INDEX

Adult safeguarding focus groups, 101
Advisory boards
  diverse voices on, 50
  research, 171, 178–179
  sustaining, 53–54
Aging PCOR Learning Collaborative, 19
Alzheimer's Society, 59–60, 67
Alzheimer's Society Northern Ireland (ASNI), 58, 66, 70
American Indian communities
  aboriginal older people, 159
  barriers to, 149–151
  context and barriers to research, 152–154
  culturally different populations, 149–151
  cultural perspectives, critical differences in, 150
  distribution of biologic samples, 158
  ethics, 154–155
  Eugenics, medical practice research informed by, 157–158
  Havasupai Tribe, 158
  knowledge and awareness, 160–162
  members partner, 159–160
  methods and ethics, 160–162
  participatory research, 160–162
  peer educators, 159
  removal and erasure, 156–157
  training intervention, effectiveness of, 159–160
  unauthorized use and, 158
  western social science research, 151–152
Anti-racism, 18
Arnstein, Sherry, 7–8
Awareness, 65–66, 160, 162

Black, Indigenous and People of Colour (BIPOC), 9
BRAIN Involve, 119
Bureau, conception of, 43
Bureau Of Sages, 42–43, 46, 54

Cameron, David, 23
CD ROM, 188–189
Centre accessibility, 18
Cherry picking individuals, 118
Citizen control, 7, 9, 16
Citizen ethicists, 130
  competent, 136–139
  public contributors. *See* Public contributors
Cognitive impairment, 24–25, 58–59, 84–85, 93–94, 118, 141
Coldness, 186, 189
Co-leadership, 16, 170
Co-led and co-designed research, 171–173
Communications processes, 12, 30–31, 34, 44, 49, 59–60, 64–65, 85, 90, 94, 97–98, 141, 159, 174, 178, 180, 186, 190
Community-based participatory research (CBPR), 116
Community members, 13–14, 42–44, 114, 159–160, 162
Community Participatory Planning and Evaluation (CPPE), 177–178
Consent, 22, 24–25, 41, 47, 58–59, 62–63, 86, 91–95, 98, 136, 157–158
Co-Principals, 16
Co-production, 131, 134, 138
Co-research, 47, 59, 170–172

COVID-19, 54–55, 88, 124, 130–131, 189
Cube framework, 124
Cultural differences, 150, 188–189

Databank, 123
Data confidentiality, 96–97
Data Protection Impact Assessment (DPIA), 96
Dementia caregiving, family conflict in
  Alzheimer's Society Northern Ireland (ASNI), 58, 66, 70
  cause of conflict, 65
  family dynamics and conflict, 63–66
  family knowledge, stigma and denial, 67–68
  future recommendations, 69–70
  integrity, 71
  people/persons with dementia (PWD), 58–59, 65
  public patient involvement (PPI), 58, 71, 73
  research ethics committee (REC), 58–59
  solutions to reduce/prevent family conflict, 65
  support services, 69–70
  systematic review of, 62–63
  user-focused research ethics, 71
Dementia, older adults with, 22–26
Democratic professionalism, 130–131
Democratic societies, 130–131
Department of Health (DOH), 84–85

Easy Read format, 88, 92–93
Engaged research
  co-led and co-designed research, 171–173
  participatory team science, 176–178
  team science, 174–176
Equality Act, 118
Erasure, removal and, 156–157
Eugenics, medical practice research informed by, 157–158
Eurocentric, 148–149, 152–153, 160
European Union's General Data Protection Regulations (GDPR), 89, 96–97
Exercises, 42–44, 87

Geary, Carol, 170, 176, 178–179
General Data Protection Regulations (GDPR), 89, 96–97
General practitioners (GPs), 70

Havasupai Tribe, 158
Healthier Black Elders Center (HBEC), 13
Health Insurance Portability and Accountability Act (HIPAA), 41
Health Research Authority (HRA), 136–137
Human rights, 41, 154–155

Indigenous populations, 149–150, 161–162
Information sheets, 72–73, 92–93, 98
Institute of Public Health (IPH), 84–85
Institutional Review Boards (IRBs), 41, 47
INVOLVE Framework, 10, 18, 114–115

Joint Data Controller Agreement, 97

Knowledge, 9, 14–15, 32, 44, 46, 59, 67–68, 116, 132, 134–135, 139, 160, 162, 170, 175, 187

Ladder of Participation, 7–8, 131
Land Grant universities, 17–18
Lay Biosketch Template, 45
LGBTQ1 community, 12–13
Lived experience, 170–173, 175–178
Logistics, 86–87

Long-term services and supports (LTSS), 54–56

McGaffigan, Erin, 10–11
Members partner, 159–160
Mental Health Act (MHA), 119
Mental health research
  citizen ethicists, 134–136
  public contributors, 130, 132, 134

National Disability Authority, Ireland, 89–90
National Health Service (NHS), 130–131
National Institute for Health and Care Excellence (NICE), 59–60
National Institute for Health Research (NIHR), 71–72, 114–115

Older Peoples External Residential Tool (OPERAT), 120
Ordway, Jeff, 170

Participatory research, 34, 43, 116, 159–160, 162, 174
Participatory team science, 174, 176, 178, 180
Patient and public involvement (PPI), 24–26, 58, 71, 73, 114, 171–172
Patient Centered Outcomes Research and Comparative Effectiveness Research (PCOR/CER), 42
Patient-Centred Outcomes Research Institute (PCORI) Rubric, 9–10, 42
Patient needs, ignorance of, 187–188
Peer educators, 159
People, approach and environment (PAE) attention framework, 11–18
People factors, 11–12, 15
People/persons with dementia (PWD), 58–59, 65
Personal reflection
  cultural differences, 188–189
  patient needs, ignorance of, 187–188
  professional indifference, 189–190
  treatment, waiting for, 186–187
Person-centred ethics
  choosing and adapting, 26–30
  cognitive impairment, 24–25
  conversational style semi-structured interviewing techniques, 27
  dementia, older adults with, 22–26
  ethnographic studies, 23, 31–32
  guidelines and scrutiny of research, 22–23
  patient and public involvement (PPI), 24–26
  qualitative methodologies, 26–27
  qualitative research, 22
  research, 23–24, 26, 30, 33
  theoretical and methodological choices, 23–24
PPI. *See* Patient and public involvement (PPI)
Professional competency, 85–86
Professional indifference, 189–190
Profile of participants, 86–87
PROSPERO, 62
Public contributors
  citizen ethicists. *See* Citizen ethicists
  competent, 136–139
  co-production, 134
  democratic professionalism, 130–131
  democratic societies, 130–131
  essential, 135–136
  flourish, 139–142
  Ladder of Citizen Participation, 131
  National Health Service (NHS), 130–131

Public Involvement Impact Assessment Framework (PiiAF), 124

Recruitment, 14, 24–25, 30, 41–42, 68, 89–90, 92, 138, 172
Research Design Service (RDS), 119
Research ethics committee (REC), 58–59, 89

Secure Anonymised Information Linkage (SAIL), 123
Semi-structured interviewing techniques, 27
Stakeholder engagement
  recognizing remaining barriers to, 54
  remaining barriers to, 54
Steering Committee, 15–16, 88, 178
Support services, 46, 69–70, 95–96
Sustaining advisory boards, 53–54
Synergy, 185–186

Team science, 170–171, 174–176, 178
Training, 14–15, 44, 47, 61, 85–86, 122–123, 132, 159–160, 191
Trust, 9, 16, 41–42, 50, 68–69, 90, 161

UK National Institute for Health Research, 131
UK Standards For Public Involvement, 117–118
  BRAIN Involve, 119
  context, 114–115
  Cube framework, 124
  evaluating the impact, 124
  levels of participation, 116–117
  mutual benefits of, 121–122
  Older Peoples External Residential Tool (OPERAT), 120
  PPI, 114
  Research Design Service (RDS), 119
  selecting individuals for, 118–121
  training, 123
User-focused research ethics, 71
User involvement
  application of, 4
  approach factors, 15–17
  centring people in, 13
  defining, 4–6
  environment factors, 17–18
  INVOLVE Framework, 10
  Ladder of Participation, 7–8
  Patient-Centred Outcomes Research Institute (PCORI) Rubric, 9–10
  people, approach and environment (PAE) attention framework, 11–18
  people factors, 11–12, 15
  research, 6–8

Value of members, acknowledging, 52
Virtually engaging, 52
Virtual Senior Center (VSC), 46–47
Voice incorporating, older adult
  advisory board, diverse voices on, 50
  barriers, 46–47
  building trust, 50
  bureau, conception of, 43
  bureau development, processes used in, 43–46
  Bureau Of Sages, 42–43
  Lay Biosketch Template, 45
  lessons learned, 48–49
  long-term services and supports (LTSS), 54–56
  members, fostering authentic engagement with, 51
  practical insights, 49–56
  respect among members, 50
  stakeholder engagement, recognizing remaining barriers to, 54
  stakeholder engagement, remaining barriers to, 54
  sustaining advisory boards, 53–54
  value of members, acknowledging, 52
  virtually engaging, 52

Vulnerable groups research
analysis and dissemination, 88
approval process, 89
avoiding harm to participants, 95–97
capacity issues, 93–95
consent, 92–95
data confidentiality, 96–97
ethical considerations, 89–98
ethical framework, 89
European Union's General Data Protection Regulations (GDPR), 89, 96–97
focus group discussions, 87–88
logistics, 86–87
methodology, 85–88
privacy risks, 96–97
process and practicalities, 84–88
profile of participants, 86–87
recruitment, 89–92
unexpected challenges, 97–98

Western social science research, 151–152

X-rays, 188