Cambridge University Press 978-1-107-02080-1 — Ethical Problems and Genetics Practice Michael Parker Index <u>More Information</u>

### Index

Abortion Act, 78 abortion and genetics professional's commitment to patient-centredness, 70-79 academic bioethics, 4 ad hoc referral, 89 adoption, 3, 47, 57 and complexities of social relatedness, 51 and paternity issues, 54 and pedigree information, 24 adrenal tumour, 45 adult and paediatric endocrinology, 10 adult-onset cancer, 95 affected females, 75 Alport's Syndrome, 72 American Anthropological Association, 138 amilial adenomatous polyposis (FAP), 25,56 anthropology, 138 anticipatory informed consent, 140 Ashkenazi founder mutations, 57 assemblage of 'families', 35 Association of Social Anthropology of the UK and the Commonwealth, 138 at risk of a genetic disorder, 37, 39 at risk of an inherited disorder, 37 at-risk families, 16, 20, 38 at-risk pregnancy and genetic testing. See genetics professional's commitment to patient-centredness autosomal dominant condition, 47 autosomal recessive condition, 54 awareness of genetic risk, 40 biased information, 64 bioethicists, 112 bioethics literature, 5 biological interdependence in socially

separated families, 53 biological relatedness, 12, 36, 38–40

vs difference of values, 44 and genetics professionals, 48-53 re-establishment of connections, 51 and sense of moral unease, 50 biology, 37 bladder cancer, 57 boundary-crossing trickster movements, 41 bowel cancer, 100, 101 BRCA carrier status, 76 testing, 90 BRCA1 carrier, 20, 23 BRCA2 family, 75 breast cancer, 15, 19, 25, 50, 51, 57, 75, 76, 90, 106, 124, 150 British Society for Human Genetics, 112 guidelines on genetic testing in children, 118 British Sociological Association, 138 cancer, 44, 51, 90, 103, 105 adult-onset, 95 bladder, 57 bowel, 100, 101 breast, 15, 19, 25, 50, 51, 57, 75, 76, 90, 106, 124 diagnosis, 11, 19 endometrial, 100 gastric, 49 GI, 106 ovarian, 19, 23, 57 pancreatic, 57 prostate, 75 registry or record, 51 at risk of inherited, 11 stomach, 33, 44 thyroid, 29 womb, 101 cancer predisposing gene, 105 cancer syndrome, 107 cardiac disease, 10

cardiology, 11

167

Cambridge University Press 978-1-107-02080-1 — Ethical Problems and Genetics Practice Michael Parker Index <u>More Information</u>

#### 168 Index

CGH testing, 95 Charcot-Marie-Tooth syndrome, 72 childhood testing of inherited disorder, 85, 118 chorionic villus sampling (CVS), 81 chromosomal translocation, 80 Clancy, Tara, 7-8 Clarke, Angus, 64 clinic and the laboratory interface, importance, 95 clinical ethics support, to health professionals, 5 clinical geneticists, 4, 10, 88 and challenging situations, 119 and day-to-day moral practices, 114 - 118moral world of, 114-118 clinical genetics, best care of patient, 34 primary roles, 38 clinical genetics, ethical problems in. See also ethics and genetics professionals burden of knowledge, 20-21 family-oriented practice, 24-28 and issue of confidentiality, 20-21 obligation to inform family, 28-31 practices relating to family, 21-24 refusal to share information, 31-33 clinical scientists, 11 clinical tests, 14 Code of Ethics, 60 codes, 22 commitment to caring for family, 38 confidentiality, 21, 35, 101 General Medical Council's guidance on, 117 conflict, sense of, 41 consent, 35, 81, 86, 90, 91, 101, 104, 106, 107, 110, 123, 139, 150, 151 anticipatory informed, 140 informed, 138, 139 valid, 62, 115 consent forms, 116 contemporary family life, 117 co-productive, 65 counselling, 1, 10, 22, 24, 25, 28, 30, 38, 40, 42, 46, 53, 55, 62, 63, 66, 67, 69, 90, 97, 98, 102, 104, 109, 150 cultural relatedness, 44 culture, 38 cystic fibrosis, 25, 26-27 cytogenetics, 11

database on family members. See family file

day-to-day clinical genetics, 13, 88 day-to-day practice of genetics, 3, 5, 12, 20, 35, 88, 107, 109, 120, 124, 125 de facto referrals, 16, 37, 38 de novo mutation, 50 deafness, 10 Declaration of Helsinki, 138 developmental disorders, 11 dilemmas, of genetics professional different practices within genetics, 107 - 110disagreements between professional groups/teams, 92-96 encounters with other specialists, 96 - 101individual differences, 89-92 relationship between research and clinical practice, 101-107 direct-to-consumer genetic testing, 2 disability rights, 64 discernable signs, 14 disease-causing mutation, 25 dissemination of information non-directiveness, 63 obligations to, 28-31 refusal to share, 31-33 District General Hospitals, 10 Douglas, Fiona, 7-8 Down Syndrome, 84 Duchenne gene, 33 Duchenne muscular dystrophy (DMD), 25, 32, 93, 109 duplexity, concept of, 140-141 dysmorphology, 10 Dysmorphology Club, 113, 147 dysmorphology syndrome, 14 dyspraxia, 49 ECG, 14 Economic and Social Research Council, 138 Edwards Syndrome, 83 endometrial cancer, 100 ethicist, 6 ethics and genetics professionals differences between individual professionals, 89-92 disagreements between professional groups/teams, 92-96 encounters with other specialists, 96 - 101practices of different professional

groups, 107–110 relationship between research and clinical practice, 101–107

# CAMBRIDGE

Cambridge University Press 978-1-107-02080-1 — Ethical Problems and Genetics Practice Michael Parker Index <u>More Information</u>

#### Index

169

ethics in ethnography, 128-130 ethics writing, 5 ethnography concept of informed consent, 140 degree of intersubjective understanding, 140 liminality and duplexity concept, 140 - 141methodological consideration, 140 negotiation in, 137-141 professional associations, 138 professional codes, 139 and research ethics, 141-145 eugenics, 61, 64 evidence-based intervention, 15 eye diseases, 10 familial adenomatous polyposis (FAP), 27, 30, 48, 82 family file, 21-24, 29, 31, 34, 35 family member referrals, 15-16 family pedigree, 12 construction of, 16-18 correct, 22 and distant relatives, 19 first generation, 17 information included in, 17 master pedigree, 21-24 process of working up a, 17 verification of, 18-19 family practitioners, 22 family referrals, 29, 37, 38, 89 family-oriented practice, challenges in, 24 - 28four generation pedigree, 18 Fragile X syndrome, 30, 97 fudging, 55 gastric cancer, 49 gender and sense of relatedness, 42 General Medical Council, 34 guidance on confidentiality, 117 general physician (GP), 15, 16, 19, 30, 56 Genethics Club, 8-13, 34, 112, 121, 146, 147-152 ethicist's role in, 148 as a form of bioethics, 13 funding, 113 meetings, 9, 148 origin and purpose, 8 people attending, 11 popularity, 113, 129 professionals attending, 10 genetic counselling, 10, 30, 61, 62, 64, 67, 68, 75, 88

genetic counsellors, 10, 88 genetic inheritance transmitted through reproduction, 39 genetic laboratories, 11 genetic mutation, 39 genetic technologies, 4 genetic testing, 2, 39, 45, 67 co-productive relationship with decisions, 2 DMD, 32 in mainstream medicine, 2 in revealing paternity, 57 geneticisation and medicalisation, 39, 40 geneticisation of understandings of health and illness, 39 genetics professional's commitment to patient-centredness, 12, 122, 145 termination of pregnancy, case study, 70 - 79certainty vs uncertainty, 79-84 childhood testing of inherited disorder, 85 patient perception about use of genetic services, 76 seriousness, 70-79 use of PGD, 84-85 genetics professionals. See also patientcentred practice and ethical challenges, 4, 21 and ethical questions, 24 as family practitioner, 19 and information-sharing obligations, 28 - 31and knowledge about branches of at-risk family, 20 and knowledge practices, 21 moral commitment to family, 37 and moral decisions, 4 and problem seeking behavior, 124-128 understanding of family as a whole, 22 genetics professionals, in context of complicated and changing relations biological connectedness, 48-53 managing relatedness, 42-48 multiple kinship, 53-57 genomic science, 39 genomics, 4, 13 GI cancer, 106 good practice, in contemporary clinical genetics, 11, 12, 90 group differences and genetics professionals, 92-96

# CAMBRIDGE

Cambridge University Press 978-1-107-02080-1 — Ethical Problems and Genetics Practice Michael Parker Index <u>More Information</u>

170 Index

Haemochromatosis, 104 health related information, importance of, 17 high-risk cancer family, 57 HNPCC mutation, 46, 96-101 HNPCC test, 47 Huntington's disease, 1, 81 test for, 3, 6 hysterectomy, 100 identical twins, 1 incidental finding, 5 individual differences, among genetics professionals, 89-92 infertility, 10 information-giving, practice of, 12 informed consent, 138, 139 anticipatory, 140 inherited condition, diagnosis of an, 14,

21, 54 genetics professional's commitment to patient-centredness, 84–85 X-linked disorder, 70–79 inherited disorders, types of, 10 interdisciplinary negotiation, 142 Internet, 2 intersubjective negotiation, 142

Katz-Rothman, Barbara, 61, 80
kinship relations, 40–42
Kleinfelter Syndrome, 96
knowledge practices, relating to the family, 21
known family, 21, 24
lab-based researchers, 104
laboratory staff, 88, 93
Li-Fraumeni, 49
liminality, concept of, 140–141
Lucassen, Anneke, 4, 7–8

Lynch Syndrome, 101

Magnetic Resonance Imaging (MRI) study, 103 Marfan Syndrome, 14 master pedigree, 31, 34, 35, 61 master pedigree of family, 22, 24, 29, 35, 38 masterclass, of medical ethics, 4 medicalisation of kinship, 39 Mendelian disorder gene, 104 misattributed paternity, 57 mistrust, 41 molecular diagnostic testing, 11 moral complexities, of genetics professionals, 4 moral craftsmanship, 12, 13, 125, 126, 127, 129, 145, 146, 152 moral difficulties, of genetic testing, 3 moral dilemmas, 90 moral practices of genetics professionals, 114-118, 128-130 ethical objects of concern, 121-124 moral relatedness, 40 moral unease, sense of, 50 multiplicity of ethics, 150 multiplicity of the family pedigree and biological relatedness, 38-40 social relatedness, 40-42 spacial, 59 temporal, 59 mutational information, 23, 26, 39, 50 myotonic dystrophy, 32 negotiation, concept of, 140 negotiational approach to ethics, 144 Neurofibromatosis type 1, 72 neurology, 11 neuromuscular conditions, 10 neurophsychiatry, 10 new genetics, 39 NHS genetics laboratories, 11 non-directiveness of information, 12, 63, 75, 122 difficulties of genetics professionals, 64 factors affecting, 66 value-neutrality, 67-69 non-paternity, issue of, 3 Nuremburg Code, 138 obstetrics, 11 oncology/cancer surgeons, 11 ovarian cancer, 23, 57 paediatrics, 10, 11 pancreatic cancer, 57 patient-centred medicine, 57

patient-centred medicine, 57 patient-centred practice. See also genetics professional's commitment to patient-centredness non-directiveness of information, 63 patient concerns, 34 provision of information, 62–63 pedigree, interpretation of, 17 polymorphisms, 27 post-natal testing, 11 Prader-Willi syndrome, 97 predictive genetic test, 32 predictive testing, 34, 38 preimplantation genetic diagnosis (PGD), 1, 40, 54, 84–85, 115

# CAMBRIDGE

Cambridge University Press 978-1-107-02080-1 — Ethical Problems and Genetics Practice Michael Parker Index <u>More Information</u>

#### Index

prenatal testing, 11, 63, 72, 115 and genetics professional's commitment to patient-centredness, 79 - 84probands, 14-15, 21, 24, 37, 38, 89 as coming from a known family, 21 and dissemination of information, 15 and personal contacts, 16 and at risk individuals, 16 at risk of inherited condition, 41 professional codes, 139 prophylactic surgery, 28, 51 prostate cancer, 75 referrals to clinical genetics, 14 de facto, 16 family member, 15-16 probands, 14-15 regional genetics centres, 10, 11 Regional Genetics Services, 147 relatedness biological, 38-40 as a burden as a benefit, 41 in the context of clinical genetics, 42 enhanced, 41 enrichment of, 40 social, 40-42 relationships and genetics, 2 reproductive autonomy in genetics, 73 reproductive partners, 2, 37

schizophrenia, 47 screening, 15 for pregnancy, 65–66 separation and biological connectedness, 48 separation, sense of, 41 shared genetic risk, 41 sharing of information, 45, 62–63, 120 single family, 53

risky relations, 39

single gene disorders, 11 sister's wellbeing, 3 social relatedness, 36, 40–42 social separation, 52 socially separated families and genetics practice, 53 specialties vs clinical genetics, 11, 96–101 spinal muscular atrophy (SMA), 31 stomach cancer, 33, 44 Strathern, Marilyn, 139 supplementary information, 21

Tentative Pregnancy, The, 61 terminally ill cancer patients, 127 termination of pregnancy and genetics professional's commitment to patient-centredness, 70–79, 115 thyroid cancer, 29 thyroid gland, tumour in, 45 toxic, members as, 39 Triple X syndrome, 70, 71, 85 trusting relationship, 43 twin's understanding of relationship, 3 United Kingdom's Association of Genetic

Nurses and Counsellors, 60 US National Society of Genetic Counselors, 60

valid consent, concept of, 62, 115 value judgements, 115, 119 value-neutrality, practice of, 12, 67–69, 75, 122 verification of family pedigree, 18–19, 23, 31, 35

Wellcome Trust, 7 womb cancer, 101 women and screening, 65–66

X-linked disorder, 1, 54, 85