## Index

Abative research, 190  
Abortion research, 40  
Access to experimental data, 42, 173, 297  
Access to research committees, 266  
Adolescents, 244  
Advanced Cell Technology (ACT), 155, 159, 196  
Advisory Committee on Human Radiation Experiments, 10n1, 11n17, 19n1, 58n2, 69, 70, 72, 116  
African Americans and research, 21, 22, 87, 149  
Aging, 31, 134, 159, 176, 178, 180, 182, 184  
Aggression in animals, 254  
AIDS, 16, 23, 42, 114, 119, 151, 221  
Alexander, Leo, 2  
Altman, Lawrence K., 109, 111, 113, 114, 290  
Alzheimer disease, 66, 204  
American College of Medical Genetics, 244  
American Society of Gene Therapy, 137  
American Veterinary Medical Association, 271  
Americans with Disabilities Act, 218  
Andersen, Per Pinstrup, 226n14  
Andrews, Lori, 133, 261  
Animal Liberation Front, 255  
Animal research, 5, 19, 80, 83, 225, 249ff, 253, 254, 255, 257, 259, 260, 262, 264  
Animal Welfare Act, 252, 269  
Annas, George, 10n3, 58n1, 68, 96n2, 199n2  
Antiglucose, 178  
Antipregnancy vaccine, 200  
Antonson, Dean L., 133  
Apologies to harmed subjects, 69  
Appeals Court of Maryland, 49  
Appelbaum, Paul, S., 58n4  
Argentina, 40  
Arras, John, 6, 7, 11n19  
Art, genetic manipulations as, 261  
Artificial hearts, 26, 140–141  
Ashburn, Ted T., 135  
Asilomar, 225, 227  
Assisted suicide, 54  
Asthma study, 51–52  
*Atlas of Man*, 171  
*Atlas of Topographic and Applied Human Anatomy*, 301  
Atomic Energy Commission, 69, 115  
Australian malaria studies, 73  
Authority, obedience to, 75  
Autonomy, 53  
Authorship, 276–277, 279–280, 281, 294, 296  
Aviation medicine, 186  
AZT, 23, 28, 32  
Baboons in research, 255, 257  
Bailey, Leonard L., 81  
Balaban, Evan, 161  
Balán, Jorge, 41  
Balint, Peter J., 226n11  
Bapst, Don, 199  
Baranaga, Marcia, 227  
Bardot, Brigitte, 259  
Barnaard, Christian, 166  
Barrett, J. Carl, 231, 232, 234, 236  
Barritt J. A., 241  
*Bartonella bacilliformis*, 111  
Baum, Michael, 34, 39, 62, 63  
Baumrin, D., 76  
Bayer, Ronald, 120  
Bayh-Dole Act, 145  
Bayne, Karen, 202  
Beauchamp, Tom L., 253, 254, 256, 258, 260, 264, 266
Beecher, Henry K., 3, 10n9
Belmont Report, The, 4, 19, 25n3, 54, 56, 76, 85, 92
Benda, Clemens E., 116
Beneficence, 4
Benjamin, Alan F., 167–168
Berman, H. H., 150
Bernard, Claude, 250
Beth Israel Deaconess Medical Center, 134
Biotechnology Industry Organization, 191
Blameworthiness defined, 5, 83–84
Blanchard, Lynn, 88
Blinding in clinical trials, 18
Blinding in publication, 275
Blood transfusions, 166
Boise Cascade, 287
Bonding in newborn monkeys, 260
Brain death, 80, 210
Breast cancer, 61, 112, 244
British Pharmaceutical Industry, 169
Brittingham, Thomas E., 112–113
Brock, Dan W., 226
Brody, Baruch, 25, 29, 36, 42, 64, 65, 131n3, 142
Brody, Howard, 20n10
Buchanan, Allen, 226
Buchanan, Mark A., 287
Bush, George W., 195, 203–206
Byrne, Peter, 210, 211

Callahan, Daniel, 182
Campbell, Keith, 199n4
Caniano, Donna A., 25, 37
Cancer studies, 61, 108, 112
Capitation fees, 136
Caplan, Arthur, 199n2, 226n12
Capron, Alexander, 109
Carrion, Daniel, 110
Carroll, Jill, 247
Case study
criticism of, 6–8
as history, 7
limitations of, 7–8
method in, 6–8
Casuistry defined, 6
Caufield, Timothy A., 158n10
Cell lines in research, 132, 204
Center for Bioethics and Human Dignity, 207
Centers for Disease Control, 35, 119
Certificate of confidentiality, 138–139, 151
Chadwick, Gary, 43
Chambers, Tod, 6, 11n18

Children
consent with, 55, 93, 100, 115, 149–150
exposure to research risk, 16, 49, 93, 100, 115, 117, 149–150, 214
maltreatment research, 138
research involving, 3, 4, 37, 45, 49, 83, 115, 117, 138, 149–150, 237
right to have, 196–197
selecting the traits of, 196–198, 216, 217, 218, 224–225, 240
Chinese research subjects, 91–92
Christian, Sue Ellen, 97
Clark, Barney, 140
Clinical alerts, 277
Clinical care for research subjects, 19
Clinton, President Bill, 124, 194, 196
Cloning, 159, 193–196, 199n3, 209
Cohen, Joel E., 165
Colapinto, John, 293
Conference Committee on Fetal Research and Application, 199n10
Community advisory boards, 87
Community consent, 85, 157
Compensation for research injuries, 169–170
Confidentiality in research, 16, 35, 40–41, 138
Conflicts of interest defined, 127
disadvantages to science, 127–128, 145
disadvantages to subjects, 129, 151, 237
policies regarding, 130–131, 137, 142, 275
in publication, 275
Consent. See Informed consent
Contracts with research subjects, 167
Cook-Deegan, Robert, 134, 158n5, 158n7, 226n4
Cookson, Clive, 205
Cooley, Denton, 26
Council for International Organizations of Medical Sciences, 119–120
Court-ordered research, 79
Cultural considerations in research, 55–56

Daniels, Norman, 226
Deaf culture, 218
DeAngelis, C. D., 190
Death, determination of, 80, 210, 211
DeBakey, Michael, 26
Deception by researchers, 33, 40–41, 56–57, 75, 77, 108, 117, 132, 171
Deception by subjects, 23
Declarations of Helsinki, 3, 309–313
Defense Authorization Act, 67
Deferred consent, 55, 64
Dekel, Sheila Coh, 96n4
Denmark, 80
Department of Health and Human Services, 124
Descartes, René, 249
Designer children, 196–198, 216, 218
DeVries, William, 140–141
Diamond v. Chakrabarty, 235
Dickert, Neal, 122
DiGregorio, Michelle Burpeau, 136, 291
Disclosure of IRB review, 90
Distribution of research benefits, 91, 98, 102, 121, 123
Distribution of research risks, 91–92, 102, 106, 123, 140–141
Diversity in IRB membership, 14
Dodman, Nicholas, 271
Dolly, cloned sheep, 159, 195
Dresser, Rebecca, 253, 254, 256, 258, 260, 264, 266
Drug injection, 151
Duplicate publication, 275–276, 286
Duty to serve in research, 106
Dyer, Jim, 118
Dying research subjects, 54
Editorial policies, 274–275, 289–290, 291
Educational research, 14, 17
Egan, Jennifer, 45, 46
Einstein, Albert, 251
Eisenstadt v. Baird, 197
Eisenstein, Barry, 134, 135
Elger, Bernice S., 244
Elia, Sherman, 199n2
ELSI, 156–157, 230
Elwood, Robert W., 254
Embargoes, 277–278, 289–290
Embryo research, 193–195, 208
Engelhardt, H. Tristam, Jr., 252n5
Enhancement, as against therapy, 236
Environment
contribution to disease, 230, 232, 236
social and material, 165
transgenic animals and, 246
Equipoise, 18, 47
Equity in subject selection, 15, 92. See also Vulnerable subjects
Ethical analysis, key questions in research, 8–9. See also Casuistry
Ethics advisory boards, 153
Ethics, disagreement in, 198–199
Eugenics, 228, 233
Exclusion criteria, 17
Expertise in IRB membership, 14, 143, 153
Farrar, Steve, 202
Farrell, Malcolm J., 158n2
Fletcher, John C., 282
Florida panther, 267
Fontanarosa, P. B., 290
Food, genetically modified, 225, 246
Food and Drug Administration (FDA), 28, 51, 140
For-profit IRBs, 148
Foubister, Vida, 44
Fox, Michael, 271
Frader, Joel, 25, 37, 125
Fragile X syndrome, 242
“Franken-food,” 246
Fraud and fabrication, 273–274, 296, 297
Freedman, Benjamin, 20n11, 48
Galen, 251
Gelsinger, Jesse, 237
Gennarelli, Thomas A., 255
Genetic research
experimental therapy, 222–223
germ-line interventions, 223, 228, 241
perceptions of, 191, 227
social effects of, 221, 223–224, 230, 261
transfer technology, 227
Genetic Savings and Clone, 271
Genetic testing, 163, 242, 244
Genetically modified food, 191
GenoChoice, 197
Genovo, 237
Geison, Gerald L., 84
Germ-line interventions, 223, 228, 241
Glantz, Leonard, 43
Glass, Eleanor Swift, 109
Glory holes, 299
Index

Gluck, John P., 253, 254, 256, 258, 260, 264, 266

“God Committee,” 98
Godsen, Roger G., 212
Golde, David W., 132
Grady, Christine, 122
Grimes v. Kennedy Krieger, 50
Grodin, Michael A., 10n3, 58n1, 96n2
Guest, Stephen, 169–170
Gundy, Steven R., 81
Guterman, Lila, 213

Haddad, Amy, 82, 123
Harding, Timothy W., 244
Harlow, Harry F., 260
Harris, Sheldon, 96n1
Hartzer, Michael K., 300
Hawthorne, Lou, 271
Head injury research, 255
Heart research, 26, 166
Heart transplantation, 166
Heger, Heinz, 96n5
Heller, Jean, 21
Hemodialysis, 98
Henderson, Gail, 88, 105
Hepatitis studies, 149
Hexamethonium, 51
History of ethics standards in research, 1–5
HIV education, 130, 151–152
HIV studies, 16, 23, 35, 42, 87, 114, 119, 151, 221, 257
Holmesburg prison, 92
Homosexual interactions, 77
Homosexual subjects, 45, 92, 157, 298
Homosexuality, origins of, 161
Hood, Leroy, 226n6
Hooton, E. A., 171
Hormone treatment for height, 217
Hornblum, Allen M., 96n6
Hospitalized subjects, 15
Houghton, Joan, 34, 39, 62, 63
Hughes, Gary, 74
Human Genome Project (HGP), 156, 222
Humphreys, Laud, 77
Huth, Edward J., 286
Hypothermia studies, 302
Hysterotomy, 210

Illegal activity as research topic, 40
Imanishi-Kari, Teresa, 274
In vitro fertilization, 194
Inclusion criteria, 17
Industry ties to universities, 145

Informed consent. See also Children; Community consent; Consent; Deception; Surrogate decision makers
deferred, 55, 64
exceptions to, 40, 61, 63, 67, 75–76, 77
IRB responsibilities for, 15, 89, 90
in practice, 54–56, 57–58, 89, 94, 104, 292
reasons for, 54
Innovation in clinical medicine, 19, 25, 26, 140–141
Intelligence, 219
International Whaling Commission, 265
Institutional Review Boards (IRBs)
conflicts of interest, 143, 148
function, 13–16, 89, 90, 147, 154
history of, 4
lawsuits against, 43
International research, 56–57, 105, 119
Investigational new drug (IND) application, 28–29
Involuntary experimentation, 53, 79
Iowa Soldiers’ Orphans’ Home, 117
Ivy, Andrew, 2, 10n3, 96n3
Ivy League posture photos, 171–172
Japan, 80, 265
Japanese World War II experimentation, 2, 91–92
Jewish Chronic Disease Hospital, 108
John Moore case, 132
John Paul II, Pope, 259
Johns Hopkins University, 51
Johnson, Wendell, 117
Jonas, Hans, 95, 97, 106–107
Jones, James H., 10n10
Jones, James W., 25, 37
Jones, R. Scott, 282
Jones, Steve, 243
Journalism standards, 45
Journal of the American Medical Association, 290
Justice, 4

Kac, Eduardo, 261
Kaebnick, Gregory, 241
Kanner, Ellen, 271
Kaplan, Jonathan Michael, 158n9
Karp, Haskell, 26
Kass, Leon, 199n5, 204
Katz, Jay, 109
Kennedy Krieger Institute, 49
Kennedy, Robert F., 149
Kent, Gerry, 90
Kevles, Daniel J., 226n6, 278n2
Kevorkian, Jack, 59, 60
King, Nancy M. P., 88, 105
King's College Hospital, 61
Kittens in research, 259
Kolata, Gina, 226n10, 241
Kopelman, Loretta M., 97
Korn, David, 43
Kuczynski-Godard, Max, 110–111
Kuhse, Helga, 10n1, 11n19
Krugman, Saul, 149
Lagnado, Lucette Matalon, 96n96
Lappe´, Marc A., 226n6
Lauritzen, Paul, 199n5
Lawsuits against researchers, 26
Lazer, Jesse, 71
Lead poisoning study, 49
Leopold, Nathan, 102
Levine, Robert J., 19n2, 43, 58n2, 76, 100, 101, 104, 170
Life extension, 178, 180, 182, 184
Lifton, Robert J., 96
Local Research Ethics Committees (UK), 169
LONGSCAN, 138–139
Loue, Sana, 20n9
Lung physiology, 51
Macklin, Ruth, 33, 105, 217
Macon county, 21
Magnus, David, 226n12
Mahowald, Mary Briody, 164
Malaria studies, 73, 102
Marketing research, 82
Marriage, 105, 180
Massachusetts Institute of Technology, 115
McCullagh, Peter, 210, 211
McCullough, Laurence B., 25, 37
McGee, Glenn, 199n5, 226n3, 226n12
McKenzie, John, 131n1
Media reporting on research, 283
Medicaid, 99
Mengele, Josef, 92
Mental health, 176
Methuselah vote, 178
Mice in research, 254, 269
Michels, Karin B., 33
Midnight chemist, 23
Milgram, Stanley, 75–76
Military experimentation, 2–3, 67, 71, 73, 250
Miller, David J., 278n1
Mind reading, 185
Moe, Kristine, 278, 303
Monaghan, Peter, 288
Money, John, 202, 292
Monitoring research, 16, 42
Monkeys in research, 255, 257, 260
Moore, John, 132
Moorehouse, Anne, 66
Moratorium on genetic research, 227
Moreno, Jonathan, 72, 103, 185, 187, 239
Mortensen, Christian, 31
Morton, David B., 253, 254, 256, 258, 260, 264, 266
Murphy, Timothy F., 97, 161–162, 175, 199n11, 209, 226n5, 240
Murphy, W. D., 79
National Academy of Sciences, 246
National Bioethics Advisory Commission, 5, 10n15, 89, 156n5, 169, 196, 199n6
National Commission for the Protection of Human Subjects, 4, 10n13, 20n12, 58n3, 96n7, 169
National Institutes of Health, 13, 161, 206, 227, 255, 292, 300
National Research Act, 194
National security, 69
Nazis
medical experimentation, 2, 16, 54, 186, 206, 301
researchers recruited by US, 186
Nelkin, Dorothy, 133, 284
Netherland Antilles, 167
Netherlands, 242
Neural tube defects, 34
New England Journal of Medicine, 128
Newton, Isaac, 251
Nontherapeutic research, 17
Nooth, James, 112
North Korea, 196
Novartis, 145
Nude posture photos, 171
Nuremberg Code, 2, 3, 54, 67, 307–308
Nussbaum, Martha C., 199n5
Oakland University, 300
Obedience to authority, 75
Oberman, Michelle, 125
Observational studies, 17, 49
Off-label use of drugs, 28, 30
Office for Human Research Protection, 43,
Office of the Inspector General, 11n16
Oklahoma Health Sciences Center, 43
Oktay, Kutluk, 212
Order of authors’ names, 279–280, 294
Oregon Hospital for the Criminally Insane, 171
Origins of fraud, 285
Orleans, F. Barbara, 253, 254, 256, 258, 260, 264, 266, 270
Orr, Robert D., 81
Ostenmeyer, Malcomb C., 254
OTC, 237
Ovarian tissue transplantation, 212
Paarlberg, Robert L., 226
Palmer, Julie Gage, 226n2, 229
Panush, R. S., 301
Parkinson’s disease, 33
Pasteur, Louis, 83, 250
Patents, 175, 235
Paton, William, 251
Payment for research participation, 71, 121, 132, 134
Payments to researchers, 136
Pedophilia, 292
Pence, Gregory E., 27, 99, 141, 166, 199n1, 199n5, 208, 219, 226n13
Peer review, 275
Permissible medical experiments, 307–308
Pernkopf, Eduard, 301
PETA, 259, 262
Petersdorf, Robert G., 285
Pets, cloning of, 271
Pharmacy research, 82
Pimple, Kenneth, 295
Placebo and placebo effect, 17–18, 33, 34, 119, 214
Plagiarism, 274
Plant, Richard, 96n5
Population, 165
Pornography, 45
Posner, Richard, 177
Pozos, Robert, 302
Prentner, Elizabeth, 197
Pregnancy in men, 202
Pregnant women in research, 34, 42, 93–94, 119, 124, 200
Prenatal diagnostic tests, 161, 163, 242
Prentice, Ernest D., 133
Prerandomization, 38
President’s Council on Bioethics, 156, 158n6, 204
Press, Eyal, 146
Primates in research, 255, 257, 264
Priorities in research, 95, 155–156, 176, 190, 194, 203–204
Prisoners in research, 79, 92, 94, 102, 104
Progressive Animal Welfare Society, 266
Property interests in biological materials, 132–133
Psychiatric disorders, 89
Rabbit, green fluorescent, 261
Racial politics, 166
Radiation experiments, 13, 69, 115–116
Ramos, Silvina, 41
Ramsey, Paul, 100
Randomization, 18, 23–24, 38
Reanimated organs, 80
Reed, Walter, 71
Regalado, Antonio, 247
Regan, Tom, 252n2
Renwick, J. H., 190
Repetitive publication, 275–276, 286
Reporting research findings, 283
Research defined, 19, 31
Research directives, 66
Researchers as subjects, 95, 109, 110–111, 112–113
Respect for persons, 4
Responsibility for disease, 232, 234
Retraction of publication, 287
Reverby, Susan M., 10n11
Rhodes, Richard, 158n1
Richter, Judith, 200–201
Riggs, Garret, 301
Robinson, Walter M., 215
Robertson, John, 199n9
Roche, Ellen, 51
Rorvik, David, 199n3
Rose, Steve, 192
Rosenblum, Ron, 171
Rothman, Barbara Katz, 158n8, 226n11
Rothman, David J., 10n12, 150
Rothman, Kenneth J., 33
Rothman, Sheila M., 10n12, 150
Runyan, Desmond K., 139
Ryder, R., 252n1
Ryle, Gerard, 74
Sabin, Albert, 262
Same-sex couples, 240
Sanctions for misconduct, 300, 304
Saunders, Christobel M., 34, 39, 62, 63
Savulescu, Julian, 52, 226n8, 238
Schmidt, Gunter, 161
Schülenk, Udo, 161
Scribner, Belding, 98
Secondhand smoke, 234
Secretary of Health and Human Services, 93
Self-experimentation, 95, 109, 110–111, 112–113, 114
Senn, Nicolas, 112
Serigos, Paul, 23–24
Sexual orientation research, 161
Sham surgery, 33
Sharp, Richard R., 231, 232, 234, 236
Sharpe, John G., 133
Shea, Christopher, 31
Sheldon, W. H., 171
Shimm, David S., 136, 291
Shioler, Ebbe, 226n14
Short bowel syndrome, 37
Shrader-Frechtet, Kristin, 267
Siegel, Barry, 303
Singer, Peter, 10n1, 11n16, 252n2
Silverman, Frank, 118
Skinner v. Oklahoma, 196
Sloan, Phillip R., 226n6
Smith, Donald J., 287
Sunstein, Cass, 199n5
Social effects of research, 147, 153ff
Somatic cell nuclear transfer (SCNT), 159, 195–196
South Africa, 166
Southam, Chester M., 108
Soviet Union, 239
Spanish-American War, 71
Spece, Roy G., Jr., 136, 291
Speciesism, 250, 251
Sponsorship of research, 155, 175
Spouse’s role in research, 105
Sprigg, M., 52
Sprigge, T. L. S., 251, 252n3
Standpoint theory, 163
Starzl, Thomas, 257
Stein, Jane, 88, 105
Stem cell research, 193–195, 203–205, 206–207
Strong, Carson, 109
Strughold, Hubert, 186
Student authorship, 294, 298, 299
Study design, 16–17, 18, 23–24, 25, 28–29, 32, 34, 38, 61, 237
Stuttering research, 117
Subject selection, 15. See also Vulnerable subjects
Sundermeyer, Peggy, 295
Sunshine laws, 266
Surgery, 25, 33, 37
Surrogate decision makers, 54, 66
Surrogate end points, 32
Syphilis studies, 21, 206
Tearoom trade, 77
Teitel, Martin, 226n13
Therapeutic misconception, 56, 64
Therapeutic research, 17
Thomasma, David, 79
Togias, Alkis, 51
Tooley, Michael, 199n1
Tracer studies, 115–116
Transparency, 157
Transplantation research, 80
Trochet, John, 253
Tsien, Joe Z., 219
Tudge, Colin, 199n43
Twin studies, 92
Tudor, Mary, 117
Tuskegee syphilis studies, 2, 3–4, 21
United Netherlands Portuguese Congregation Mikva Israel-Emanuel, 167
United States ethics practices, 2
United States Navy, 1
United States Public Health Service, 21
University of California, Berkeley, 145
University of California, Los Angeles, 132
University of Denver, 187
Use of unethically obtained data, 278, 301, 302
Vaccine research, 83, 87, 114, 250
Vandalized Lovemaps, 292
Veatch, Robert M., 82, 123
Verruga peruana, 110–111
Vivisection, 262
Voting rights, 178
Vulnerable populations, 15–16
Wade, Nicolas, 226n1, 301
Walters, LeRoy, 226n2, 226n9, 229
War research, 91–92, 239
Washburn, Jennifer, 146
Weijer, Charles, 83, 158n12
Weisstub, David N., 66, 120
Whales in research, 265
Wickler, Daniel, 226
Wickware, Porter, 160
Williams-Jones, Bryn, 158n10
Willowbrook hepatitis studies, 4, 149, 278
Wilmoth, John, 31
Wilmut, Ian, 199n4
Wilson, James Q., 199n5, 237
Wilson, Kimberly, 226n13
Wilson, Sharon K., 135
Wiltse, John C., 133
Wines, William A., 287
Women as research subjects, 30, 34, 40, 61, 105
World Health Organization, 105
World Medical Association, 3
World War II, 2, 16, 54, 75, 91–92, 102, 186
Wrong-doing defined, 5

Xenografts, 257

Yellow fever study, 71

Zagury, Daniel, 114
Zilinkas, Raymond A., 226n11