

Index

- abortion
 pressures to have an, 130–1, 135, 157, 176
 reversal of previous decision to undergo a
 first trimester termination, 175, 177
 selective, 129, 133, 136–9
 sex selection, 175
- AIDS, 77, 170, 172
- amniocentesis, 100, 138, 176
- anthropologist as diviner, 15, 64
- anthropology, 2–3, 20, 36
 bioethics, 37
 comparative, 31
 cultural, 46, 51
 current curricula, 45
 and ethics, *see* ethics
 and genetics, 54, 159; *see also* sociobiology,
 anthropological critique of
 medical, 36, 44, 167
- of morals, 34, 51; *see also* ethics, indigenous
 moralities
 social, 52, 53, 57
 study of ethics, 35
 syntax of genetics, 54
 theory, 44, 47, 52
- Anthropology and Ethics* (May and Abraham
 Edel), 36
- Appadurai, Arjun, 169
- Ardener, Edwin, 13
- Atkinson, Jane Monnig, 121–2
- Bailey, F. G., 93
- Berlin, Isaiah, 167
- biobanks, 155–6
- bioethics, 4, 37, 38, 145, 152–3, 158, 167
 American-ness of, 167
 critiques of, 37
 dilemmas of truth telling, 27, 87–90
 feminist, 38
 literature, 88–9
 non- maleficence, 126–7
- biology
 critical scholarship, 47
 cultural study of, 46
 ethical landscape, 53
- Blind Watchmaker, The* (R. Dawkins), 45
- Bok, Sissela, 92, 93, 100
- Bouquet, Mary, 90
- British government, 2
- British Medical Association, 88
- Canada, 166
- cancer
 bladder, 12
 colon, 12
- Canguilhem, Georges, 16
- 'Cardio', 178
- carrier testing, 164
- case studies, 61–72, 90–6
 Daley family, 94–6, 100–3, 162, 176;
 Isobel, 134
 Jeffrys family, 68–70, 72, 77; Dylan, 66–7
 Kingston family, 163; Ann, 111–15;
 Charles, 111–12; Claire, 115; Rex, 111,
 112–13, 115; *see also* Richardson family
- Mcdonald family, 162; Belinda, 77; Sam,
 61–2, 72–6, 170
- Opie family, 90–4, 103–4, 129–34, 162;
 Daisy, 96, 99
- Richardson family; Mabel, 112, 113–14;
 Nelly, 112, 114; *see also* Kingston family
- Williams family, 162; kung fu dispute,
 117–20; Lucy, 66, 79–83, 117;

- case studies (*cont.*)
 Hanno, 79, 118–20; Laurie, 62, 170;
 Rupert, 80, 117–20
- Cashinahua or Huni Kuin (peoples from the
 Brazilian–Peruvian borderlands in
 Amazonia), 98–9, 174
- Celera Genomics, 53
- Chadwick, Ruth, 87–8, 173
- Chagga, 38
- chemical sensitivity
 disease prediction, 12
- chiasma*, 55, 168
 between natural and social sciences, 56
- Christakis, Nicholas A., 38, 70, 71–2, 77,
 84
- Code of Codes, The* (Daniel Kevles and Leroy
 Hood), 47
- Collins, Francis, 11
- collusive lying, 93
- Comaroff, John and Jean, 170
- ‘complex disease’, 146
- consumer education, 148–9
- counselling, 87, 89, 95, 102, 104, 123, 126,
 127, 137, 140, 141, 147, 157, 171,
 172
- contradictions, 66
- literature, 67
- protocol (Britain), 66–7, 171
- cross-cultural comparisons, 4, 19, 20, 34, 35,
 37, 51, 82, 123, 158–9
- cultural imagery of progress, 30
- cultural relativism, 37, 167
- culturgens, 42
 critique of, 43, 46
see also Lumsden and Wilson
- Death Foretold* (Nicholas A. Christakis), 70
- DeHart, Scott, 170
- diagnosis as prognosis, 70–2, 75
- ‘diagnostic supremacy’, 71
- disclosure
 between estranged kin, 94
 ethics of, 89
 ‘verbal missiles’, 63–4
see also ‘kinship’, local moralities
 (of non-disclosure), non-disclosure,
 ‘right to know’ and
 ‘right not to know’, truth-telling
- discrimination
 familial, 139
- divination, 122, 123
- anthropological study of, 3, 18–19,
 165
- decision making in everyday life, 20
- ethnographic analyses of, 17–20
- divinatory knowledge
 Temne, 18
- DNA, 47–9
 chip, 154, 156–7
 coded information, 18, 63–4, 122
 as information or language, 46, 47–9, 167,
 168
 social value imputed, 47
- ‘do-it-yourself’ DNA testing kits, 10, 15
- Down’s syndrome, 1, 135, 169, 177; *see also*
 case studies, Daley family
- Doyle, Richard, 169
- Edel, May and Abraham, 36
- embryo
 ambiguous social entity, 21, 28
- empathetic witness
 problems of, 78–9, 80, 81, 83
- ethical system (testing system), 67
- ethics, 150
 based on individualism, 37–8
 ‘cold’ ethics, 31–5
 critique of Western, 36, 37
 cross-culture consensus, 30
 disclosure, 94, 101, 104, 173
 Gahuka-Gama ethics (Papua New Guinea),
 35
 relational, 138, 145; *see also* kin
 termination after single cell diagnosis,
 124–5
 termination in the case of late onset
 diseases, 125–6
- ethnocentrism, 34, 37, 44, 45, 121
- ‘ethno-ethics’, 20, 26
- ethnographic problem, 11
- ethnographies of morality, 4
- ethnography, 57
 comparative, 38
 ‘uncertain’, 77
- eugenics, 16
 ‘new eugenics’, 16, 28
- Evans-Pritchard, 3, 18, 19, 165
- evolution
 genetic and cultural, 42
see also sociobiology
- evolutionary ethics, 110; *see also* Spencer,
 Herbert

- exogenetic information
 intergenerational transmission of, 42
 'exogenic culture', 42
 experimental technology as anticipatory ritual,
 65–8
 explanatory models, 82
- Farmer, Paul, 38
- foreknowledge, 117, 125, 133, 139, 142
 and common future, 114
 and foretelling, 15, 27, 61–5, 152
 foretelling of the self, 83
 and genetic agency as relational, 85–6
 and fatalism, 148
 and liabilities of veracity, 100–5
 and moral systems, 15; *see also*
 pre-symptomatic
 and prognostic moralities, 5, 25, 70–2, 78
see also 'kinship' secrets and relations
- Foucault, M., 16
- Freeman, Derek, 42, 46
- Firth, Raymond, 35, 168
- Frank, Geyla, 172
- friends, 80–1, 83
- 'genealogical ethics', 4, 15, 153
 'genealogical method' (W. H. R. Rivers), 90
 genealogy
 importance of anthropology to, 89–90
 'gene action', 49
- genes
 as agents, 54, 55, 169
 as biological markers of kinship and cultural
 differentiation, 117; inadequacy of, 120
Genes, Mind and Culture (Edward O. Wilson
 and Charles Lumsden), 43
- genethics, 21, 50
 anthropology dialogue on personhood, 52
 critique, 52
 literature, 50; culture, 51
 popular science, 51
- genetic altruism, 110
- genetic donors, 155
- genetic health policy, 145
- genetic health services, 67
- genetic information, 14–15, 17, 27, 49, 52,
 87–9, 96, 109, 122, 126, 137, 144, 152–4,
 156, 159, 170, 171
 choice, 154
 choosing not to know, 67, 150, 157
 commodification, 116
 cross-disciplinary sources, 154–8
 decision-making, 85
 indigenous accounts of, 145
 right to know, 104, 178
see also disclosure
 'genetic oracle', 65
 genetic privacy, 14
 genetic science, as informational, 48
 genetic surveillance, 153, 156
 genetic testing
 commercialisation, 147–9, 150, 152–3,
 178
 false negatives, 148
 newborns, 178
 pressures to undergo genetic testing, 150
see also predictive genetic testing
- genetics
 activists, 51
 anthropology, 54, 56; gift theory, 56
 family, 84; 'linkage', 168
 matter of public accountability, 57
 as origins story, 54
 spatialised methodology, 55
- Genetics White Paper, 155, 156
- genomics
 comparative, 168
 global, 51
- Gille, Elizabeth, 9, 13
- Gnau (people of Papua New Guinea), 98
- gnosis
 limits of as epistemological framework, 86
- Goffman E., 81
- Gould, Stephen Jay, 32–5, 39, 51
- Guidelines for the Molecular Genetic
 Predictive test in HD, 170
- Hamilton, William 'Bill', 110
- Haraway, Donna, 169
- Harris, Marvin, 44
- Hausa
 medical culture, 96–8
- health care professionals
 attitudes towards predictive testing, 65
 clinicians, 124–5
 education, 67
 orthodox views, 136–7
- health policy administrators, 12
- Hereditary Disease Foundation, 24
- Heyd, David, 51
- Hippocratic practitioners, 71, 172
- Hoffmaster, Barry, 36

- House of Commons Science and Technology Committee (London), 171
 Human Genetics Commission (UK), 15, 17, 175
 human genome, 3, 9, 29
 ‘as [common] heritage of humanity’, 30
 ‘ownership’ of, 53
 Human Genome Initiative, 54
 Human Genome Project, 11, 53
 humanities and social sciences, 158
 Humphrey, Caroline, 36
 Huntington’s Disease (HD), 22
 community, 22–3
 ‘early onset’, 136, 177
 gene mutation, 22
 as late onset disease, 125–6
 Huntington’s Disease Association, 23
- indigenous moralities, 35, 52
 individualism, 41, 88, 109, 123, 139, 167, 173
 pre-emptive, 151–8, 159
 social critique of, 152
 interdisciplinary discourse, 4–5, 57
 intergenerational transmission of genetic [non] knowledge, 27
 International Bioethics Committee, 166
 International Human Genome Sequencing Consortium, 53
 interviewees, 160
 interviews, 23–4, 160–1
- James, Wendy, 38
 Jones, Steve, 47
- Kay, Lily, 48–9
 Keller, Evelyn Fox, 48
 Kevles, Daniel and Leroy Hood, 47
 kin, 85, 109, 149, 153, 157
 discrimination, 139
 dividing lines, 122
 loyalty, 110–17, 139
 outsiders, 112, 123; *see also* case studies, Kingston family
 parents and children, 104, 115, 131–4;
 see also Opie family
 selection, 41
 siblings, 131–3
 see also ethics, relational
 ‘kinship’
 children, 138
- communication, 63
 disclosure, 93–4, 127
 embryo as future relation, 125
 ethics, 15, 68, 109, 112, 145, 170
 and exclusion, 28, 109–23, 124–45, 149, 157
 medicalisation of, 52
 as relational ethics, 4, 76, 104, 109, 110, 120, 121, 145, 158
 relations, 9
 renewed theoretical interest, 90
 secrets and relations, 90; *see also* case studies, Opie family
 Kleinman, Arthur, 21, 37–8, 82
- La Crabe sur la Banquette Arrière* (Elizabeth Gille), 9
Language of the Genes, The (Steve Jones), 47
 Last, Murray, 28, 96–8
 Leach, Edmund, 42–3, 46
 Lévi-Strauss Claude, 121
 Lewis, Gilbert, 28, 98
 Lieban, Richard, 20
 living at risk, 73–5
 local moralities (of non disclosure), 101
 Lock, Margaret, 19, 165
 Lock and Kaufert, 76
 Lumsden, Charles, 43
- McCallum, Cecilia, 28, 98, 174
 McClintock, Barbara, 169
 Macpherson, 41
 Malinowski, Bronislaw, 54, 63
Mapping Fate, (Alice Wexler), 24
 Mattingly, Cheryl, 65, 70
 Mauss, Marcel, 56
 media, 5, 11, 16
 medical confidentiality, 87, 173, 178
 ‘Modern Synthesis’, 48, 49
 monogenic, 1, 4, 14, 22, 146, 166
 Montagu, Ashley, 40
 moral choices, 153
 moral prognostication, 84
 different tolerances for, 85
 family, 84
 morality
 decision-making, 76
 of divination, 20
 positivist, 36
 multidisciplinary teams, 127–8, 147

- narrative analysis, 21
 and 'therapeutic plots'
- narrative ethics, 15, 21, 165
- narrative gap between a-symptomatic and culturally classified as 'presymptomatic', 70
- NAT2 gene variation, 12
- National Health Service, 12, 66
 plans, 151
- National Human Genome Research Institute (NHGRI), 11
- National Institute for Clinical Excellence (NICE), 12
- 'natural selection', 28, 41–2, 45
- 'naturalistic ethics', 110; *see also* Wilson, Edward O.
- Neo-Darwinism, 39, 44
- new diagnostics, 17
- non-disclosure, 87–105, 109, 126, 134, 150
- non-knowledge, 24, 27, 86, 88, 89, 92, 97, 104, 126, 128, 144
- Nuffield Council on Bioethics, 88
- Nukaga, 166
- Nyole, 77, 82, 83, 103, 170
- Orissa, marriage ceremonies and bridewealth speeches, 93
- Panamanian Indians, shamanic practices, 121
- parental concerns, 68, 69, 72–6, 96
 planning for the future, 140
 responsibility, 144
- Parkin, David, 35
- Pauling, Linus, 16, 17
- Peek, Philip, 20
- Pellegrino, 38
- personhood, anthropology, 52
- Petersen, Alan and Robin Bunton, 13, 151
- pharmaceutical companies, 10
- phenylketonuria, 2
- philosophy, 36
- physicians, 71
- Pocock, David, 35
- polygenic, 1, 4, 10
- polymorphisms (gene variations), 11
- Popper, Karl, 170
- postgenomic synthesis, 46, 50
- public policy debates, 14, 171
- predictive genetic testing
 anticipating future illness before and after, 27
- dilemmas of, 5, 13, 24, 25
- future of, 9
- imprecision, 146
- rate of uptake amongst HD community, 5, 25
- reasons not to take, 67
- reasons to go through with, 65
- routinised, 17, 156, 164
- predictive medicine, 146–8
 as multifaceted enterprise, 11
see also 'genetic oracle'
- pre-implantation genetic diagnosis (PGD), 28, 124–9, 174–5
- dissent, 176
- as exclusion of the embryo, 125–6
- as exclusion of knowledge (right to know), 126–7
- logistical difficulties for maintaining secrecy, 127–8
- non-disclosure, 126; ethical considerations of the potential adult, 128–9
- as stilling selection (de-selection), 133, 138;
see also kinship
 and termination, 137
- pre-natal embryogenesis, 38
- prenatal testing, 2, 100, 133, 135, 137, 175
 low uptake for HD, 177
- parental decision-making in practice, 137
- pre-symptomatic, 1, 2, 21, 64, 92, 132, 149, 153, 161
 assumption of pre-symptomatic status, 25, 72, 157
- cultural imagery, 25
 and disability, 178–9
- living with pre-symptomatic diagnosis, 5, 14
- meaning of, 83–6
- morality of divination, 19
 and symptomatic illness, 82
- temporal gap between diagnosis and prognosis, 75, 78
- tests, 16
- pre-symptomatically symptomatic person
 paradox of, 82
- 'preventive health', 12
- prognosis, 70
 anticipated, 84, 172
 embodied, 84
 gap between diagnosis and, 13, 23, 70–2, 75, 78, 150

- prognostic uncertainty, as used by doctors, 85
 prophecy, 13–14
- Rabinow, Paul, 11, 167
 Rapp, Rayna, 66, 138, 171, 176
 Read, Kenneth, 35
 relations, 9, 13, 27
 religion, 62, 170
 reproductive choices, 124–45
 research participants, 169
 Ridley, Matt, 47
 right to disability, 176
 ‘right to know’ and ‘right not to know’
 debates, 17, 87–9, 104, 109–23, 178
 child’s, 175
 ritualisation of optimism, 76
 Rivers, W.H.R., 90
 Rose, Hilary and Steven Rose, 110
 Rose, Steven, 58, 168
 Rothman, Barbara Katz, 100
- Sahlins, Marshall, 40–1, 44
 Schneider, David, 45
 science
 role of metaphor in, 169
 Western, 30; cultural studies of, 32; and falsification, 64; and ‘non-overlapping magisteria’ (NOMA), 32; and objectivism (in chapter 1), 32, 33, 76; relation to social values, 2, 31–5; and truth, 61, 65, 76, 86
 science wars, 32
 scientists
 normative, 32
 objectivist, 32
 Sciona Ltd, 164
 secrets, 100
 secrets and discretion, 92; *see also* Bok, Sissela selecting-in, 157
 self-diagnostics, 151, 152–3
 co-opting of, 151
Selfish Gene, The (R. Dawkins), 45
 Shaw, Rosalind, 18
 sibling equivalence, 131–3, 134–43, 145;
 see also ‘kinship’
 Singer, Merrill, 36
 Snow, C.P., 33
 social anatomies of interdependence, heredity
 as, 121, 153; *see also* ethics, relational
- sociobiology, 39
 anthropological critique of, 39–47, 109, 123
 ‘Modern Synthesis’, 40
Sociobiology: The New Synthesis (Edward O. Wilson), 39
 Sociobiology Study Group of Science for the People, 39
 Spencer, Herbert, 110
 Strathern, Marilyn, 58
 ‘surveillance medicine’, 13
 susceptibility testing, 164
 Suzuki, David and Peter Knudtson, 51
 systems biology, 154
- testees
 potential and counselling, 66
 reactions to results, 64–5
 testing children for adult onset conditions,
 (juvenile genetic testing)
 mainstream professional opinion,
 139
 rights of children, parents and professional
 opinion, 142
 ‘thousand dollar genome’, 10, 151, 164
 Tokar, Brian, 51
 translocation, 26, 55–8, 158–59
 Robertsonian, 56
 trinucleotide CAG expansion repeats
 (characterizing the HD gene), 170
 Trobriand ritual speech, 63
 truth-telling, 89, 90–3
 ‘family of untruth’, 94, 104
 ‘open secrets’, 93
 ‘truth dumping’, 85
 see also disclosure, non-disclosure, case
 studies, Opie family, secrets
- UNESCO, 29, 30
 Universal Declaration on the Human Genome
 and Human Rights, 29
 reactions to, 31
 unsolicited disclosure, 27, 87, 104
 parents, 137
 UK Biobank, 178
 UK GTN, 177
Use and Abuse of Biology (Marshall Sahlins),
 40
- value, concept of, 35, 37, 168
 Venter, Craig, 53

Index

203

- Voice of Prophecy, The* (Edwin Ardener),
13
- Wana shamans, 121–2, 174
- Wexler, Alice, 24
- Wexler, Nancy, 165
- Who Wrote the Book of Life?* (Lily Kay),
48
- ‘Whose Hands on Your Genes’, 14–15
- Whyte, Susan Reynolds, 77, 82, 83, 103, 170;
see also Nyole
- Wilson, Edward O., 39–40, 110
- Witchcraft, Oracles, Magic among the Azande*
(E. E. Evans-Pritchard), 3
- Young, Katharine, 172