

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
 Corsico, Paolo, 168, 170
 Council for International
 Organizations of Medical
 Sciences (CIOMS) Guidelines,
 disclosure of health research
 findings and, 43
 counterstories, 197

 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-person 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

- 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

 racial/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
 Rehmman-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
- Schildrick, 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
 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
- Young, Iris Marion, 93, 191