

Curriculum Vitae

Robert Mullan Cook-Deegan, MD

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Current Position

Professor, School for the Future of Innovation in Society and Consortium for Science, Policy & Outcomes, College of Global Futures, Global Futures Laboratory, Arizona State University

Education

B.A. Harvard College, chemistry, *magna cum laude*, 1975
M.D. University of Colorado, 1979

Academic Positions

Professor, School for the Future of Innovation in Society and Consortium on Science, Policy & Outcomes, College of Global Futures, Arizona State University, 2016-present
Research Professor of Public Policy, Sanford School of Public Policy, Duke University, 2003-2016
Professor, Track V, Division of General Internal Medicine, Department of Internal Medicine, School of Medicine, Duke University, 2003-2016
Research Professor, Department of Biology, Trinity College of Arts & Sciences, Duke University, 2006-2016
Visiting Professor, School for the Future of Innovation in Society, Arizona State University, Fall 2015.
Director, Center for Genome Ethics, Law and Policy, Institute for Genome Sciences & Policy, Duke University, 2002-2012
Faculty Affiliate, Kennedy Institute of Ethics, Georgetown University, 2001-2014;
Senior Research Fellow, 1986-2001
Seminar Instructor, Stanford-in-Washington (undergraduate tutorials and seminars on health and biomedical research policy), 1996-2003
Cecil and Ida Green Senior Fellow, Green Center for the Study of Science and Society, University of Texas, Dallas, Spring (January-April) 1996
Associate, Department of Health Policy and Management, School of Hygiene and Public Health, The Johns Hopkins University, 1988-2001

Nonacademic Positions

National Academy of Sciences, Washington, DC. Director, Division of Biobehavioral Sciences and Mental Disorders, Institute of Medicine, 1991-1994; Senior Program Officer, Committee on Allocation of Federal Funds for Science and Technology (“Press Report”), 1994-1996; Director, National Cancer Policy Board, National Research Council and

Institute of Medicine, 1996-2000; Senior Program Officer, Committee on Human Research Protection Programs, 2000; Director, Robert Wood Johnson Foundation Health Policy Fellowship Program, Institute of Medicine, 2001-2002
National Center for Human Genome Research, National Institutes of Health, Expert (consultant to Center Director, James D. Watson) 1989-1990
Biomedical Ethics Board, U.S. Congress, and Biomedical Ethics Advisory Committee, Washington, DC, 1988-1989. Acting Executive Director of a small congressional agency that operated for one year
Office of Technology Assessment, U.S. Congress, Washington, DC. OTA Fellow 1982-3, Project Director and Analyst 1983-4, Senior Analyst 1985-6, Senior Associate 1987-1988

State, National and International Committees and Boards

Member, Acceptable Thresholds Committee (advisory committee for the nonprofit Center for Genomic Interpretation, focused on quality assurance in molecular diagnostics), 2023-
Member, Advisory Committee, Australian Open Stem Cell Research Network, 2020-2023
Member, Technical Advisory Committee, Canadian Network for Learning Healthcare Systems and Cost-Effective ‘Omics Innovation (CLEOnet), a project funded by BC Cancer, BC Genomics, and GenomeCanada, 2021-2024
Member, Polaris (advisory committee to the Science, Technology Assessment and Analytics unit of the Government Accountability Office, US Congress), 2020-
Member, Ethics, Legal and Social Issues subcommittee, Earth BioGenome Project (Hank Greely, Stanford, chair; and Melissa Goldstein, Geo. Washington U., co-chair). Project to sequence the full range of biological diversity based at UC Davis (Harris Lewin, overall project chair), May 2020-
Member, Advisory Committee to TRANSGENE, University of Edinburgh project on history and comparative genomics (Miguel Garcia Sancho and James Lowe, PIs), 2019-2022
Co-chair, Embedded ELSI (ethical, legal and social implications) program, Human Pangenome Reference Consortium (HPRC), and member of the overall HPRC committee, based at University of California, Santa Cruz, and coordinated through Washington University, Saint Louis, 2019-2024
Member, International Scientific Advisory Board, GenomeQuebec, 2018-
Member, National Conference of Lawyers and Scientists, American Association for the Advancement of Science, 2019-2023
Member, Advisory Committee to the Center for Scientific Evidence in Public Issues, American Association for the Advancement of Science, 2019-2023
Member, Science and Technology Policy Fellowship Advisory Committee, American Association for the Advancement of Science, 2015-2021
Member, Steering Committee, BRCA Challenge, Global Alliance for Genomics and Health, 2015-
Co-chair, Regulatory and Ethics Working Group task force on patient engagement, Global Alliance for Genomics and Health, 2016-2020
Chair, Advisory Committee for “Making Genomic Medicine,” a project funded by the Wellcome Trust and based at the University of Edinburgh (Steven Sturdy, PI) 2014-2018
Member (consultant), National Academies’ Google-funded pilot project to combat misinformation on the Internet related to science and health, (Kara Laney, project officer) 2018-2019
Member, Committee on Science, Engineering and Public Policy, American Association for the Advancement of Science (AAAS), 2011-2017

Member, Advisory Committee to MedSeq Project, Brigham & Women's Hospital, Boston, 2015-2017

Member, Steering Committee for Free the Data, an effort to establish and maintain a robust commons for scientific and clinical interpretation of human genomic variants, a consortium of nonprofits, non-government organizations, and firms committed to data access and research transparency organized by the Genetic Alliance, 2013-2017

Member, Third Modality Advisory Group (Chair: Eric Meslin), Genome Canada, 2013-2016

Member, Human Genome Organization (HUGO) Committee on Genomics and Bioeconomy, 2011-

Member, The Hinxton Group, in particular, participant in meeting October 2010 at University of Manchester that produced the *Statement on Policies and Practices Governing Data and Materials Sharing and Intellectual Property in Stem Cell Science* (January 2011)

Chair, External Advisory Committee, REVEAL study (four-site clinical trial of ApoE genetic testing for Alzheimer's susceptibility), Robert Green— Principal Investigator, Boston University, 2000-2009 and Brigham and Women's Hospital and Harvard Medical School, 2010-2015

Member, AAAS Committee on Council Affairs, 2009-2011

Member, National Research Council Committee on University Management of Intellectual Property, Board on Science, Technology and Economic Policy and Committee on Science, Technology and the Law, The National Academies, June 2008-February 2010. (Committee produced a report, *Managing University Intellectual Property in the Public Interest* [Washington, D.C.: National Academies Press, 2010]) http://www.nap.edu/catalog.php?record_id=13001#toc

Council Delegate and Section X Nominating Committee, AAAS Section on Societal Impacts of Science and Engineering, 2007-2011

Member, NAS-AAAS Committee on Assessing Fundamental Attitudes of Life Scientists as a Basis for Biosecurity Education, National Research Council Committee, 2007-2009 (Committee produced a report, *A Survey of Attitudes and Actions on Dual Use Research in the Life Sciences*, a collaborative effort of the National Research Council and the American Association for the Advancement of Science [Washington, D.C.: National Academies Press, 2009]) http://www.nap.edu/catalog.php?record_id=12460

Member, Advisory Committee for the Graduate Student Forum on Science, Technology, and Health Policy, National Academies of Science and Engineering and Institute of Medicine, National Academy of Sciences, 2007-2010

Consultant, Gene Patents and Licensing Practices Task Force, Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS), Department of Health and Human Services, 2007-2010

Member, Task Force on Patent Reform, American Association of Universities, Association of American Medical Colleges, Council on Government Relations, American Council on Education, and Association of Public and Land-Grant Universities (APLU, formerly National Association of State Universities and Land Grant Colleges), 2005-2009

Member, Committee on Alternative Funding Strategies for Department of Defense's Peer-Reviewed Medical Research Programs, Institute of Medicine, January-May 2004 (Committee produced a report, *Strategies to Leverage Research Funding* [Washington, DC: National Academies Press]) http://www.nap.edu/download.php?record_id=11089

Consultant, Comparative Approach to Genomics of Complex Traits, Department of Health and Human Services Grant, 2003-2004

Member, Project Advisory Panel on Reprogenetics: A Blueprint for Meaningful Moral Debate and Responsible Public Policy, The Hastings Center, 2001- 2003 (Report: *Reprogenetics and Public Policy: Reflections and Recommendations* by Erik Parens and Lori P. Knowles, *Hastings Center Report Special Supplement*, July/Aug 2003)

Member, History and Health Policy Cluster Group, Robert Wood Johnson Foundation, 2003-2005

Member, Task Force for Genomics and Public Health, North Carolina Department of Health and Human Services Office of Genomics, 2002-2005

Member, Expert Advisory Panel, Accessible Genetics Research Ethics Education (AGREE) grant, US Department of Energy, 2002-2005 (J Sugarman– Principal Investigator, The Johns Hopkins University)

Member, Ethical Issues in the Management of Financial Conflicts of Interest in Research in Health, Medicine, and the Biomedical Sciences, The Hastings Center, 2002-2005

Member, World Health Organization Advisory Group on Genomics, 2000-2001

Member, Working Group on Germ Line Gene Therapy, American Association for the Advancement of Science, 1998-2000

Member, Council for the American Association for the Advancement of Science 1998-1999 (as retiring chair of Section X)

Trustee and Secretary, Foundation for Genetic Medicine, 1997-2003

Chair, National Academy of Sciences' Committee to Review Studies on Human Subjects (Institutional Review Board for the National Academies of Sciences and Engineering, the National Research Council, and the Institute of Medicine), 1997-2000

Chair, Section X (Societal Impacts of Science and Engineering), American Association for the Advancement of Science, 1997-1998

National Advisory Board and visiting faculty, Dartmouth College genome curriculum project, 1996-1998, 2000-2003

Advisory Committee, Human Genome Education Model, Project II: Collaborative Education for Allied Health Professionals, Alliance of Genetic Support Groups and Georgetown University, 1996-2002

Chair, Royalty Fund Advisory Committee, Alzheimer's Disease and Related Disorders Association (committee to oversee distribution of research funds derived from tacrine royalties) member 1994; chair 1995-2003

Member, Committee on Science and Human Values, US Conference of Catholic Bishops, 1995-1999

Advisory Board, Science + Literacy for Health, Human Genome Project (advised on production of *Your Genes, Your Choices: Exploring the Issues Raised by Genetic Research* by Catherine Baker), American Association for the Advancement of Science, 1995-1997. <http://ehrweb.aaas.org/ehr/books/index.html>

Consultant, DNA Patent Database, Kennedy Institute of Ethics, Georgetown University, 1994-2004. <http://dnapatents.georgetown.edu/>

Chair, workshop on international genomics, Office of Technology Assessment, US Congress, March 1994

Participant, workshop on commercial genomics and patenting DNA sequences, Office of Technology Assessment, US Congress, January 1994

Member, Advisory Panel on *Commercializing Emerging Technologies*, Office of Technology Assessment, US Congress, 1994-1995

Member, Advisory Panel on *The Human Genome Project and DNA Patenting*, Office of Technology Assessment, US Congress, 1993-1995

Founding member, the Dana Alliance on Brain Initiatives, Charles A. Dana Foundation, 1992-present

Joint Working Group on Ethical, Legal, and Social Issues, National Institutes of Health and Department of Energy, 1989-1995

Scientific Coordination Committee on the human genome to the Director General of the United Nations Educational, Scientific, and Cultural Organization (UNESCO), 1988-1991

Member, Technical Advisory Committee, Alzheimer's Medicare Demonstration, Mathematica Policy Research, Inc. (under contract to Health Care Financing Administration), 1987-1988

Member, National Advisory Committee, Robert Wood Johnson Foundation, Dementia Care and Respite Services Program, 1987-1991

Member *ex officio*, Human Gene Therapy Subcommittee, Recombinant DNA Advisory Committee, National Institutes of Health, Liaison member, 1987-1991

Member, Health Services Research Task Force, Alzheimer's Disease and Related Disorders Association (also executive committee), 1987-88

Honorary Board Member, Family Respite Center, Falls Church, Virginia, 1987-2000

National Advisory Board Member, Alzheimer's Research Center, Cleveland, Ohio, 1987-1990

National Coordinator, Health Professionals' Network, Amnesty International USA, 1985-1988; National Steering Committee 1988-1998

Board of Directors, Physicians for Human Rights, 1988-1996; Advisory Board, 1987-88; Treasurer and Executive Committee, 1994-1996; Co-chair, Fundraising Committee, 1994-1996

University Service

Arizona State University, 2016-

Director, Masters in Public Interest Technology program, School for the Future of Innovation in Society, College of Global Futures, Arizona State University, 2021-2023

Member, Masters Degree Charter Awards Selection Committee, 2021-

Member, Justice, Equity, Diversity and Inclusion Task Force, School for the Future of Innovation in Society, College of Global Futures, Arizona State University, 2020-2021

Masters in Public Interest Technology, admissions and advisory committees, 2020-2021

Masters in Science and Technology Policy, Admissions and advisory committees, 2015-2020

BioDesign Institute Advisory Committee, 2017-2019

ASU Leadership Academy, Behavioral Genomics initiative (Beate Peter, lead), 2017-2019

ASU Clinical Trials Network, 2019-2020

Duke University, 2002-2016

Member, Stem Cell Research Oversight Committee, Duke University Health System, 2010-2015

Member, *Ad Hoc* Committee on Genetics, Duke University School of Medicine, 2012-2015

Member, Faculty Advisory Board, Duke Human Rights Center at the John Hope Franklin Humanities Institute, 2011-2015

Chair, Committee to review reappointment of Noah Pickus as Nannerl O. Keohane Director of the Kenan Institute of Ethics, 2012

Member, Committee to Reappoint Anthony So, Professor of the Practice, Sanford School of Public Policy (Phil Cook, chair), 2011

Faculty Committee, Genome Sciences & Policy Certificate Program, 2008-2016

Member, Baldwin Scholars Program Review (Sarah Deutsch, chair), 2008-2009

Member, Executive Committee, Duke Global Health Institute, 2007-2014
Faculty and Executive Committee Member, Ethics Certificate Program, 2007-2010
Group Advisor, Universities Allied for Essential Medicines (UAEM), 2007-2010
Member, Fulbright Scholarship faculty interview panels, 2009-2012
Member, Truman Scholarship faculty interview panels, 2008-2013
Member, Rhodes/Marshall/Mitchell Scholarship faculty interview panels, 2007-2015
Faculty Member, History and Philosophy of Science, Technology and Medicine Program,
Departments of Philosophy and History, Duke University, 2006-2010
Member, Faculty Council, Kenan Institute of Ethics, 2006-2009
Faculty Affiliate, Race, Ethnicity, & Gender in the Social Sciences, Social Science Research
Institute, 2006-2016
Faculty Advisor, Physicians for Human Rights, Duke Undergraduate and Medical School
Chapters, 2004-2009
Faculty Associate, Trent Center for Bioethics, Humanities and History of Medicine, 2003-2015
Faculty-In-Residence, Alspaugh Residence Hall, 2003-2010
Faculty Member, Health Policy Certificate Program, 2006-2010
Faculty Member, Genome Revolution Focus program and selection committee, 2006-2008,
2011-2012
Member, Duke Translational Medicine Institute Leadership Group, 2006-2010
Member, Committee to review Provost Peter Lange for reappointment (Randall A. Kramer,
chair), 2007-2008
Chair, Search Committee, Associate Director, Kenan Institute of Ethics, 2007 (separate from
similar 2003-2004 search committee below)
Member, Committee to review appointment of Anthony So to Department of Public Policy
Studies, Fall 2007
Chair, Committee to review Graham Glenday for reappointment to Department of Public Policy
Studies, Spring 2007
Member, Center for Comparative Biology of Vulnerable Populations (Division of Pulmonary
Medicine and Nicholas School, D Schwartz and ML Miranda, PI's), 2007-2009
Member, Campus Culture Initiative Steering Committee, 2006-2007
Member, Institute for Genome Sciences & Policy Executive Committee, 2005-2008, 2010-2011
Co-Chair (with Barton Haynes), Global Health Initiative Steering Committee, November 2004-
June 2006
Member, Global Health Panel, Inauguration of President Richard Brodhead, September 2004
Member, Search Committee, Director of Center for the Study of Medical Ethics and Humanities,
2004-2005
Chair, Search Committee, Associate Director, Kenan Institute of Ethics, 2003-2004
Member, Working Group, Neurosciences Microarray Center of Duke University Medical Center,
June 2002-2006
Member, Steering Committee, Making Meaning of Genomic Information grant, Howard Hughes
Medical Institute, September 2002-2005 (R Thompson, PI)

Mentorship

Postdoctoral fellows

Under P50 HG003391 (Center for Public Genomics, Duke University)

Colin Crossman, J.D., "The use of bioinformatics to quantify the reach of patents on DNA,"
2005-2006

Ilse Wiechers, M.D., M.P.P., “The role of intellectual property on development and dissemination of genomic technologies,” March 2005-Summer 2006
Jennifer Reineke Pohlhaus, Ph.D., “Government and nonprofit funding of genomic research worldwide”, June-August 2006
Sapna Kumar, J.D., “Synthetic biology: the intellectual property puzzle,” and “FTC, the ‘other’ patent agency” 2006-2007
Subhashini Chandrasekharan, Ph.D., “The role of intellectual property on the growth and dissemination of genomics research and genomic technologies,” Oct 2006-Oct 2008
Wayne Beyer, Ph.D., “Constructing DNA biobanks to promote research into rare disorders,” Jan 2009-Jan 2010
Britt Rusert, Ph.D., “Patented DNA Sequence Methods” and “Patents and race in BiDiI: a case study, June 2009-Aug 2010 (secondary mentor; primary mentor, Charmaine Royal)
Michele Easter, Ph.D., “Behavioral Genetics and Genomics,” Aug 2010-Aug 2012
Mollie Minear, Ph.D., “Translational genomics and clinical care,” Aug 2012-present
Richard Yamada, Ph.D., “Bioinformatics and genomics technology,” Aug 2012-Jan 2013
Saurabh Vishnubhakat. J.D., L.L.M., “Intellectual Property and Genomics,” Jan 2014-March 2015 (secondary mentor; primary mentor, Arti Rai, Duke School of Law)

Under “The Sulston Project: Making the Knowledge Commons for Cancer Genomic Variants More Effective”

Janis Geary, ASU and University of Alberta, April 2019-
Amanda Gutierrez, ASU and Baylor College of Medicine, June 2020-Aug 2022 (diversity supplement)

Postbaccalaureate fellows (research supervisor)

Alessa Colaianni, Duke, 2007-2008
Lane Baldwin, Duke, 2012-2015
Kathryn Grace Maxson Jones (nee Maxson), Duke, 2010-2014
Abhi Sanka, ASU (undergraduate from Duke), 2017-2018
Sonia Dermer, ASU (undergraduate from William and Mary), 2018
Kara Hapke, ASU, 2019-2023
Zuzana Skvarkova, ASU, 2022-

Resident medical fellows, K awards, Greenwall Scholars and other

Hassan Shanawani, M.D., “Race and Genetics in Biomedical Research,” fellow in pulmonary medicine, Department of Internal Medicine, Duke School of Medicine, 2004-2006 (primary mentor; secondary mentor, David Schwartz)
William Copeland, Ph.D., “Gene-Environment Interplay in Mental and Substance Abuse Disorders, K23 MH080230, Department of Psychiatry, Duke School of Medicine, 2008-2013 (secondary mentor; primary mentor, E. Jane Costello)
Anne D. Lyerly, M.D., Greenwall Scholar, “Ethical Issues Involving Women in Research,” Department of Obstetrics and Gynecology, Duke School of Medicine, 2003-2007 (co-mentor with Ruth Faden, Johns Hopkins Univ.)
Anne D. Lyerly, M.D., K01 Award in “Ethics of Biomedical Research,” 5K01HL072437, Department of Obstetrics and Gynecology, Duke School of Medicine, 2003-2010 (co-mentor)

Charmaine Royal, Ph.D., Greenwall Scholar, “Ethics as a Guide for the Use of ‘Race’ and Ancestry in Research and Clinical Practice” Institute for Genome Sciences & Policy and Department of African and African American Studies, Duke University, 2009-2012 (co-mentor with Huntington Willard)

Jennifer Wagner, J.D., Ph.D., K99/R00 HG006446, “Multidisciplinary Study of Race, Appearance, Ancestry, Discrimination and Prejudice,” 2012-2018 (co-mentor for K99 component, 2012-2014 with Reed Pyeritz, Univ. Pennsylvania). AAAS congressional Science and Technology Policy Fellow 2014-15 with Sen. Edward Markey; then on her mentorship committee for Geisinger Health, 2015-2021; now faculty at Pennsylvania State University

Teaching

Arizona State University (2015-present)

“Malignant: Cancer Politics and Policy,” HON 494/HSD 598, co-taught Fall 2015 with Jennifer Dyck Brian, Arizona State University for Barrett Honors College and several graduate programs

“Science and Technology Policy,” HSD 501/POS 571, Core course in Science and Technology Policy Masters program at Arizona State University, Fall 2015-2018

“Health and Science Policy” FIS 494/HON 494/HSD 598, Spring and Fall 2017, Fall 2018-19

“Technology Assessment,” PIT 503, core in the PIT program, Fall 2020, Spring & Fall 2021, Fall 2022

“Professional Development Seminar,” HSD 591, for MSTP program, Fall 2022 and Spring 2023

“Applied Project,” PIT 593, culminating capstone for MS-PIT program, Fall 2021, Fall 2022, Spring 2023

Duke University (2003-2016)

“Political and Ethical Conflict in Health and Science Policy,” PubPol 390A, Spring 2016, Spring 2015 (Duke in Washington, DC program), a seminar course in addition to the research independent study for each student

“Cancer in Our Lives,” PubPol 641S/Genome 641S, Fall 2014

“Science, Law and Literature,” English 390S/PubPol 290S/Women’s Studies 290S, Fall 2014 (with Priscilla Wald, English and Women’s Studies)

“Cancer and the Genome,” Genome 590S.10/PubPol 590S.10, Fall 2013

“Science, Law and Policy,” PubPol 590S.07/Law 333.01/Genome 590S.07, Fall 2013 (with Nita Farahany, Law)

Duke in Washington program, course listed as research independent study for each student, supervising a project based on internship, senior thesis preparation, or a specific project, Spring 2013, 2014, 2015, 2016

“The Genome and the Internet: Growing Up Together,” GENOME 108FCS/PUBPOL 81FCS. For ‘Genomes in Our Lives: Science and Conscience’ Focus course cluster, Fall 2011

“Responsible Genomics,” Public Policy 240/Computational Biology and Bioinformatics 212, spring 2004, fall 2005, spring 2007-2012 (except 2011)

“Health Policy Capstone,” Public Policy 255S: final course for Health Policy Certificate Program. Undergraduate section, spring 2004. Graduate and professional student section (with Christopher Conover), spring 2007. Undergraduate and graduate/professional students, spring 2010

“Genome Sciences and Policy Capstone,” final course for undergraduate Genome Science and Policy Certificate Program, spring 2010, 2012, 2013 (with Hunt Willard, Director of the

Institute for Genome Sciences & Policy, and Professor of Biology and of Molecular Genetics and Microbiology), Spring 2014 (with Lauren Dame, Law and IGSP), Spring 2015 and 2016 (with Misha Angrist)

“Evolution in Science and Culture” (with Priscilla Wald, Professor of English), English 193S/Genome 178S, fall 2009

“Social and Political History of Genomics,” Public Policy 264, fall 2004. Taught a similar course of the same title for the Focus program, ‘The Genome Revolution and Its Impact on Society,’ as Public Policy 196S/History 105S (fall 2006) and Public Policy 81FCS/History89FCS (fall 2007), Public Policy Studies 190FS/History 190FS (fall 2012)

“Health, Science, and Human Rights,” Public Policy 195S, for ‘Humanitarian Challenges at Home and Abroad’ Focus program fall 2003, and for ‘Global Health’ Focus program spring 2006

House course faculty sponsor: “The Physician Activist,” fall and spring 2005

Other Teaching

University of Vienna, Summer graduate course, Univie Summer School—Scientific World Conceptions “Genomics: Philosophy, Ethics, and Policy,” 3-14 July 2017, with Jennifer Reardon, University of California, Santa Cruz, and Paul Griffiths, University of Sydney
Stanford-in-Washington Seminar and Tutorial director, “How Policy Decisions Get Made about Health Research and Health Policy,” Fall 1996-Winter 2003 (offered 13 quarters)
Summer Intensive Bioethics Course, Georgetown University, June 1987 and 1988

Student theses and supervision

Graduate and Professional Student Supervisor (Arizona State University)

Barnaby Wasson, MS in Public Interest Technology, 2021-2023 (chair for applied project)

Lionel Gamath-Boubili, MS in Public Interest Technology, 2021-2023 (chair for applied project)

Dina Carpenter-Graffy, MS Public Interest Technology, 2020-2021 (chair for applied project)

Pooja Chitre, PhD candidate in Human and Social Dimensions of Science & Technology, researcher on the Sulston Project, Spring 2021- (chair, Erik Johnston).

Amanda Arnold, PhD in Human and Social Dimensions of Science & Technology, School for the Future of Innovation in Society, ABD starting April 2020 (co-chair with Heather Ross), 2020-2023

Josh Massad, Masters in Public Interest Technology, second-year project (Katina Michael, chair) 2020-2021

Walter Johnson, Masters in Science and Technology Policy, May 2017

Theora Tiffney, PhD in Biology and Society program, School of Life Sciences, December 2020 (co-chair with Jim Collins)

Nathaniel Wade, PhD candidate in Human and Social Dimensions of Science & Technology, School for the Future of Innovation in Society, 2016-2019 (Barry Bozeman, chair)

Neehta Hamidi, Masters in Science & Technology Policy, December 2015 (Andrew Maynard, chair)

Nicole Frank, Masters in Science and Technology Policy internship, summer 2017

Graduate and Professional Student Supervisor (Duke University)

Jenae Emily Logan, M.Sc. Global Health, 2016 (Subhashini Chandrasekharan, chair)
Julia Carbone Gold, S.J.D., 2009-2016 (Arti Rai, chair)
Sonya Jooma, Masters in Bioethics and Science Policy, 2015 (chair)
Andrew Darnell, Masters in Bioethics and Science Policy, 2015 (chair)
Jessica Ordax, Masters in Bioethics and Science Policy, 2015 (Misha Angrist, chair)
Guangyangzi (Gwen) Shu, MPP candidate, 2013-2014 (Anthony So, chair)
Lisa Warner Pfefferle, Biology PhD, 2008-2013 (Gregory Wray, chair)
Erin McCarthy, MPP candidate, 2009-2010 (Anthony So, chair)
Jeremy Block, Biochemistry PhD candidate, MPP project 2008-2009 (chair of MPP)
Matthew DeCamp, Philosophy PhD, July 2002-May 2007 (MD 2008; co-chair of PhD committee with Allen Buchanan)
Elana Fric-Shamji, MPP (already had her MD), May 2007-May 2008 (chair of MPP)
Deirdre Parsons, MS in Molecular Genetics & Microbiology, May-December 2007 (Hunt Willard, chair)
Eric Hoefer, MPP, MBA, 2004 (chair MPP)
Noah Perin, MPP, MBA, 2005 (chair MPP)
Charles Mathews, MPP, 2004 (chair)

Undergraduate Thesis Supervisor (Arizona State University)

Sanjay Srinivas, Barrett Honors College, May 2017 (Daniel Sarewitz, chair)
Sidney Stoffer, Barrett Honors College, May 2016 (Jennifer Brian, chair)

Undergraduate Thesis Supervisor (Duke University)

Jennifer Zhao, May 2015 (Public Policy Studies)
Camille Peebles, December 2014 (Public Policy Studies); main supervisor was Jenni Owen, I supervised one semester and was a final reader
Alexandra Young, May 2014 (thesis outside the disciplines): <http://hdl.handle.net/10161/8933>
Stephanie Chen, Public Policy Studies, May 2014: <http://hdl.handle.net/10161/8924>
Shreya Prasad, May 2010 (International Comparative Studies)
Swathi Padmanabhan, May 2010 (Public Policy Studies):
<http://dukespace.lib.duke.edu/dspace/handle/10161/1699>.
Matthew Piehl, May 2008 (Biology, graduation with distinction)
Sarah Wallace, December 2007 (Public Policy Studies)
Catherine Alessandra Colaianni, May 2007 (Biology and Philosophy)
Joe Fore, December 2006 (Public Policy Studies)
Daidree Tofano, May 2006 (Program II)

Undergraduate Research Program supervisor (ASU)

Kelsey Beck, spring 2018-2020
Julianna Smith, spring 2018-2020
Jillian Leaver, summer 2020-2022
Marina Filipek, summer 2020-2022
Adriane Inocencio, summer 2020-
Maya Shrikant, spring 2021
Zuzana Skvarkova 2021-2022
Imtithal Noor 2021-2023

Britney Hill 2021-2023
Venus Kapadia 2021-2023
Keerthana Balaji 2022-2023

Undergraduate Research Program supervisor or mentor (other universities)

Kavyaa Choudhary, University of Texas, 2021-2022 (co-mentor, Amanda Gutierrez, Baylor College of Medicine
Sudhanvan Iyen, University of Texas, 2021-2023) (co-mentor Mary Majumder, Baylor College of Medicine)

Independent Study and Research Independent studies at Duke:

2009-2016: Biology (1), Public Policy (53), and Genome Sciences and Policy (3) (total = 57)

Program II supervision (Duke's alternative to a disciplinary major)

Sanjay Kishore, graduated 2013
Daidree Tofano, graduated 2006

Thesis supervision for students outside Duke and ASU

Knut Jorgen Egelie, May 2019 Ph.D. in Department of Biology, Norwegian University of Science and Technology (NTNU), "Access to knowledge - university management of intellectual property to govern knowledge dispersion" Trondheim, Norway

Alison Cool, 2013 PhD in Cultural Anthropology, New York University (Rayna Rapp, chair):

http://www.worldcat.org/title/translating-twins-twin-research-and-the-production-of-genetic-and-economic-knowledge-in-the-swedish-welfare-state/oclc/872612982&referer=brief_results

Esther van Zimmeren, 2011 PhD in law, University of Leuven (Geertrui van Overwalle, chair)

Amanda Seagroves, 2014 undergraduate honors thesis at Queen's College, Charlotte, NC:

<http://hdl.handle.net/10161/8923>.

Annie Niehaus, 2014 undergraduate honors thesis at Pomona College, Claremont, CA:

<http://hdl.handle.net/10161/8930>.

Medical Background

Internship: Pathology, University of Colorado Health Sciences Center Hospitals, 1979-80

Residency: Pathology, University of Colorado Health Sciences Center Hospitals, 1980-1982

Medical License: State of Maryland, D31433, 1984-1992

Fellowships and Specialized Coursework

Fellow, the Hastings Center, elected 2018

Senior Fellow, FasterCures, a Center of the Milken Institute (Washington, DC), 2013-2020

Scholar in Residence, Fondation Brocher (<http://www.brocher.ch/>), Hermance, Switzerland, February-July 2011

Fellow, American Association for the Advancement of Science, 1989-present (Section X: Societal Impacts of Science and Engineering)

Intensive Bioethics Course, Kennedy Institute for Ethics, Georgetown University, June 1983; faculty June 1987-1990; advanced course faculty, December 1987

Congressional Science and Engineering Policy Fellowship, American Association for the Advancement of Science (AAAS), 1982-83 (OTA Fellow)

Neurobiology Course, Marine Biological Laboratories, Woods Hole, June-August 1982
NIH National Research Service Award, University of Colorado, 1980-82
National Endowment for the Humanities Summer Fellowship, University of Chicago, summer 1981
Student Honors and Research Committee Award, University of Colorado Medical School, 1979
Chester H. Elliott Award in Pathology, University of Colorado Medical School, 1978
Detur Book Prize, Harvard College, 1974
Student Summer Fellowship in Nuclear Chemistry, Lawrence Berkeley National Laboratory (Atomic Energy Commission) and University of California at Berkeley, Summer 1974
Special Student, mathematics, University of Colorado, Denver; 1971, 1973, 1977

Research grants and paid fellowships

Principal Investigator, “Policies to improve assessment of inherited cancer risk,” Greenwall Foundation, November 2022-October 2023; \$50,000.
Investigator, “BRAINShare: Sharing Data in BRAIN Initiative Studies,” subaward under R01 MH126937 (PIs, Amy McGuire and Sameer Sheth, Baylor College of Medicine). Aug 2021-Jul 2025. PI of Aim 1, case studies and interviews. Parent grant \$1,930,582.
Co-Investigator, “An Embedded ELSI Approach to the Creation of a Novel Human Pangenome Reference: Administrative Supplement,” co-PI with Barbara Koenig (UC San Francisco), Karen Miga (UC Santa Cruz), Nanibaa’ Garrison (UCLA) under U01 HG010971 (David Haussler, UC Santa Cruz, PI of parent grant). Aug 2021-July 2022, subaward to ASU (\$64,651 of \$270,526 total). Extended as a supplement 2022-2024.
Co-Principal Investigator (with Amy McGuire, Baylor College of Medicine), “The Sulston Project: Making the Knowledge Commons for Interpreting Cancer Genomic Variants More Effective,” R01 CA237118. ~\$3M over 4 years, April 2019-March 2023.
Co-Principal Investigator and principal supervisor, “A Case Study on Latinx Community Perspectives about Creating a Cancer Genomic Variant Commons,” diversity supplement to the above grant; ~\$130,000 Sep 2020-Mar 2022. This diversity supplement is led by Amanda Gutierrez, who joined ASU to do this work. I am principal supervisor from the ASU Washington, DC office, with co-PI and co-supervisor Amy McGuire at Baylor College of Medicine in Houston.
Investigator, “Eliminating Variants for Uncertain Significance in BRCA1, BRCA2 and Beyond,” (Sep 2020-Aug 2021 supplement to U01 CA242954; PI is Melissa Cline, UC Santa Cruz). National Cancer Institute subaward to conduct interviews with health plans and online support group participants to assess feasibility of using software container methods to extract data to interpret genomic variants while leaving private, confidential data in place. The parent grant is housed at UC Santa Cruz. Interviews are being led and coordinated by Jill Holdren through ASU; PI of the parent grant and collaborator on this grant, Melissa Cline, is the curator of BRCA Exchange.
Principal Investigator, open access publication grant from Wellcome Trust (UK) for publication of Jones KM, Ankeny RA, and Cook-Deegan R, “The Bermuda Triangle: The Politics, Principles, and Pragmatics of Data Sharing in the History of the Human Genome Project” in *Journal of the History of Biology* <https://doi.org/10.1007/s10739-018-9538-7> 2 Nov 2018 online; Open Access URL: <https://rdcu.be/baDNg> in a special issue on the history of the Human Genome Project edited by Christopher Donohue and Eric Green (~\$3,000).
Principal Investigator (project directors Andrea Downing and Jill Holdren), “Toward a New Model of Collective Data-Governance for Hereditary Cancer Social Networks,” Robert Wood Johnson Foundation (~\$150,000, October 2018-June 2019).

Principal Investigator, “Workshop on Building a BRCA Commons” grant from Chan-Zuckerberg Initiative, September 2017-March 2018 (~\$50,000).

Co-Principal Investigator, Building a Medical Information Commons, with Amy McGuire of Baylor College of Medicine, R01 HG 008918, Sept 2015-June 2018 (~\$1M).

Principal Investigator, Intellectual Property and Access to Noninvasive Prenatal Testing, took over as PI when Subhashini Chandrasekharan became a AAAS Science and Technology Policy Fellow at USAID, September 2015; R01 HG007074; resigned as PI August 2016.

Principal Investigator, Center for Public Genomics 2.0. Duke University, Center of Excellence for ELSI Research Center, National Human Genome Research Institute (P50 HG 003391 renewal April 2011-August 2016, Overall PI; ~\$12 million total)

Investigator, PoliSeq: Clinical Integration of Next-Generation Sequencing, subcontract to Duke through Baylor College of Medicine, Amy McGuire, PI, R01 HG 006460, Aug 2012-July 2017

Principal Investigator, Ewing Marion Kauffman Foundation, Case Studies in Constructing and Using Open and Collaborative Research Models, 2011-2012 (~\$50,000)

Principal Investigator, Josiah Charles Trent Memorial Foundation, Cervical Cancer Vaccines– Analysis/Technical Legal, Regulatory and Societal Challenges in India, 2008-2011 (~\$10,000)

Principal Investigator, Duke Interdisciplinary Working Group “Cognitive and Behavioral Genomics, Evolution, and Race? What Lies Ahead?” (Provost’s Common Fund) 2007–2009 (~\$10,000)

Principal Investigator, Policy Ethics and Law Core, Duke Translational Medicine Institute (Clinical Translational Science Award), National Center for Research Resources, 2006-2007; Investigator 2007-2010 (Ross McKinney became PI in 2007)

Principal Investigator, Policy, Ethics, and Law Core, Southeast Regional Center of Excellence for Emerging Infections and Biodefense (SERCEB), National Institute of Allergy and Infectious Diseases (Overall SERCEB PI was Barton Haynes, Duke, and then Fred Sparling, UNC), 2004-2010 (~\$700,000)

Grantee, Burroughs Wellcome Fund, Stanford-in-Washington, for a case study on international funding of genomics research, in collaboration with the Global Forum for Health Research (Geneva) and the World Health Organization, 2000-2001 (~\$20,000)

Robert Wood Johnson Foundation Investigator Award in Health Policy Research, Georgetown University, 1999-2002 (~\$180,000)

Principal Investigator, grants from Robert Wood Johnson Foundation and National Cancer Institute, on youth tobacco control, 1992-1994

Principal Investigator, Alfred P. Sloan Foundation grant to write a political history of the Human Genome Project, Georgetown University 1988-1991 (~\$50,000)

Principal Investigator, National Science Foundation grant to establish an oral history resource and Human Genome Archive at Georgetown University, 1990-1991 (~\$50,000)

Postdoctoral fellow, molecular biology. Tyrosine kinases encoded by retroviral oncogenes, Raymond L. Erikson, Department of Pathology, University of Colorado (during pathology residency, PGY 2 and 3, supported in part by a National Research Service Award), July 1980-June 1982

Research coordinator and medical student researcher, primarily on Mendelian dominant (inherited) Alzheimer’s Disease: James H. Austin, M.D., mentor, University of Colorado, Chair, Department of Neurology; also worked in that laboratory 1971-82 (part time in high school, full-time summer 1978, then regularly as medical student 1976-1979, and intermittently as postdoc and resident 1979-1982)

Medical student researcher, D. Carleton Gajdusek Laboratory, National Institute of Neurological and Communicative Disorders and Stroke, National Institutes of Health, November 1979-January 1980; “slow virus” encephalopathies

Editorial Positions

Board of Reviewing Editors, *Science*, 2011- (over 350 articles reviewed)
Editorial Committee, *Annual Review of Genomics and Human Genetics*, 2016-2022
Co-editor of special issue on “Building the Medical Information Commons” for *Journal of Law, Medicine and Ethics* (with Amy McGuire and Mary Majumder), Spring 2019; open access at <https://journals.sagepub.com/toc/lmec/47/1>
Co-editor of special issue on “Ethics of Fieldwork in Dangerous Places” for *Health and Human Rights Journal* (with Rachel Clifford-Hall, James Lavery and David Addiss), June 2019; open access at <https://www.hhrjournal.org/volume-21-issue-1-june-2019/>
Editorial Board, *Human Gene Therapy*, 1989-2009
Editorial Board, *American Journal of Alzheimer’s Disease*, 1997-2007
Editorial Advisory Board, *Courts, Health Science, and the Law*, 1989-1992
Special Features Editor, *Genomics*, 1989-1992

External peer review

For Journals

American Journal of Bioethics
American Journal of Human Genetics
Annual Review of Genomics and Human Genetics
The CRISPR Journal
European Journal of Human Genetics
Frontiers in Genetics
Genetics in Medicine
Health and Human Rights Journal
History and Philosophy of the Life Sciences
Human Mutation
Journal of Law and the Biosciences
Journal of Law, Medicine and Ethics
Kennedy Institute of Ethics Journal
Medical Humanities
Mutation
Nature Biotechnology
New England Journal of Medicine
Progress in Community Health Partnerships: Research, Education, and Action
Research Policy
Science
Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences
Trends in Genetics

For Funders

National Institutes of Health, Center for Scientific Review (Ethical, Legal and Social Implications *ad hoc* study section for H3Africa, April 2018, standing study section review Feb 2019, and several previous study sections in 2006 and dating back to late 1980s)
National Science Foundation, Directorate on Social and Behavioral Sciences (various *ad hoc* reviews)
Genome Canada (GE³LS proposals and large-scale genomics projects)

Publications

To request an item that is not available online, email: cookdeegan@gmail.com or bcd@asu.edu

Peer-Reviewed Publications

Book

The Gene Wars: Science, Politics, and the Human Genome (New York and London: WW Norton & Co., 1994; paperback 1996). Published also in Korean (translated by Shin Won Literary Agency, published by Minum, 1995), Japanese (translated by K. and G. Ishidate, published by Kogaku Dojin, 1996), and Chinese (Bardon Chinese Media, 2020). Peer-reviewed and accepted for publication by Oxford University Press, University of California Press, and Harvard University Press. Full text available online (with kind permission of publisher WW Norton & Co.): <<http://hdl.handle.net/10822/545515>> and <<http://dukespace.lib.duke.edu/dspace/handle/10161/8990>>.

Articles and Chapters

1. Deverka P, Geary J, Mathews C, Cohen M, Hooker G, Majumder M, and **Cook-Deegan R**, “Payer reimbursement practices and incentives for improving interpretation of germline genetic testing,” *Journal of Law and the Biosciences* **10** (2): 9 July 2023; open access at <https://doi.org/10.1093/jlb/lad020> and <https://academic.oup.com/jlb/article/10/2/lad020/7218896>.
2. Robinson JO, Daoud A, Geary J, Rahimzadeh V, Bollinger J, Guerrini CJ, **Cook-Deegan R**, McGuire AL, and Majumder MA, “Policy options to facilitate cancer genomic variant data sharing: outcomes of a modified policy Delphi,” *Journal of Law and the Biosciences* **10** (2): 14 July 2023; open access at <https://doi.org/10.1093/jlb/lad022> and <https://academic.oup.com/jlb/article/10/2/lad022/7222293>.
3. **Cook-Deegan R**, “Research for Health: Improving the US System of Health Research,” in *Building a Better NIH*, Brookings Economic Studies, Good Science Project and Institute for Progress, based on a workshop; open access at: <https://www.brookings.edu/product/building-a-better-nih/> for download at <https://www.brookings.edu/wp-content/uploads/2023/05/CookDeeganFinal-3.pdf>, 16 May 2023.
4. Liao, Wen-Wei; Asri, Mobin; Ebler, Jana; Doerr, Daniel; Haukness, Marina; Hickey, Glenn; Lu, Shuangjia; Lucas, Julian K; Monlong, Jean; Abel, Haley J; Buonaiuto, Silvia; Chang, Xian H; Cheng, Haoyu; Chu, Justin; Colonna, Vincenza; Eizenga, Jordan M; Feng, Xiaowen; Fischer, Christian; Fulton, Robert S; Garg, Shilpa; Groza, Cristian; Guarracino, Andrea; Harvey, William T; Heumos, Simon; Howe, Kerstin; Jain, Miten; Lu, Tsung-Yu; Markello, Charles; Martin, Fergal J; Mitchell, Matthew W; Munson, Katherine M; Mwaniki, Moses Njagi; Novak, Adam M; Olsen, Hugh E; Pesout, Trevor; Porubsky, David; Prins, Pjotr; Sibbesen, Jonas A; Sirén, Jouni; Tomlinson, Chad; Villani, Flavia; Vollger, Mitchell R; Antonacci-Fulton, Lucinda L; Baid, Gunjan; Baker, Carl A; Belyaeva, Anastasiya; Billis, Konstantinos; Carroll, Andrew; Chang, Pi-Chuan; Cody, Sarah; Cook, Daniel E; **Cook-Deegan, Robert M**; Cornejo, Omar E; Diekhans, Mark; Ebert, Peter; Fairley, Susan; Fedrigo, Olivier; Felsenfeld, Adam L; Formenti, Giulio; Frankish, Adam; Gao, Yan; Garrison, Nanibaa, A A; Giron, Carlos Garcia; Green, Richard E; Haggerty, Leanne; Hoekzema, Kendra; Hourlier, Thibaut; Ji, Hanlee P; Kenny, Eimear E; Koenig, Barbara A; Kolesnikov, Alexey; Korbel, Jan O; Kordosky,

Jennifer; Koren, Sergey; Lee, HoJoon; Lewis, Alexandra P; Magalhães, Hugo; Marco-Sola, Santiago; Marijon, Pierre; McCartney, Ann; McDaniel, Jennifer; Mountcastle, Jacquelyn; Nattestad, Maria; Nurk, Sergey; Olson, Nathan D; Popejoy, Alice B; Puiu, Daniela; Rautiainen, Mikko; Regier, Allison A; Rhie, Arang; Sacco, Samuel; Sanders, Ashley D; Schneider, Valerie A; Schultz, Baergen I; Shafin, Kishwar; Smith, Michael W; Sofia, Heidi J; Abou Tayoun, Ahmad N; Thibaud-Nissen, Françoise; Tricomi, Francesca Floriana; Wagner, Justin; Walenz, Brian; Wood, Jonathan M D; Zimin, Aleksey V; Bourque, Guillaume; Chaisson, Mark J P; Flicek, Paul; Phillippy, Adam M; Zook, Justin M; Eichler, Evan E; Haussler, David; Wang, Ting; Jarvis, Erich D; Miga, Karen H; Garrison, Erik; Marschall, Tobias; Hall, Ira M; Li, Heng; and Paten, Benedict, “A draft human pangenome reference,” *Nature* **617** (11 May 2023; 7960): 312-324. Available at <https://rdcu.be/dcdf>.

5. Christi Guerrini, Mary A. Majumder, Jill Robinson, **Robert Cook-Deegan**, Matthew Blank, Juli Bollinger, Janis Geary, Amanda M. Gutierrez, Maya Shrikant, and Amy L. McGuire, “Fresh Takes on Data Sharing,” *Frontiers in Big Data* **6** (6 Feb 2023) <https://www.frontiersin.org/articles/10.3389/fdata.2023.1095119/full>.
6. Ameet Sarpatwari, Aaron S. Kesselheim and **Robert Cook-Deegan**, “Bayh-Dole at 40: Accomplishments, Challenges and Possible Reforms,” *Journal of Health Politics, Policy and Law* **10041247** (14 July 2022), open access at <https://doi.org/10.1215/03616878-10041247>.
7. Ting Wang, Lucinda Antonacci-Fulton, Kerstin Howe, Heather A. Lawson, Julian K. Lucas, Adam M. Phillippy, Alice B. Popejoy, Mobin Asri, Caryn Carson, Mark J.P. Chaisson, Xian Chang, **Robert Cook-Deegan**, Adam L. Felsenfeld, Robert S. Fulton, Erik P. Garrison, Nanibaa’ A. Garrison, Tina A. Graves-Lindsay, Hanlee Ji, Eimear E. Kenny, Barbara A. Koenig, Daofeng Li, Tobias Marschall, Joshua F. McMichael, Adam M. Novak, Deepak Purushotham, Valerie A. Schneider, Baergen I. Schultz, Michael W. Smith, Heidi J. Sofia, Tsachy Weissman, Paul Flicek, Heng Li, Karen H. Miga, Benedict Paten, Erich D. Jarvis, Ira M. Hall, Evan E. Eichler, David Haussler and the Human Pangenome Reference Consortium, “The Human Pangenome Project: A Global resource to Map Genomic Diversity,” *Nature* **604** (21 April): 437-446, 2022; <https://doi.org/10.1038/s41586-022-04601-8>.
8. Tiffney TW, **Cook-Deegan R**, and Ross HM, “Breathing Fresh Air into the Debate: Ventilators and the United States' Intellectual Property Problem,” *Health Policy OPEN* (7 April 2022) <https://doi.org/10.1016/j.hpopen.2022.100069>.
9. **Cook-Deegan R**, Sarpatwari A, and Kesselheim AS, “Updating the Bayh-Dole Act: March-In Rights and Transparency,” *Journal of the American Medical Association*, **322**(10):923-924, 8 March 2022; <https://doi:10.1001/jama.2022.0895>. PMID: 35201276.
10. Geary J, Majumder M, Guerrini C, and **Cook-Deegan R**, “Who Tests Which Cancer-Risk Genes? Development of an Open Database of Genes Included in Hereditary Cancer Genetic Testing Panels Available from Major Providers in the US,” *JAMA Oncology*, <https://jamanetwork.com/journals/jamaoncology/fullarticle/2788564> (open access) 3 Feb 2022.
11. Rehm HL, Page AJH, Smith L, Adams JB, Alterovitz G, Babb LJ, Barkley MP, Baudis M, Beauvais MJS, Beck T, Beckmann JS, Beltran S, Bernick D, Bernier A, Bonfield JK, Boughtwood TF, Bourque G, Bowers SR, Brookes AJ, Brudno M, Brush MH, Bujold D, Burdett T, Buske OJ, Cabili MN, Cameron DL, Carroll RJ, Casas-Silva E, Chakravarty D, Chaudhari BP, Chen SH, Cherry JM, Chung J, Cline M, Clissold HL, **Cook-Deegan RM**, Courtot M, Cunningham F, Cupak M, Davies RM, Denisko D, Doerr MJ, Dolman

- LI, Dove ES, Dursi LJ, Dyke SOM, Eddy JA, Eilbeck K, Ellrott KP, Fairley S, Fakhro KA, Firth HV, Fitzsimons MS, Fiume M, Flicek P, Fore IM, Freeberg MA, Freimuth RR, Fromont LA, Fuerth J, Gaff CL, Gan W, Ghanaim EM, Glazer D, Green RC, Griffith M, Griffith OL, Grossman RL, Groza T, Guidry Auvil JM, Guigó R, Gupta D, Haendel MA, Hamosh A, Hansen DP, Hart RK, Hartley DM, Haussler D, Hendricks-Sturup RM, Ho CWL, Hobb AE, Hoffman MM, Hofmann OM, Holub P, Hsu JS, Hubaux J-P, Hunt SE, Husami A, Jacobsen JO, Jamuar SS, Janes EL, Francis Jeanson F, Aina Jené, Johns AL, Joly Y, Jones SJM, Kanitz A, Kato K, Keane TM, Kekesi-Lafrance K, Jerome Kelleher J, Kerry G, Khor S-S, Knoppers BM, Konopko MA, Kosaki K, Kuba M, Lawson J, Leinonen R, Li S, Lin MF, Linden M, Liu X, Liyanage IU, Lopez J, Lucassen AM, Lukowski M, Mann AL, Marshall J, Mattioni M, Metke-Jimenez A, Middleton A, Milne RJ, Molnár-Gábor F, Mulder N, Muñoz-Torres MC, Nag R, Nakagawa H, Nasir J, Navarro A, Nelson TH, Niewielska A, Nisselle A, Niu J, Nyrönen TH, O'Connor BD, Oesterle S, Ogishima S, Wang VO, Paglione LAD, Emilio Palumbo E, Parkinson HE, Philippakis AA, Pizarro AD, Prlic A, Rambla J, Rendon A, Rider RA, Robinson PN, Rodarmer KW, Rodriguez LL, Rubin AF, Rueda M, Rushton GA, Ryan RS, Saunders GI, Schuilenburg H, Schwede T, Scollen S, Senf A, Sheffield NC, Skantharajah N, Smith AV, Sofia HJ, Spalding D, Spurdle AB, Stark Z, Stein LD, Suematsu M, Tan P, Tedds JA, Thomson AA, Thorogood A, Tickle TL, Tokunaga K, Juha Törnroos, Torrents D, Upchurch S, Valencia A, Guimera RV, Vamathevan J, Varma S, Vears DF, Viner C, Voisin C, Wagner AH, Wallace SE, Walsh BP, Williams MS, Winkler EC, Wold BJ, Wood GM, Woolley JP, Yamasaki C, Yates AD, Yung CK, Zass LJ, Zaytseva K, Zhang J, Goodhand P, North K, Birney E, “GA4GH: International policies and standards for data sharing across genomic research and healthcare,” *Cell Genomics* **1**(2): 100029, 2021; ISSN 2666-979X, <https://doi.org/10.1016/j.xgen.2021.100029> (<https://www.sciencedirect.com/science/article/pii/S2666979X21000367>).
12. Sherkow, Jacob S, Barker K, Braverman I, **Cook-Deegan RM**, Durbin R, Easter C, Goldstein M, Hudson M, Kress WJ, Lewin H, Mathews DJH, McCarthy C, McCartney A, da Silva M, Torrance AW, and Greely HT, “Ethical, Legal, and Social Issues in the Earth BioGenome Project.” *Proceedings of the National Academy of Sciences*, **119**(4): e2115859119, 17 Jan 2022 <https://www.pnas.org/content/119/4/e2115859119>. Earlier draft available at SSRN: <https://ssrn.com/abstract=3840280>.
 13. McCartney AM, Anderson J, Liggins L, Maui L, Hudson ML, TeAika B, Geary J, **Cook-Deegan R**, Patel HR, and Phillippy AM, “Balancing Openness with Indigenous Data Sovereignty—an opportunity to leave no one behind in the journey to sequence all of life” *Proceedings of the National Academy of Sciences*, **119** (4) e2115860119; <https://doi.org/10.1073/pnas.2115860119>; 17 Jan 2022.
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 15. Katsanis SH, Claes P, Doerr M, **Cook-Deegan R**, Tennenbaum JD, Evans BJ, LeeMK, Anderton J, Weinberg SM, and Wagner JK, “A Survey of US Public Perspectives on Facial Recognition Technology and Facial Imaging Data Practices in Health and Research Contexts,” *PLoS One*, 14 October 2021 <https://doi.org/10.1371/journal.pone.0257923>.

16. LeRoy Walters, **Robert M. Cook-Deegan**, and Eli Y. Adashi, “The National Institutes of Health and Germline Genetic Intervention: A Textual History and a Proposal for the Future,” *CRISPR Journal* 4(4); online 16 August 2021
<https://doi.org/10.1089/crispr.2021.0043>.
17. Mary A Majumder, Matthew L Blank, Janis Geary, Juli M Bollinger, Christi J Guerrini, Jill Oliver Robinson, Isabel Canfield, **Robert Cook-Deegan**, and Amy L McGuire, “Challenges to Building a Gene Variant Commons to Assess Hereditary Cancer Risk: Results of a Delphi Panel Deliberation,” *J Personalized Medicine* 11(7): 646, 2021;
<https://doi.org/10.3390/jpm11070646>.
18. Katsanis SH, Claes P, Doerr M, **Cook-Deegan R**, Tenenbaum JD, Evans BJ, Lee MK, Anderton J, Weinberg SM, and Wagner JK: “A survey of U.S. public perspectives on facial recognition technology and facial imaging data practices in health and research contexts.” *PLoS ONE* 16(10): e0257923, 2021;
<https://doi.org/10.1371/journal.pone.0257923>.
19. Maxson Jones K and **Cook-Deegan R**: “An Ethos of Rapid Data Sharing, More Relevant than Ever,” *Science* 371(46529; 5 Feb): 564-565, 2021;
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21. Graves Z and **Cook-Deegan R**: “Incorporating Ethics into Technology Assessment” *Issues in Science and Technology* 36 (Fall 2019): <https://issues.org/issue/36-1/>.
22. **Cook-Deegan R**: “Does NIH Need a DARPA?” reprinted from *Issues in Science and Technology in Bonvillian WB, van Atta R, and Windham P, Eds., The DARPA Model for Transformative Technologies—Perspectives on the Defense Advanced Research Projects Agency* (Cambridge, UK: Open Book Publishers, 2020), pp. 238-244;
<https://www.openbookpublishers.com/product/1079>.
23. Akerlof K, Tyler C, Foxen SE, Heath E, Soler MG, Allegra A, Cloyd ET, Hird JA, Nelson SM, Nguyen CT, Cameryn J, Gonnella CJ, Liam A. Berigan LA, Abeledo CR, Al-Yakoub TA, Andoh HF, Boeira LdS, van Boheemen P, Cairney P, **Cook-Deegan R**, Gavin Costigan G, Meghnath Dhimal M, Di Marco MH, Dube D, Egbetokun A, El Kharraz J, Galindo LE, Ferguson MWJ, Franco J, Graves Z, Hayter E, Hernández-Mondragón AC, Hobbs AD, Holden KL, Isselmuiden C, Jegede AS, Krstic SB, Mbonyintwali J-M, Mengesha SD, Michalek T, Nagano H, Nentwich M, Nouri A, Ntale PD, Ogundele OM, Omenma JT, Pau L-F, Peha43 JM, Prescott EM, Ramos-Vielba I, Roberts R, Sandifer PA, Saner MA, Sanganyado E, Sanni M, Santillán O, Stine DD, Straf ML, Tangney P, Carla-Leanne Washbourne C-L, Winderickx W, and Yarime M, “A collaboratively derived international research agenda on legislative science advice,” *Palgrave Communications* (Nature) 5:108, 2019; <https://doi.org/10.1057/s41599-019-0318-6>.
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- E. Richard Gold, Tania Bubela, **Robert Cook-Deegan**, James P. Evans, Julian Kinderler, and Dianne Nicol. *Amici Curiae* Brief for Academics in Law, Medicine, Health Policy and Clinical Genetics in Support of Neither Party, *Association for Molecular Pathology v. Myriad Genetics, Inc.*, 653 F.3d 1329 (January 2013) (SCOTUS No. 12-398) for US Supreme Court, available at: <http://dukespace.lib.duke.edu/dspace/handle/10161/7566>
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Book and other reviews

- “No Ordinary Documentary,” Review of *No Ordinary Campaign*, a video documentary about I AM ALS for *Issues in Science and Technology*; <https://issues.org/no-ordinary-campaign-cook-deegan/> (30 June 2023).
- “CRISPR’s Icarus,” Review of *Make People Better*, a documentary film in *Issues in Science and Technology*; <https://issues.org/crispr-make-people-better-documentary-cook-deegan/> (19 January 2023).
- “Not So Fast,” Review of *CRISPR People: The Science and Ethics of Editing the Human Genome* by Henry T. Greely. *Issues in Science and Technology* **37**, (No. 4; Summer 2021): 92–93; <https://issues.org/crispr-people-greely-review-cook-deegan/>.
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- “An Elusive Consensus,” review of *Altered Inheritance* by Francoise Baylis, *Human Flourishing in an Age of Gene Editing*, edited by Erik Parens and Josephine Johnston, and *Designing Babies* by Robert L. Klitzman, in *Issues in Science and Technology* **37** (1, Fall): 89-92, 2020; <https://issues.org/elusive-consensus-crispr-gene-editing-cook-deegan-review/>.
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- Review of *Brain Policy: How the New Neuroscience Will Change Our Lives and Our Politics* by Robert H. Blank. *Cerebrum*. 1 (Spring): 104-109, 1999.
- Review of *The Baltimore Case: A Trial of Politics, Science, and Character* by Daniel Kevles. *Recent Science Newsletter* 1 (Spring): 8-10, 1999.
- Review of *Clone: The Road to Dolly and the Path Ahead* by Gina Kolata. *Issues in Science and Technology*, 14 (Spring): 90-95, 1998.
- Review of *The Moral Challenge of Alzheimer’s Disease*, by Stephen Post. *New England Journal of Medicine*, **334** (2 May): 1204, 1996.
- Review of *Alzheimer’s Disease Research: Ethical and Legal Issues*, in *New England Journal of Medicine*, **327**: 60-61, 1992.
- A Landmark in Medical Genetics. Review of *Ethics and Human Genetics: A Cross Cultural Perspective*. Wertz and Fletcher, eds. in *Bioethics Books*, **1** (4): 75-77, 1990.
- Review of *Biotechnology and the Human Genome*. Woodhead and Barnhart, eds. in *Bioscience* **39**: 402-403, 1989.
- Review of *Invisible Frontiers* by Stephen Hall and *Natural Obsessions* by Natalie Angier, in *Journal of the American Medical Association* **261**: 773-773, February 3, 1989.

“Scientists and the Dawn of Industrial Pharmacology.” Review of *Academic Scientists and the Pharmaceutical Industry* by John Swann for *Medical Humanities Review* 3: 84-86, January 1989.

Reports

Note of Explanation: The reports below were prepared when I was staff for Washington-based organizations. Most are book-length reports subjected to extensive external review, but not peer-reviewed in the sense usually meant in academia. I have described my contribution in each case.

National Cancer Policy Board Reports

“CellPro: a case study in intellectual property related to cancer therapeutics.” Background memo, June 2001 (Coauthor with Avital Bar-Shalom)

State Programs Can Reduce Tobacco Use. February 2000 (Main writer and study director)

Expanding Medicare Reimbursement for Clinical Trials, H Aaron and H Gelband, eds., Washington, DC: National Academy Press, December 1999 (Supervision only, no authorship. This study was administratively housed with the Board, but the report was formally from IOM as a whole) <http://books.nap.edu/catalog/9762.html>

Ensuring Quality Cancer Care, M Hewitt and J Simone, eds., Washington, DC: National Academy Press, April 1999 (Supervision and editing only, no authorship) <http://books.nap.edu/catalog/6467.html>

Taking Action to Reduce Tobacco Use. National Academy Press, 1998 (Principal staff writer/editor and study director) <http://www.nap.edu/readingroom/books/tobacco>

Letter on tobacco control to Donna Shalala, Bruce Reed, and Members of Congress from the National Cancer Policy Board, July 19, 1997 (Staff writer and study director)

Background paper on Tobacco Control, July 1997 (Staff writer. Background paper prepared for Board).

National Academy of Sciences Reports

Strategies to Leverage Research Funding: Guiding DOD's Peer-Reviewed Medical Research Programs, Michael McGeary and Kathi E. Hanna, eds. Washington, DC, The National Academies Press, 2004. This study was supported by the National Academy of Sciences and the U.S. Department of Defense (Committee member, principal writer of a few short sections; main writers were Kathi Hanna and Michael McGeary; chair was Joseph Pagano, University of North Carolina Cancer Center)

<https://www.nap.edu/catalog/11089/strategies-to-leverage-research-funding-guiding-dods-peer-reviewed-medical>.

Allocating Federal Funds for Science and Technology. National Academy Press, 1995 (Senior Program Officer; staff writer for some sections and executive summary, and several background papers. Committee chair, Frank Press; study director, Norman Metzger. Other staff writers: Christopher Hill, Michael McGeary, and Julie Esanu)

<http://www.nap.edu/catalog/5040.html>.

Institute of Medicine Reports

Preserving Public Trust: Accrediting Human Research Participant Protection Programs.

Washington, DC: National Academy Press, 2001 (primary staff writer for fast-track project; Chair, Daniel Federman, Harvard Medical School; study director, L Rodriguez;

Division of Health Sciences Policy, Institute of Medicine)
<http://books.nap.edu/catalog/10085.html>

The following reports were initiated and substantially completed in the Division of Biobehavioral Sciences and Mental Disorders, 1991-1994, while I was Division Director at the Institute of Medicine, National Academy of Sciences

The Development of Medications for the Treatment of Opiate and Cocaine Addictions, CE Fulco, CT Liverman, and LE Early, eds. Washington, DC: National Academy Press, 1995 (Supervision only, no authorship)

<http://www.nap.edu/books/0309052440/html/index.html>

Federal Regulation of Methadone Treatment, Richard A. Rettig and Adam Yarmolinsky, eds. Washington, DC: National Academy Press, 1995 (Supervision only, no authorship)

<http://www.nap.edu/catalog/4899.html>

Growing Up Tobacco Free: Preventing Nicotine Addiction in Children and Youths, BS Lynch and RJ Bonnie, eds. Washington, DC: National Academy Press, 1994 (Co-author of first and last chapters. Overall supervision. Main writers were study director Barbara Lynch and committee member Richard Bonnie)

http://www.nap.edu/catalog.php?record_id=4757

AIDS and Behavior: An Integrated Approach, JD Auerbach, C Wypijewska, H Keith and H Brodie, eds. Washington, DC: National Academy Press, 1994 (wrote one section of one chapter on biology. Main writers were study director Judith Auerbach and her research associate, Christina Wypiejewska) <http://www.nap.edu/catalog/4770.html>

The Dynamic Brain, by Robert Pool for the Institute of Medicine Washington, DC: National Academy Press, 1994 (Supervision and editing only)

Reducing Risks of Mental Disorders: Frontiers of Preventive Intervention Research, PJ Mrazek and RJ Haggerty, eds. Washington, DC: National Academy Press, 1994 (wrote one chapter section on specific disorders and sections of two policy chapters and aided in editing; main staff author/editor was study director, Patricia Mrazek)

<http://www.nap.edu/catalog/2139.html>

Discovering the Brain, by Sandra Ackerman for the Institute of Medicine, Washington, DC: National Academy Press, 1992. (I was ghost author of James D. Watson preface and did overall project supervision) <http://www.nap.edu/catalog/1785.html>

Assessing Future Research Needs: Mental and Addictive Disorders in Women. C Pechura, ed. Washington, DC: Division of Health Sciences Policy and Division of Biobehavioral Sciences and Mental Disorders, Institute of Medicine, 1991 (No authorship. Main writer was study director, Constance Pechura)

Office of Technology Assessment Reports

Reports are available at Princeton University's *OTA Legacy* website:

<http://www.princeton.edu/~ota/>. More recent and higher quality scans are at the Federation of American Scientists' *OTA archive*: <http://ota.fas.org/>.

Mapping Our Genes – Genome Projects: How Big? How Fast? Project director. April 1988. Reprinted by The Johns Hopkins University Press, Baltimore, Maryland, 1988; and Human Sciences Press, New York, 1988. Received Notable Documents of 1988 Award, National Library Association, 1989. (Author of executive summary and several chapters. Overall project director. Other staff authors: Patricia Hoben, Gladys White, Jacqueline Courteau and David Guston) <http://ota-cdn.fas.org/reports/8827.pdf>

Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias. Project director. April 1987. Reprinted by JP Lippincott, Philadelphia, PA, as *Confronting Alzheimer's Disease and Other Dementias*, 1988, and by Human Sciences Press, 1988 under its original title. Listed among 20 Federal reports in Godort "Notable Documents" for 1987, and one of 17 "Historic Documents 1987" by *Congressional Quarterly*. (Project director and author of congressional summary and chapter 3. Other chapter authors: Katie Maslow, L. Val Giddings, Dana Gelb [Safran], Teresa Schwab Myers, David Chavkin, Mary Ann Baily, Catherine Hawes and Nancy Mace).

Technology and Aging in America, June 1985 (Senior analyst, with primary responsibility for sections on biomedical research, chronic disorders, and medications).

Human Gene Therapy, December 1984 (Study director and principal writer).

Impacts of Neuroscience, March 1984 (Study director and principal writer).

Commercial Biotechnology: An International Analysis. January 1984. Reprinted by the North Carolina Biotechnology Center, Durham, NC, and Pergamon Press, Elmwood, NY. (Special Contributor. Wrote a few short chapter sections and background papers. Main staff writers: Nanette Newell, Susan Clymer, Geoffrey Karny, Thomas Bugbee, James A. Thomas, Louise Williams and Raymond Zlinskas).