

Robert Cook-Deegan

List of Publications by Year in descending order

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125
papers

4,225
citations

168829

31
h-index

145109

60
g-index

133
all docs

133
docs citations

133
times ranked

4816
citing authors

#	ARTICLE	IF	CITATIONS
1	U.S. Adult Perspectives on Facial Images, DNA, and Other Biometrics. IEEE Transactions on Technology and Society, 2022, 3, 9-15.	2.4	3
2	Ethical, legal, and social issues in the Earth BioGenome Project. Proceedings of the National Academy of Sciences of the United States of America, 2022, 119, e2115859119.	3.3	8
3	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 of the United States of America, 2022, 119, .	3.3	33
4	The Human Pangenome Project: a global resource to map genomic diversity. Nature, 2022, 604, 437-446.	13.7	192
5	Complicated legacies: The human genome at 20. Science, 2021, 371, 564-569.	6.0	11
6	Challenges to Building a Gene Variant Commons to Assess Hereditary Cancer Risk: Results of a Modified Policy Delphi Panel Deliberation. Journal of Personalized Medicine, 2021, 11, 646.	1.1	3
7	Governing Heritable Human Genome Editing: A Textual History and a Proposal for the Future. CRISPR Journal, 2021, 4, 469-476.	1.4	1
8	A survey of U.S. public perspectives on facial recognition technology and facial imaging data practices in health and research contexts. PLoS ONE, 2021, 16, e0257923.	1.1	10
9	Reactions to the National Academies/Royal Society Report on Heritable Human Genome Editing. CRISPR Journal, 2020, 3, 332-349.	1.4	15
10	Introduction: Sharing Data in a Medical Information Commons. Journal of Law, Medicine and Ethics, 2019, 47, 7-11.	0.4	11
11	Characterizing the Biomedical Data-Sharing Landscape. Journal of Law, Medicine and Ethics, 2019, 47, 21-30.	0.4	18
12	Genomic Data-Sharing Practices. Journal of Law, Medicine and Ethics, 2019, 47, 31-40.	0.4	12
13	In support of mitochondrial replacement therapy. Nature Medicine, 2019, 25, 870-871.	15.2	10
14	LeRoy Walters's Legacy of Bioethics in Genetics and Biotechnology Policy. Kennedy Institute of Ethics Journal, 2019, 29, 51-66.	0.3	0
15	BRCA1/2 Variant Data-Sharing Practices. Journal of Law, Medicine and Ethics, 2019, 47, 88-96.	0.4	4
16	The continuing saga of patents and non-invasive prenatal testing. Prenatal Diagnosis, 2019, 39, 441-447.	1.1	5
17	National Partnership for Maternal Safety: Consensus Bundle on Venous Thromboembolism. Obstetrics and Gynecology, 2019, 134, 1115-1117.	1.2	1
18	A collaboratively derived international research agenda on legislative science advice. Palgrave Communications, 2019, 5, .	4.7	9

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19	Open science precision medicine in Canada: Points to consider. <i>Facets</i> , 2019, 4, 1-19.	1.1	7
20	15. Does NIH need a DARPA?. , 2019, , 453-460.		2
21	Ethics of Global Health Photography: A Focus on Being More Human. <i>Health and Human Rights</i> , 2019, 21, 49-62.	1.3	0
22	A randomized controlled trial of disclosing genetic risk information for Alzheimer disease via telephone. <i>Genetics in Medicine</i> , 2018, 20, 132-141.	1.1	36
23	BRCA Challenge: BRCA Exchange as a global resource for variants in BRCA1 and BRCA2. <i>PLoS Genetics</i> , 2018, 14, e1007752.	1.5	148
24	CRISPR Patents: Aspiring to Coherent Patent Policy. <i>American Journal of Bioethics</i> , 2018, 18, 51-54.	0.5	2
25	The Bermuda Triangle: The Pragmatics, Policies, and Principles for Data Sharing in the History of the Human Genome Project. <i>Journal of the History of Biology</i> , 2018, 51, 693-805.	0.2	42
26	Universities: The Fallen Angels of Bayh-Dole?. <i>Daedalus</i> , 2018, 147, 76-89.	0.9	17
27	Participant-Partners in Genetic Research: An Exome Study with Families of Children with Unexplained Medical Conditions. <i>Journal of Participatory Medicine</i> , 2018, 10, e2.	0.7	2
28	Public variant databases: liability?. <i>Genetics in Medicine</i> , 2017, 19, 838-841.	1.1	21
29	Sharing Data to Build a Medical Information Commons: From Bermuda to the Global Alliance. <i>Annual Review of Genomics and Human Genetics</i> , 2017, 18, 389-415.	2.5	22
30	What's the Use? <i><i>Disparate Purposes of U.S. Federal Bioethics Commissions</i></i> . <i>Hastings Center Report</i> , 2017, 47, S14-S16.	0.7	3
31	Sharing data under the 21st Century Cures Act. <i>Genetics in Medicine</i> , 2017, 19, 1289-1294.	1.1	20
32	Moving beyond Bermuda: sharing data to build a medical information commons. <i>Genome Research</i> , 2017, 27, 897-901.	2.4	27
33	Fostering reproducibility in industry-academia research. <i>Science</i> , 2017, 357, 759-761.	6.0	28
34	Racing for academic glory and patents: Lessons from CRISPR. <i>Science</i> , 2017, 358, 874-876.	6.0	8
35	Barriers to clinical adoption of next-generation sequencing: a policy Delphi panel's solutions. <i>Personalized Medicine</i> , 2017, 14, 339-354.	0.8	15
36	Creating a data resource: what will it take to build a medical information commons?. <i>Genome Medicine</i> , 2017, 9, 84.	3.6	36

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37	Beyond Our Borders? Public Resistance to Global Genomic Data Sharing. <i>PLoS Biology</i> , 2016, 14, e2000206.	2.6	33
38	<i>Sequenom v. Ariosa</i> – The Death of a Genetic Testing Patent. <i>New England Journal of Medicine</i> , 2016, 375, 2418-2419.	13.9	2
39	Disclosing Pleiotropic Effects During Genetic Risk Assessment for Alzheimer Disease. <i>Annals of Internal Medicine</i> , 2016, 164, 155.	2.0	34
40	Developing context-specific next-generation sequencing policy. <i>Nature Biotechnology</i> , 2016, 34, 466-470.	9.4	5
41	The mouse that trolled (again). <i>Journal of Law and the Biosciences</i> , 2016, 3, 185-191.	0.8	1
42	Barriers to clinical adoption of next generation sequencing: Perspectives of a policy Delphi panel. <i>Applied & Translational Genomics</i> , 2016, 10, 19-24.	2.1	30
43	Community crystal gazing. <i>Nature Biotechnology</i> , 2016, 34, 276-283.	9.4	1
44	The mouse that trolled: the long and tortuous history of a gene mutation patent that became an expensive impediment to Alzheimer's research. <i>Journal of Law and the Biosciences</i> , 2015, 2, 213-262.	0.8	7
45	Perspectives on Genetic and Genomic Technologies in an Academic Medical Center: The Duke Experience. <i>Journal of Personalized Medicine</i> , 2015, 5, 67-82.	1.1	15
46	A randomized noninferiority trial of condensed protocols for genetic risk disclosure of Alzheimer's disease. <i>Alzheimer's and Dementia</i> , 2015, 11, 1222-1230.	0.4	28
47	Keeping score, strengthening policy and fighting bad actors over access to research tools. <i>Nature Biotechnology</i> , 2015, 33, 143-147.	9.4	5
48	Broad Consent for Research With Biological Samples: Workshop Conclusions. <i>American Journal of Bioethics</i> , 2015, 15, 34-42.	0.5	221
49	Perceptions of Personalized Medicine in an Academic Health System: Educational Findings. <i>Journal of Contemporary Medical Education</i> , 2015, 3, 14.	0.2	15
50	After Myriad: Genetic Testing in the Wake of Recent Supreme Court Decisions about Gene Patents. <i>Current Genetic Medicine Reports</i> , 2014, 2, 223-241.	1.9	29
51	Patents and Genome-Wide DNA Sequence Analysis: Is it Safe to Go into the Human Genome?. <i>Journal of Law, Medicine and Ethics</i> , 2014, 42, 42-50.	0.4	6
52	Variants of uncertain significance in BRCA: a harbinger of ethical and policy issues to come?. <i>Genome Medicine</i> , 2014, 6, 121.	3.6	74
53	Distributing the future: The weak justifications for keeping human genomic databases secret and the challenges and opportunities in reverse engineering them. <i>Applied & Translational Genomics</i> , 2014, 3, 124-127.	2.1	13
54	Is Bayh-Dole Good for Developing Countries? Lessons from the U.S. Experience. , 2014, , 201-215.		1

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55	MYRIAD AFTER THE PROPRIETARY DATA DILEMMA. North Carolina Journal of Law & Technology, 2014, 15, 597-637.	2.0	17
56	Constructing narratives of heroism and villainy: case study of Myriad's BRACAnalysis [®] compared to Genentech's Herceptin [®] . Genome Medicine, 2013, 5, 8.	3.6	17
57	Gene Patenting "The Supreme Court Finally Speaks. New England Journal of Medicine, 2013, 369, 869-875.	13.9	58
58	Commercial landscape of noninvasive prenatal testing in the United States. Prenatal Diagnosis, 2013, 33, 521-531.	1.1	115
59	Patents and Misplaced Angst: Lessons for Translational Stem Cell Research from Genomics. Cell Stem Cell, 2013, 12, 508-512.	5.2	11
60	Moving Beyond "Isolated" Gene Patents. Science, 2013, 341, 137-138.	6.0	10
61	The emergence of commercial genomics: analysis of the rise of a biotechnology subsector during the Human Genome Project, 1990 to 2004. Genome Medicine, 2013, 5, 83.	3.6	11
62	Harm, hype and evidence: ELSI research and policy guidance. Genome Medicine, 2013, 5, 21.	3.6	39
63	<i>AMP v. Myriad</i> : A Surgical Strike on Blockbuster Business Models. Science Translational Medicine, 2013, 5, 192ed9.	5.8	11
64	Reflections on the Cost of "Low-Cost" Whole Genome Sequencing: Framing the Health Policy Debate. PLoS Biology, 2013, 11, e1001699.	2.6	67
65	The next controversy in genetic testing: clinical data as trade secrets?. European Journal of Human Genetics, 2013, 21, 585-588.	1.4	73
66	Are Human Genes Patentable?. Annals of Internal Medicine, 2013, 159, 298-9.	2.0	3
67	Genomics and Patents. , 2013, , 464-473.		0
68	Cystic Fibrosis Patents: A Case Study of Successful Licensing. LES Nouvelles, 2013, , 21-30.	0.5	1
69	Law and Science Collide Over Human Gene Patents. Science, 2012, 338, 745-747.	6.0	14
70	Rules for Growth: Promoting Innovation and Growth Through Legal Reform. SSRN Electronic Journal, 2011, , .	0.4	2
71	Boosting Health Services Research. Science, 2011, 333, 1384-1385.	6.0	6
72	Gene Patents: The Shadow of Uncertainty. Science, 2011, 331, 873-874.	6.0	3

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73	Intellectual property, technology transfer and manufacture of low-cost HPV vaccines in India. <i>Nature Biotechnology</i> , 2010, 28, 671-678.	9.4	42
74	DNA patents and diagnostics: not a pretty picture. <i>Nature Biotechnology</i> , 2010, 28, 784-791.	9.4	27
75	Reply to Wrong fixes for gene patents. <i>Nature Biotechnology</i> , 2010, 28, 1243-1243.	9.4	1
76	Impact of gene patents and licensing practices on access to genetic testing for hereditary hemochromatosis. <i>Genetics in Medicine</i> , 2010, 12, S155-S170.	1.1	9
77	Impact of gene patents and licensing practices on access to genetic testing for long QT syndrome. <i>Genetics in Medicine</i> , 2010, 12, S111-S154.	1.1	17
78	Impact of gene patents and licensing practices on access to genetic testing for Alzheimer disease. <i>Genetics in Medicine</i> , 2010, 12, S71-S82.	1.1	10
79	Spinocerebellar ataxia: Patient and health professional perspectives on whether and how patents affect access to clinical genetic testing. <i>Genetics in Medicine</i> , 2010, 12, S83-S110.	1.1	20
80	Impact of gene patents and licensing practices on access to genetic testing and carrier screening for Tay-Sachs and Canavan disease. <i>Genetics in Medicine</i> , 2010, 12, S5-S14.	1.1	23
81	Impact of gene patents and licensing practices on access to genetic testing for inherited susceptibility to cancer: Comparing breast and ovarian cancers with colon cancers. <i>Genetics in Medicine</i> , 2010, 12, S15-S38.	1.1	37
82	Gene patents and licensing: Case studies prepared for the Secretary's Advisory Committee on Genetics, Health, and Society. <i>Genetics in Medicine</i> , 2010, 12, S1-S2.	1.1	13
83	Impact of gene patents and licensing practices on access to genetic testing for cystic fibrosis. <i>Genetics in Medicine</i> , 2010, 12, S194-S211.	1.1	36
84	Fertility patients' views about frozen embryo disposition: results of a multi-institutional U.S. survey. <i>Fertility and Sterility</i> , 2010, 93, 499-509.	0.5	113
85	Metastasizing patent claims on BRCA1. <i>Genomics</i> , 2010, 95, 312-314.	1.3	16
86	Patents in Genomics and Human Genetics. <i>Annual Review of Genomics and Human Genetics</i> , 2010, 11, 383-425.	2.5	88
87	DNA sequence patents are not in the grave yet. <i>Nature Biotechnology</i> , 2009, 27, 122-122.	9.4	0
88	The dangers of diagnostic monopolies. <i>Nature</i> , 2009, 458, 405-406.	13.7	27
89	Columbia University's Axel Patents: Technology Transfer and Implications for the Bayh-Dole Act. <i>Milbank Quarterly</i> , 2009, 87, 683-715.	2.1	54
90	Gene patents and personalized medicine - what lies ahead?. <i>Genome Medicine</i> , 2009, 1, 92.	3.6	17

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91	Direct-to-consumer genetic tests: beyond medical regulation?. <i>Genome Medicine</i> , 2009, 1, 17.	3.6	32
92	Disclosure of <i>APOE</i> Genotype for Risk of Alzheimer's Disease. <i>New England Journal of Medicine</i> , 2009, 361, 245-254.	13.9	490
93	Dr. Varmus Goes to Washington. <i>American Scientist</i> , 2009, 97, 152.	0.1	0
94	Publicâ€”Private Interactions in Genomic Medicine: Research and Development. , 2009, , 434-444.		1
95	Incorporating ethnicity into genetic risk assessment for Alzheimer disease: the REVEAL study experience. <i>Genetics in Medicine</i> , 2008, 10, 207-214.	1.1	36
96	Ethical and Practical Issues Associated with Aggregating Databases. <i>PLoS Medicine</i> , 2008, 5, e190.	3.9	28
97	Is Bayh-Dole Good for Developing Countries? Lessons from the US Experience. <i>PLoS Biology</i> , 2008, 6, e262.	2.6	83
98	How Bioethics Can Inform Policy Decisions About Genetic Enhancement. <i>Philosophy and Medicine</i> , 2008, , 161-198.	0.3	0
99	SCIENCE AND SECURITY: Practical Experiences in Dual-Use Review. <i>Science</i> , 2007, 316, 1432-1433.	6.0	10
100	The science commons in health research: structure, function, and value. <i>Journal of Technology Transfer</i> , 2007, 32, 133-156.	2.5	31
101	The effects of business practices, licensing, and intellectual property on development and dissemination of the polymerase chain reaction: case study. <i>Journal of Biomedical Discovery and Collaboration</i> , 2006, 1, 7.	2.0	40
102	Factors that affect infertility patientsâ€™ decisions about disposition of frozen embryos. <i>Fertility and Sterility</i> , 2006, 85, 1623-1630.	0.5	87
103	The science commons in life science research: structure, function, and value of access to genetic diversity. <i>International Social Science Journal</i> , 2006, 58, 299-317.	1.0	17
104	Evidence and anecdotes: an analysis of human gene patenting controversies. <i>Nature Biotechnology</i> , 2006, 24, 1091-1094.	9.4	101
105	The licensing of DNA patents by US academic institutions: an empirical survey. <i>Nature Biotechnology</i> , 2006, 24, 31-39.	9.4	72
106	PUBLIC HEALTH: Genomics and Medicine at a Crossroads in Chernobyl. <i>Science</i> , 2006, 314, 62-63.	6.0	2
107	Non-reporting and inconsistent reporting of race and ethnicity in articles that claim associations among genotype, outcome, and race or ethnicity. <i>Journal of Medical Ethics</i> , 2006, 32, 724-728.	1.0	44
108	Genetic Testing For Alzheimerâ€™s Disease And Its Impact On Insurance Purchasing Behavior. <i>Health Affairs</i> , 2005, 24, 483-490.	2.5	127

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109	Neurocognitive enhancement: what can we do and what should we do?. Nature Reviews Neuroscience, 2004, 5, 421-425.	4.9	546
110	Patents and Innovation in Cancer Therapeutics: Lessons from CellPro. Milbank Quarterly, 2002, 80, 637-676.	2.1	29
111	Privacy, families, and human subject protections: Some lessons from pedigree research. Journal of Continuing Education in the Health Professions, 2001, 21, 224-237.	0.4	16
112	INTELLECTUAL PROPERTY: Patents, Secrecy, and DNA. Science, 2001, 293, 217-217.	6.0	48
113	The Human Genome Project after a decade: policy issues. Nature Genetics, 1998, 20, 333-335.	9.4	20
114	Commentary on "distinguishing genetic from nongenetic medical tests: Some implications for antidiscrimination legislation" (J. S. Alper and J. Beckwith). Science and Engineering Ethics, 1998, 4, 151-154.	1.7	0
115	Alzheimer Testing at Silver Years. Cambridge Quarterly of Healthcare Ethics, 1998, 7, 294-307.	0.5	1
116	Gene quests and the social ethics of research. Amyloid: the International Journal of Experimental and Clinical Investigation: the Official Journal of the International Society of Amyloidosis, 1994, 1, 283-285.	1.4	0
117	Private arts. The Sciences, 1994, 34, 18-23.	0.1	2
118	The Genesis of The Human Genome Project. , 1991, 1, 1-75.		3
119	Social and Ethical Implications of Advances in Human Genetics. Southern Medical Journal, 1990, 83, 879-882.	0.3	1
120	Report of the X chromosome workshop. Genomics, 1990, 7, 647-654.	1.3	3
121	The large DNA insert cloning workshop. Genomics, 1990, 7, 654-660.	1.3	1
122	Mapping the Human Genome Biotechnology and the Human Genome: Innovations and Impact Avril D. Woodhead Benjamin J. Barnhart. BioScience, 1989, 39, 402-403.	2.2	0
123	The alta summit, December 1984. Genomics, 1989, 5, 661-663.	1.3	35
124	The researcher as a congressional director. Trends in Biochemical Sciences, 1982, 7, 434.	3.7	1
125	Biomedical Research Policy and Innovation (1940s"Present). , 0, , 181-196.		0