

## *Index*

- abortion, 41, 50, 52–7, 61–2, 64 *see also*  
   reproductive choice
  - abuse, of children, 64, 66
  - accountability, 16, 20, 118–40, 143, 156–7,  
   175 ff. 180–81, 190 *see also* audit,  
   openness
  - actuarial fairness *see* insurance
  - adoption, 64, 68–9
  - Adorno, Theodore, 23
  - adverse selection *see* insurance
  - agriculture, 2, 5, 11, 120, 122, 162–3, 168,  
   177–8
  - Alder Hey, 146, 154–5
  - Alzheimers, 113
  - animal
    - rights, 3
    - testing, 126, 138, 142
    - welfare, 5, 126, 138, 170
  - animals, 5, 6
  - anonymisation of data *see* data  
   protection
  - anti-paternalism *see* paternalism
  - Aristotelian ethics, 77
  - Association of British Insurers (ABI)*, 112–14
  - audiences *see* communication
  - audit, 129–34, 137, 156–8, 166
    - financial, 131, 175
    - second-order, 132 *and see*  
   accountability
    - society, 21, 131–3
  - authoritarian personality, 23
  - authority
    - arguments from, 90, 93
    - medical, 99
    - of reason, 91 ff
    - public, 3, 107, 121
  - autonomous decision-making
  - autonomy *passim* but especially chs. 1–4
    - and trust, ix, 1–4, 15–27
    - as fundamental to morality, 29
    - as independence, ix, 21, 28
    - as reflective scrutiny, 33–4, 37
    - as self-determination, self-mastery, 33
    - as trait, 29 *see also* moral development
  - conceptions of, 16–27, 28–48
  - formula of, 84
  - individual, 1, 2, 20–27, 28–48, 49–72,  
   73–4, 82, 85, 90–6, 101, 109, 148,  
   151–2, 166–9, 182, 184, 192
  - of cities or states, 29–31
  - of patients, 4, 16, 20–7, 37–8, 434,  
   48–9
  - personal *see* autonomy, individual
  - principled, 73–95, 145, 149–51, 192
  - reproductive *see* reproductive  
   autonomy
  - triumph of in bioethics, 43–7
- babies, designer *see* genetic enhancement
  - Baier, Annette, 13
  - Beauchamp, Thomas, 22, 34–5, 46
  - beneficence, 34–5, 39
  - biodiversity, 11
  - bioethics declarations, 129
  - bioethics, ix–xi, 1–2, 4–7, 12, 17, 22–8,  
   34–48, 53, 73–4, 76, 118, 125, 166,  
   180 ff. *and see* ethics
  - biotechnology *passim and see* technology

blame, 10  
 blood, blood donors, 41, 120, 146–7, 152, 158  
 Brandeis, Louis D., 54–5  
 broadcasting, 174–6, 177–8, 180, 186, 190  
     public service, 180  
 BSE, 15, 120, 128, 161  
 bureaucracy, 130–1  
 business *see* companies, insurance  
  
 campaigners, campaigning groups, 1, 3, 10, 135, 137, 170, 172–4, 177, 188, 190  
     environmental, 9, 12, 121, 141, 170  
 carrier status, 104, 106, 110  
 Cassandra Problem, 141, 165  
 censorship, 180, 189–91 *see* ethics of  
     media, freedom of press  
 character, 23, 31–4  
 child support, 100  
 Child Support Agency, 108  
 children and parents, 18, 40–1, 46, 51–70, 155–6  
 Childress, James F., 34–5, 46  
 choice  
     consumer, 43–4, 168  
     life-style, 5, 167  
     mere, 25, 28, 31, 38, 90, 185  
     rational, 46  
     reflective, 26  
 citizens' juries, 172–3 *see* democratic  
     legitimation  
 CJD, 128, 146  
 clinical trials, 42, 124, 143  
 cloning, 58, 67–9  
 codes, professional *see* professional codes  
 coercion, 31, 86–7, 97–8, 107, 123, 138, 145, 151–3, 160, 185  
 coercion, reproductive *see* reproductive  
     coercion  
 communication, 6, 12, 165–92  
     accuracy of *see* reporting  
     assessability of, 182, 185, 187, 189, 191–2  
     one and two way, 186–7

communitarians, 22  
 companies, 9, 120, 137, 141, 143, 172, 186  
     *see* media  
 complaints, 21, 26, 39  
 compliance, 116, 123, 126, 129, 145, 166, 191  
 confidence *see* trust  
 confidentiality, 20, 35, 97, 101–2 *see* data  
     protection, rights to privacy  
 conflicts of interest, 12, 135, 151, 176, 190  
     *see* declarations of interest  
 consent  
     and harm, 45  
     as propositional attitude, 42–4, 154–5  
     familial, 102  
     forms, 155–8, 160, 165  
     genuine, 157–9  
     incapacity to, 40–42, 151–2  
     informed, x, 2–3, 17, 22, 27, 35, 37–48, 49, 73, 96–7, 101–2, 105, 125, 141–64, 165, 167  
     proxy, 40–1, 152  
     refusal of, 158–9  
 consultation, public *see* public  
     consultation  
 consumers  
     consumer protection, 116, 144  
     consumerism, 47–48  
 contraception, 41, 51–4, 56, 61–2 *see*  
     technologies, reproductive  
 coroner, coroner's authority, 145–6, 152–4  
 corruption *see* deception  
 counselling,  
     genetic *see* genetic counselling  
     prenuptial, 76  
 couples, 56, 65 *see* reproductive choice  
 credibility *see* trust  
 credulity *see* trust  
 cynicism *see* trust  
  
 data, databases  
     databases, 99, 127  
     data protection, 101, 109–10, 127, 159–60

- data, personal, 2, 99, 101–2, 105, 159
  - see* databases, data protection;
  - insurance; medical data
- data, secondary analysis of, 42, 146, 155–6
- death rates, 8, 11, 51, 134, 143, 150
- debate, ‘wide-open, robust’, 183, 185, 187, 191
- deception, 97–9, 100, 107, 119–20, 123–6, 145, 151–3, 160, 185–6, 188
  - of patients, 119, 123
  - of public, 120 *see also* trust, abuse of.
- declarations of interest, 135–6, 176, 178, 191
- deliberation, public *see* public deliberation
- dementia, 40–1
- democracy, 178, 181, 183
- democratic legitimisation, 75–6, 168–74
- desires, 30–3, 37
  - first- and second-order, 34, 37, 90
- discrimination, 114
- disinformation *see* deception, trust
- distrust *see* trust
- DNA technologies *see* technologies, genetic
- DNA test results, 102–4, 110–16
- doctor–patient relationship, 17–27, 35, 38–9
- doctors, 3, 9, 12, 17–27, 118–20, 130, 141, 175, 190
- donors *see* blood, egg donors, sperm donors, tissues
- drug trials *see* clinical trials
- duties *see* obligations
- Dworkin, Gerald, 21–2
- Dworkin, Ronald, 55, 60
- eco-systems, 5, 6
- egg donors, 57, 69–70, 146
- ELSI requirements, 1, 125 *see* obligations
- energy use and saving, 163, 167
- environment, 2–7, 10–11, 45–6, 143–4, 161–4, 166–8
- environmental campaigners *see* campaigners, environmental
- epidemiology, 100
- ethics
  - committees, 11, 28, 58–60
  - environmental, 2, 4–7
  - medical, 1–2, 4–7, 16–27, 34–48, 49, 73–4, 100 *see* bioethics
  - of media, 184–92 *see* communication
  - virtue, 22
- expertise, experts, 3, 118, 120–1, 133–5, 137–8, 142–3, 166, 170, 172–5, 191–2
- Faden, Ruth, 22
- familial consent *see* consent, familial
- familial genetic data *see* genetic exceptionalism
- family relationships
  - ambiguous, 67–8
  - confused, 67–8
- fertility, 51–72
  - control, 51–4, 57–8
- food safety, 5, 8–10, 45, 126–8, 142, 162–4, 166
- forensic use of genetic data *see* genetic data, forensic use of
- fostering, 68–9
- fraud, 120
- freedom
  - of information, 136
  - of the press, 180–1, 183–4, 189–92
  - of (self) expression, 60, 182–5, 187
  - of thought, 56
- gene therapy, 70–1
  - germ line, 71, 99 *see* genetic engineering; genetically modified organisms
- genealogy, 68
- genetic
  - data, human, 71, 99–101, 103, 105, 107–16, 128
  - databases, 99
  - database, forensic use of, 106–8, 171–2
  - disease, 110–11
  - engineering, 99
  - enhancement, 100

- genetic (*cont.*)  
   exceptionalism, 101–5  
   fingerprints *see* genetic profiles  
   profiles, 100, 105–10  
   technologies *see* technologies, genetic  
   tests, 41, 99, 100, 102–16  
 genetically modified organisms (GMOs),  
   120, 128, 139, 143, 161–2, 168, 177,  
   180  
 genetically targeted medicines, 100  
 gift relationship, 158  
 giving *see* blood donors, egg donors,  
   sperm donors, tissues  
 globalisation, 8, 125, 150  
 good will, 13  
 good, theories of, 76–7, 90  
 gossip, 179, 188  
 government, 10, 118, 170  
  
 harms, 45–6, 66, 73  
 Harris, John, 58–60, 63  
 health care, 26, 149–51, 169–70  
 Hill, Thomas E. Jnr., 21 n, 22 n  
 Hippocratic principle, 20, 35 *see*  
   professional codes  
 honesty *see* deception  
 hospital medicine *see* medicine,  
   hospital-based  
 human genetics *see* genetic data, human  
 human tissues *see* tissues  
 humanism, 7  
 Humphries, John, 178  
 Huntington's, 102, 110, 113  
  
 Immigration, 100, 109  
*in vitro* fertilisation (IVF) *see* technologies,  
   reproductive  
 independence *see* autonomy, individual  
 individual risk level, 114  
 individuality, 31–4, 37, 85 *see* autonomy,  
   individual  
 industry *see* companies, 9  
 infertility *see* fertility  
 information *see* communication,  
   databases, technologies, information  
  
 informed consent *see* consent, informed  
 insurance, 39, 110–16  
   and genetics, 99–100, 103, 110–16  
   life, 111–2, 114  
 IVF *see* reproductive medicine  
  
 journalism, 174–92 *see* broadcasting,  
   communication, freedom of the  
   press  
   chequebook, 189  
   investigative, 182, 189, 191  
   print, 175 ff., 185–6, 189, 191  
   tabloid, 177  
   undermining trust, 175 ff, 184–92 *see*  
     communication  
 judgement, practical, 123–5  
 justice, xi, 4, 35, 76  
  
 Kant, Immanuel, 22 n, 23, 29–31, 74,  
   83–95  
 Kantian autonomy *see* autonomy,  
   principled  
  
 league tables, 133–4 *see* accountability,  
   openness,  
 legislation, 126–7, 129, 166  
 legitimisation, democratic, 75–6  
 liberals, 167  
 libertarians, 167–8  
 liberty, 32–3, 45–6, 88 *see* freedom, rights  
 life, sanctity of, 60 *see* rights to life  
 litigation, 21  
 lying *see* deception  
  
 marriage, forced *see* reproductive,  
   coercion  
 media, 181–2, 188–92 *see* broadcasting,  
   ethics of media, journalism, press,  
   medical  
   coercion, 20  
   data, 100–101  
   ethics *see* ethics, medical  
   practice, 1–2, 10, 16–27, 34–48, 99,  
     126, 149–51  
   system, 35

## Index

211

- medicine
  - alternative, 12, 121–2, 127, 143, 163
  - high tech/hospital-based, x, 4, 8, 39, 143
- Milgram experiments, 24
- Mill, John Stuart, 23, 29–34, 37, 40, 45, 66
- misinformation *see* deception, information, trust
- mistrust *see* trust
- monitoring, 131 *see* audit
- Monsanto, 15, 120 *see* genetically modified organisms
- moral development, 23–4, 31
- mortality *see* death rates
- Murray, Thomas, H., 41 n
  
- naturalism, non-naturalism, 29–34, 37
- newspapers *see* freedom of the press, journalism, reporting
- Nolan Principles, 174 ff. *see* openness
  
- obligation, x, 6, 10, 25, 77–95
  - to reject coercion, 86–7, 97, 124–5, 149–50
  - to reject deception, 97–9, 124–5, 150, 185, 190–2 *see* ethics of media
  - to reject indifference, 88
  - to reject injury, 87–8, 96, 150
- obligations
  - and action, 79–82, 86–8, 166
  - and rights *see* rights and obligations
  - derived from principled autonomy, 86–95, 149–51
  - to share information, 104
  - parental, 62–70
  - professional, 126, 129, 149–50
- officials *see* public sector and public service
- Opacity *see* consent, as propositional attitude
- openness, 131, 134–40, 166
- opinion polls, 8–9, 135, 171
- Oregon experiment, 169–70
- organic crops *see* agriculture
  
- parents *see* children and parents
- paternalism, 5, 33
  - medical, 2, 16–27, 53
- paternity tests, 70, 108–9
- patient choice, 18
- patients, 3–4, 17–26, 38–42, 118, 145, 151–4
- pharmaceutical companies, 42, 126, 141–2
- pharmacogenetics *see* genetically targeted medicines
- physicians *see* doctors
- Piaget, Jean, 24
- planned parenthood, 50–1
- politicians, 1, 135, 175, 188
- pollution, 3–6, 10, 15, 122, 162, 166
- population, 5, 8, 51 *see* death rates
- potentiality, argument from, 57
- practical reason, 73–4, 89–95 *see* autonomy, principled
- practitioners, alternative *see* medicine, alternative
- precautionary principle, 10, 162–4
- press, 3, 9, 174–92
  - freedom *see* freedom of the press
- principles, 34–5, 123–5
  - and action, 35
  - and judgement *see* judgement, practical
  - in bioethics, 34, 46
- privacy, 20, 22, 35 *see* data protection, rights to privacy
- procreation *see* reproduction
- professions, professional
  - certification, 20, 39, 126
  - codes, 20, 21, 127, 129, 154
  - failures, 9, 39, 119–20
  - honour, 14, 134
  - judgement, 14, 133
  - malpractice, 15–16, 119–20 *see* trust, abuse of
  - oaths, 17, 130
  - relationships, 17–27
  - self-regulation, 127, 129
  - standards, 39, 123, 126–7, 133–4, 190–2
  - see* doctors, experts

- propositional attitudes *see* consent, as propositional attitude
- public
  - consultation, 140, 170–3
  - deliberation, 170–1, 173
  - goods, 4
  - harms, 4
  - health, 4, 7, 45–6, 126, 144, 161–4, 166–8
  - policy, 118–40, 143–4, 161–4, 168–74
  - policy and consent, 45, 161–4
  - relations, 173, 188
  - sector and public service, 118, 131, 133, 135, 137–41, 144, 166, 172, 175–6, 190–2
  - understanding, 171, 173
- rape *see* reproductive coercion
- record keeping *see* accountability, databases
- referendums, 173
- referential opacity *see* consent, as propositional attitude
- regulation, 44–5, 9, 11, 16, 21, 109–10, 123, 126, 128–9, 137–40, 142–3, 150, 166, 175, 180, 192
- relationships
  - face-to-face, 39
  - institutional, 39
- reliability, 14–16, 166 *see* trust
- remarriage *see* reproductive choice
- reporting, 178–84, 186–8
- reproduction, 48–72, 126–7
  - assisted, 56–72
- reproductive
  - autonomy, 55–72, 96
  - choice, 49–72
  - coercion, 50, 64
  - decisions, 41, 50
  - ethics, 48, 50
  - freedom, 50–72
  - medicine, 49–72
  - technologies, x, 50–72
- reprogenetics, 58, 70–2
- research, scientific and medical *see passim*
  - on children, 41
  - subjects, 41–2 *see also* genetics, tissues, reproduction
- respect
  - for patients, 21 *see also* rights, autonomy
  - for persons, 2, 6, 11, 16–17
- rights, 2, 6, 11, 25, 78–82, 166
  - and obligations, 78–83, 149–51, 166–9, 181–2
  - human, 6–7, 74–6, 78
  - justiciable, 150
  - language of, 6, 78, 81–2
  - to choose and to refuse, 2, 49, 51–72
  - to found a family, 61
  - to health, 10, 79, 150
  - to health care, 150
  - to know, 102, 104
  - to life, 21–21
  - to privacy, 53–7, 178
  - to reproduce *see* reproductive autonomy
  - to underwrite, 117
- risk, 7–12, 122, 131, 160–5, 169, 175
  - and trust *see* trust and risk control, 8
  - information, 116–17, 163
  - perception, 8
  - pools, 114, 117
  - society, 7–12 *and see* precautionary principle
- Robertson, John A. 58–9
- rules *see* principles
- safety *see* risk
- scandals, 177, 192
- scepticism, 12, 122, 141
- science and scientists *see passim*.
- secrecy *see* openness
- self-expression, 55, 61, 66, 73, 84 *see also*
  - autonomy, freedom of the press
- self-legislation, 84–6, 93–5

- sensationalism, 177, 179–80  
 sentimentality, 179–80  
 sociology, 7–8, 12, 26  
 speciesism, 6–7  
 sperm donors, 57, 69–70, 146  
 spin, 188  
 sterilisation, 41, 55 *see* reproductive coercion  
 ‘stories’, 175, 178, 183, 188–90  
 suspicion *see* trust
- technology, technologies,  
   biotechnologies, 15, 120–2  
   genetic, 8, 35, 48–9, 99–117  
   green, 11, 121, 167  
   information, 8, 100, 136–7  
   nuclear, x, 15  
   reproductive, 35, 49–72, 139, 143  
 testimony, 139–40  
 tests, genetic *see* genetic tests  
 theft *see* deception  
 Thompson, John 130–1  
 tissue, tissues, 127, 143–61  
   donors, 146–57  
   market in, 147–8, 158  
   removal of, 127, 143–61  
 Titmuss, Richard, 158  
 transparency *see* openness  
 transplants *see* tissue donors  
 trust *passim*, but especially, 118–40 and, 165–92  
   abuse of, 18, 34, 116, 119, 122, 124, 141, 191  
   and good will, 13  
   and risk, 122, 143, 160  
   and role, 13–14, 20, 25  
   blind, 18, 143  
   crisis and loss of, ix, 3, 7–9, 12, 25, 99, 110–11, 128, 130–1, 137, 142–3, 161, 164  
   depletion of, 97, 132, 191  
   economising on, 130–2  
   maintenance of, 100  
   misplaced, 119, 141, 143, 165  
   of strangers, 13, 20  
   placing of, 9, 11–16, 97, 116, 118, 121–3, 140–3, 173, 187, 192  
   public, 3, 7, 9, 15, 73, 113, 137–40, 161, 174–6, 191–2  
   reasonable, 8, 11, 15–6, 21, 154, 161  
   reciprocal, 12  
   relations of x, 4, 17–18, 20, 24, 38, 95, 130  
   restoration of, 131, 133, 145, 153–4, 157, 161, 174–5, 191–2  
   well-placed, 142  
   withdrawal of, 119–21, 143 *and see* reliability  
 trustworthiness, untrustworthiness, xx, 3, 9, 11–12, 15, 97–8, 118–40, 141–2, 165–92
- US Constitution, 56, 60  
*Universal Declaration of Human Rights*, 61, 75  
 utilitarianism, 32–3, 73, 77
- vaccination, 46  
 vulnerability, 38, 40–42, 44, 66, 70, 88–9
- Walden, George, 178  
 water, 2, 5, 8, 10–11, 45, 122, 142, 161, 166, 168  
 wealth, x–xi, 8  
 well-being, 32  
 Wood, Allen, 89–90