratives, 69, 72
on identity as characterisation, 25
on intelligibility, 81
on narrative identity, 61, 63, 65, 66, 71, 193
on practical identity, 23
on prenarrative truth about the self, 109
reality constraint and, 73, 104
on relational narrativity, 68
schizophrenia, 80, 158, 169
damaging narrative contents and, 203
psychiatric neuroimaging and, 163
screening programmes, 17, 18, 41, 221, 250
Scully, Jackie Leach, 239
on ascertaining where others’ interests lie, 232, 243
on mitochondrial replacement therapy, 60, 197
self-characterisation, 25, 35, 48, 63
self-constituting narratives, 61–88, 94
coherence and, 74
constraints on, 72–5
contents of, 65
objections to, 70–2
practical and evaluative capacities of, 75–9
selfhood, 63
self-narratives. see identity narratives
shared social responsibilities, 244
Shildrick, Margrit, 91, 92
sickle cell disease, 204
single-photon emission computed tomography (SPECT), 158
sleep-monitoring apps, 116
smart technologies, 4, 18, 44
potential bioinformation disclosers and, 221
tracking pandemics and, 6, 260
social construction, of identity significance, 191
social identity, 24
social responsibilities, shared, 244
somatic identity, 54
species identity, 21
SPECT (single-photon emission computed tomography), 158
Stewart, George, 33
Strawson, Galen, 70, 79
structure of identity, as relates to contents, 205–8
subject access rights under the Data Protection Act (DPA), 41, 45
sustainability, 184, 201
Taylor, Charles, 62, 67, 77
the body and, 94
on identity, 78, 86
on relational narrativity, 68
on self-constitution, 68
Taylor, Mark, 14, 15
terminology used in this book, 12–28
thyroid disease, 103
tracking devices, 44
governance and, 260
pandemics and, 6, 260
potential bioinformation disclosers and, 221
transphobia, oppressive master narratives and, 87
Type-1 diabetes, 207
UK Donor Conceived Register, 126
UK Longitudinal Study of Assisted Reproduction Families, 126, 131
UK National Screening Committee, 41, 221
UNCRC (United Nations Convention on the Rights of the Child), 33
unification, 75
Universal Declaration of Human Rights, 32
Velleman, David, 62
on acquaintance with genetic parents, 58, 107, 137
on observing family resemblances, 117, 137
on self-narratives, 75
vulnerability, 222–5, 226, 238
Walker, Mary, 60, 62
  on achievability, 83
  on brain data, 10
  on characteristics, 70
  on coherence, concerning
    asymptomatic disease, 85, 208
  distortion of self-conceptions and,
    115, 117
  on dramatic personal changes,
    76, 111

Young, Iris Marion, 93, 191

on identity narratives, 74
on making sense of who we are,
  76
on ‘revealing identity’, 108
Widdows, Heather, 27, 60, 247
Wilson, Sarah, 58, 107, 136
worthwhile narratives, 58, 87,
  184