

# Jane Kaye

## List of Publications by Year in descending order

Source: <https://exaly.com/author-pdf/5894582/publications.pdf>

Version: 2024-02-01

116  
papers

6,604  
citations

87723

38  
h-index

74018

75  
g-index

120  
all docs

120  
docs citations

120  
times ranked

10333  
citing authors

#	ARTICLE	IF	CITATIONS
1	The UK10K project identifies rare variants in health and disease. <i>Nature</i> , 2015, 526, 82-90.	13.7	1,014
2	Dynamic consent: a patient interface for twenty-first century research networks. <i>European Journal of Human Genetics</i> , 2015, 23, 141-146.	1.4	476
3	Data sharing in genomics “re-shaping scientific practice. <i>Nature Reviews Genetics</i> , 2009, 10, 331-335.	7.7	253
4	From patients to partners: participant-centric initiatives in biomedical research. <i>Nature Reviews Genetics</i> , 2012, 13, 371-376.	7.7	250
5	Prepublication data sharing. <i>Nature</i> , 2009, 461, 168-170.	13.7	243
6	Dynamic Consent: a potential solution to some of the challenges of modern biomedical research. <i>BMC Medical Ethics</i> , 2017, 18, 4.	1.0	223
7	Research Ethics Recommendations for Whole-Genome Research: Consensus Statement. <i>PLoS Biology</i> , 2008, 6, e73.	2.6	212
8	The Tension Between Data Sharing and the Protection of Privacy in Genomics Research. <i>Annual Review of Genomics and Human Genetics</i> , 2012, 13, 415-431.	2.5	191
9	Marketing of unproven stem cell-based interventions: A call to action. <i>Science Translational Medicine</i> , 2017, 9, .	5.8	147
10	Toward a roadmap in global biobanking for health. <i>European Journal of Human Genetics</i> , 2012, 20, 1105-1111.	1.4	139
11	Patient Perspectives on Sharing Anonymized Personal Health Data Using a Digital System for Dynamic Consent and Research Feedback: A Qualitative Study. <i>Journal of Medical Internet Research</i> , 2016, 18, e66.	2.1	139
12	From consent to institutions: Designing adaptive governance for genomic biobanks. <i>Social Science and Medicine</i> , 2011, 73, 367-374.	1.8	138
13	Citizen science or scientific citizenship? Disentangling the uses of public engagement rhetoric in national research initiatives. <i>BMC Medical Ethics</i> , 2016, 17, 33.	1.0	138
14	Legislation on direct-to-consumer genetic testing in seven European countries. <i>European Journal of Human Genetics</i> , 2012, 20, 715-721.	1.4	119
15	The regulation of direct-to-consumer genetic tests. <i>Human Molecular Genetics</i> , 2008, 17, R180-R183.	1.4	115
16	Direct-to-consumer genetic testing for predicting sports performance and talent identification: Consensus statement. <i>British Journal of Sports Medicine</i> , 2015, 49, 1486-1491.	3.1	113
17	From single biobanks to international networks: developing e-governance. <i>Human Genetics</i> , 2011, 130, 377-382.	1.8	106
18	Assessing the Privacy Risks of Data Sharing in Genomics. <i>Public Health Genomics</i> , 2011, 14, 17-25.	0.6	99

#	ARTICLE	IF	CITATIONS
19	Ethical implications of the use of whole genome methods in medical research. <i>European Journal of Human Genetics</i> , 2010, 18, 398-403.	1.4	98
20	Broad Consent in Biobanking: Reflections on Seemingly Insurmountable Dilemmas. <i>Medical Law International</i> , 2009, 10, 85-100.	0.4	95
21	Towards a data sharing Code of Conduct for international genomic research. <i>Genome Medicine</i> , 2011, 3, 46.	3.6	95
22	Dynamic Consent: A Possible Solution to Improve Patient Confidence and Trust in How Electronic Patient Records Are Used in Medical Research. <i>JMIR Medical Informatics</i> , 2015, 3, e3.	1.3	95
23	A review of the key issues associated with the commercialization of biobanks. <i>Journal of Law and the Biosciences</i> , 2014, 1, 94-110.	0.8	87
24	Has the biobank bubble burst? Withstanding the challenges for sustainable biobanking in the digital era. <i>BMC Medical Ethics</i> , 2016, 17, 39.	1.0	81
25	Public Access to Genome-Wide Data: Five Views on Balancing Research with Privacy and Protection. <i>PLoS Genetics</i> , 2009, 5, e1000665.	1.5	71
26	Are "pseudonymised" data always personal data? Implications of the GDPR for administrative data research in the UK. <i>Computer Law and Security Review</i> , 2018, 34, 222-233.	1.3	70
27	Governing UK Biobank: the importance of ensuring public trust. <i>Trends in Biotechnology</i> , 2004, 22, 284-285.	4.9	64
28	eRegistries: Electronic registries for maternal and child health. <i>BMC Pregnancy and Childbirth</i> , 2016, 16, 11.	0.9	61
29	Do we need a uniform regulatory system for biobanks across Europe?. <i>European Journal of Human Genetics</i> , 2006, 14, 245-248.	1.4	55
30	Reflections on dynamic consent in biomedical research: the story so far. <i>European Journal of Human Genetics</i> , 2021, 29, 649-656.	1.4	51
31	Including all voices in international data-sharing governance. <i>Human Genomics</i> , 2018, 12, 13.	1.4	50
32	StemBANCC: Governing Access to Material and Data in a Large Stem Cell Research Consortium. <i>Stem Cell Reviews and Reports</i> , 2015, 11, 681-687.	5.6	49
33	The RUDY study platform "a novel approach to patient driven research in rare musculoskeletal diseases. <i>Orphanet Journal of Rare Diseases</i> , 2016, 11, 150.	1.2	49
34	Equitable Participation in Biobanks: The Risks and Benefits of a "Dynamic Consent" Approach. <i>Frontiers in Public Health</i> , 2018, 6, 253.	1.3	49
35	Data sharing policy design for consortia: challenges for sustainability. <i>Genome Medicine</i> , 2014, 6, 4.	3.6	48
36	Health-related quality of life and a cost-utility simulation of adults in the UK with osteogenesis imperfecta, X-linked hypophosphatemia and fibrous dysplasia. <i>Orphanet Journal of Rare Diseases</i> , 2016, 11, 160.	1.2	44

#	ARTICLE	IF	CITATIONS
37	Safeguards for research using large scale DNA collections. <i>BMJ: British Medical Journal</i> , 2000, 321, 1146-1149.	2.4	43
38	Governing Genetic Databases: Challenges Facing Research Regulation and Practice. <i>Journal of Law and Society</i> , 2007, 34, 163-189.	0.4	43
39	Consent and Research Governance in Biobanks: Evidence from Focus Groups with Medical Researchers. <i>Public Health Genomics</i> , 2012, 15, 232-242.	0.6	40
40	ELSI 2.0 for Genomics and Society. <i>Science</i> , 2012, 336, 673-674.	6.0	39
41	The RUDY study: using digital technologies to enable a research partnership. <i>European Journal of Human Genetics</i> , 2017, 25, 816-822.	1.4	39
42	Sample, data use and protection in biobanking in Europe: legal issues. <i>Pharmacogenomics</i> , 2008, 9, 773-781.	0.6	38
43	Managing clinically significant findings in research: the UK10K example. <i>European Journal of Human Genetics</i> , 2014, 22, 1100-1104.	1.4	38
44	Dynamic Consent: An Evaluation and Reporting Framework. <i>Journal of Empirical Research on Human Research Ethics</i> , 2020, 15, 175-186.	0.6	38
45	Building a data sharing model for global genomic research. <i>Genome Biology</i> , 2014, 15, 430.	3.8	37
46	Towards "Engagement 2.0": Insights from a study of dynamic consent with biobank participants. <i>Digital Health</i> , 2015, 1, 205520761560564.	0.9	37
47	Implementing a successful data-management framework: the UK10K managed access model. <i>Genome Medicine</i> , 2013, 5, 100.	3.6	36
48	Sharing data for future research'engaging participants' views about data governance beyond the original project: a DIRECT Study. <i>Genetics in Medicine</i> , 2019, 21, 1131-1138.	1.1	34
49	The European General Data Protection Regulation: challenges and considerations for iPSC researchers and biobanks. <i>Regenerative Medicine</i> , 2017, 12, 693-703.	0.8	33
50	"CTRL": an online, Dynamic Consent and participant engagement platform working towards solving the complexities of consent in genomic research. <i>European Journal of Human Genetics</i> , 2021, 29, 687-698.	1.4	31
51	Toward better governance of human genomic data. <i>Nature Genetics</i> , 2021, 53, 2-8.	9.4	31
52	Motivations for data sharing"views of research participants from four European countries: A DIRECT study. <i>European Journal of Human Genetics</i> , 2019, 27, 721-729.	1.4	30
53	The evolution of withdrawal: negotiating research relationships in biobanking. <i>Life Sciences, Society and Policy</i> , 2014, 10, 16.	3.1	28
54	Consent for Biobanking: The Legal Frameworks of Countries in the BioSHaRE-EU Project. <i>Biopreservation and Biobanking</i> , 2016, 14, 195-200.	0.5	27

#	ARTICLE	IF	CITATIONS
55	Are Requirements to Deposit Data in Research Repositories Compatible With the European Union's General Data Protection Regulation?. <i>Annals of Internal Medicine</i> , 2019, 170, 332.	2.0	27
56	Selected Legislation and Jurisprudence OECD Guidelines on Human Biobanks and Genetic Research Databases. <i>European Journal of Health Law</i> , 2010, 17, 187-204.	0.1	26
57	A P3G generic access agreement for population genomic studies. <i>Nature Biotechnology</i> , 2013, 31, 384-385.	9.4	24
58	Feedback of Individual Genetic Results to Research Participants: Is It Feasible in Europe?. <i>Biopreservation and Biobanking</i> , 2016, 14, 241-248.	0.5	24
59	Governing Genetic Databases: Collection, Storage and Use. <i>King's Law Journal</i> , 2007, 18, 201-208.	0.3	23
60	Privacy, Fairness, and Respect for Individuals. <i>EGEMS (Washington, DC)</i> , 2017, 4, 7.	2.0	22
61	Access Governance for Biobanks: The Case of the BioSHaRE-EU Cohorts. <i>Biopreservation and Biobanking</i> , 2016, 14, 201-206.	0.5	20
62	A dynamic model of patient consent to sharing of medical record data. <i>BMJ, The</i> , 2014, 348, g1294-g1294.	3.0	19
63	Using digital technologies to engage with medical research: views of myotonic dystrophy patients in Japan. <i>BMC Medical Ethics</i> , 2016, 17, 51.	1.0	19
64	Lessons from European Population Genetic Databases: Comparing the Law in Estonia, Iceland, Sweden and the United Kingdom. <i>European Journal of Health Law</i> , 2005, 12, 103-134.	0.1	18
65	Returning Results in Biobank Research: Global Trends and Solutions. <i>Genetic Testing and Molecular Biomarkers</i> , 2017, 21, 128-131.	0.3	18
66	The emerging need for family-centric initiatives for obtaining consent in personal genome research. <i>Genome Medicine</i> , 2014, 6, 118.	3.6	17
67	Exploring the potential duty of care in clinical genomics under UK law. <i>Medical Law International</i> , 2017, 17, 158-182.	0.4	17
68	CAN I ACCESS MY PERSONAL GENOME? THE CURRENT LEGAL POSITION IN THE UK. <i>Medical Law Review</i> , 2013, 22, 64-86.	0.2	16
69	Marking Shifts in Human Research Ethics in the Development of Biobanking. <i>Public Health Ethics</i> , 2015, 8, 63-71.	0.4	16
70	Processes Underlying Glycemic Deterioration in Type 2 Diabetes: An IMI DIRECT Study. <i>Diabetes Care</i> , 2021, 44, 511-518.	4.3	16
71	Consent Forms in Genomics: The Difference between Law and Practice. <i>European Journal of Health Law</i> , 2011, 18, 491-519.	0.1	15
72	eRegistries: governance for electronic maternal and child health registries. <i>BMC Pregnancy and Childbirth</i> , 2016, 16, 279.	0.9	15

#	ARTICLE	IF	CITATIONS
73	Australian Aboriginal and Torres Strait Islander Collections of Genetic Heritage: The Legal, Ethical and Practical Considerations of a Dynamic Consent Approach to Decision Making. <i>Journal of Law, Medicine and Ethics</i> , 2020, 48, 205-217.	0.4	15
74	ELSI challenges and strategies of national biobank infrastructures. <i>Norsk Epidemiologi</i> , 2012, 21, .	0.2	15
75	Patents and translational research in genomics. <i>Nature Biotechnology</i> , 2007, 25, 739-741.	9.4	14
76	Revoking consent: A “blind spot” in data protection law?. <i>Computer Law and Security Review</i> , 2010, 26, 273-283.	1.3	14
77	Governance of research consortia: challenges of implementing Responsible Research and Innovation within Europe. <i>Life Sciences, Society and Policy</i> , 2020, 16, 13.	3.1	13
78	Public Health Genomics (PHG) and Public Participation: Points to Consider. <i>Journal of Deliberative Democracy</i> , 2008, 5, .	0.3	13
79	Genetic research on the UK population “do new principles need to be developed?”. <i>Trends in Molecular Medicine</i> , 2001, 7, 528-530.	3.5	11
80	From genomic databases to translation: a call to action. <i>Journal of Medical Ethics</i> , 2011, 37, 515-516.	1.0	11
81	A comparative analysis of the requirements for the use of data in biobanks based in Finland, Germany, the Netherlands, Norway and the United Kingdom. <i>Medical Law International</i> , 2014, 14, 187-212.	0.4	11
82	Preferences of the Public for Sharing Health Data: Discrete Choice Experiment. <i>JMIR Medical Informatics</i> , 2021, 9, e29614.	1.3	11
83	Genetic testing without consent: the implications of the new Human Tissue Act 2004. <i>Journal of Medical Ethics</i> , 2006, 32, 690-692.	1.0	10
84	New technologies for DNA analysis “a review of the READNA Project. <i>New Biotechnology</i> , 2016, 33, 311-330.	2.4	10
85	Regulating human stem cell research and therapy in low- and middle-income countries: Malaysian perspectives. <i>New Genetics and Society</i> , 2018, 37, 2-20.	0.7	10
86	The practice of active patient involvement in rare disease research using ICT: experiences and lessons from the RUDY JAPAN project. <i>Research Involvement and Engagement</i> , 2021, 7, 9.	1.1	10
87	Challenges and opportunities for ELSI early career researchers. <i>BMC Medical Ethics</i> , 2016, 17, 37.	1.0	9
88	Consent insufficient for data release. <i>Science</i> , 2019, 364, 445-446.	6.0	9
89	Health Data Linkage for Public Interest Research in the UK: Key Obstacles and Solutions. <i>International Journal of Population Data Science</i> , 2019, 4, 1093.	0.1	9
90	Embedding biobanks as tools for personalised medicine. <i>Norsk Epidemiologi</i> , 2012, 21, .	0.2	9

#	ARTICLE	IF	CITATIONS
91	Personalized assent for pediatric biobanks. BMC Medical Ethics, 2016, 17, 59.	1.0	7
92	Desiderata for digital consent in genomic research. Journal of Community Genetics, 2018, 9, 191-194.	0.5	7
93	The governance structure for data access in the DIRECT consortium: an innovative medicines initiative (IMI) project. Life Sciences, Society and Policy, 2018, 14, 20.	3.1	7
94	The Tension Between Data Sharing and the Protection of Privacy in Genomics Research. The International Library of Ethics, Law and Technology, 2015, , 101-120.	0.2	7
95	Planning for translational research in genomics. Genome Medicine, 2009, 1, 87.	3.6	6
96	“Pop-Up” Governance: developing internal governance frameworks for consortia: the example of UK10K. Life Sciences, Society and Policy, 2015, 11, 10.	3.1	6
97	Governance mechanisms for sharing of health data: An approach towards selecting attributes for complex discrete choice experiment studies. Technology in Society, 2021, 66, 101625.	4.8	6
98	Landscape of Participant-Centric Initiatives for Medical Research in the United States, the United Kingdom, and Japan: Scoping Review. Journal of Medical Internet Research, 2020, 22, e16441.	2.1	5
99	Restore public trust in care.data project. Nature, 2014, 508, 458-458.	13.7	4
100	Biobank Report: United Kingdom. Journal of Law, Medicine and Ethics, 2016, 44, 96-105.	0.4	4
101	Regulating human genetic databases in Europe. , 0, , 91-96.		3
102	Making the most of the waiting room: Electronic patient engagement, a mixed methods study. Digital Health, 2018, 4, 205520761775130.	0.9	3
103	A Factorial Survey Investigating the Effect of Disclosing Parental Intellectual Disability on Risk Assessments by Children’s Social Workers in Child Safeguarding Scenarios. British Journal of Social Work, 2020, 50, 1185-1200.	0.9	3
104	The Long Now of Cyberinfrastructure. , 2010, , 40-44.		2
105	Participant-Centric Initiatives and Medical Research: Scoping Review Protocol. JMIR Research Protocols, 2017, 6, e245.	0.5	2
106	Dynamic consent “Improving translational research. Pathology, 2018, 50, S31.	0.3	1
107	Governance guidance for an eRegistry for maternal and child health: lessons from the occupied Palestinian territory. Lancet, The, 2018, 391, S35.	6.3	1
108	Consent for Data Processing Under the General Data Protection Regulation: Could 'Dynamic Consent' Assist Researchers?. SSRN Electronic Journal, 0, , .	0.4	1

#	ARTICLE	IF	CITATIONS
109	Creative regulatory practices to develop stem-cell technology: the way forward for Malaysia. <i>Regenerative Medicine</i> , 2022, 17, 91-105.	0.8	1
110	Biomodifying the "natural": from Adaptive Regulation to Adaptive Societal Governance. <i>Journal of Law and the Biosciences</i> , 2022, 9, .	0.8	1
111	The legal jigsaw governing population genetic databases: concluding remarks on the ELSAGEN legal findings. , 0, , 141-146.		0
112	The Path Forward for DNA Data. <i>Science</i> , 2008, 322, 1186-1187.	6.0	0
113	Spies, data and research. <i>EMBO Reports</i> , 2014, 15, 200-200.	2.0	0
114	The Regulation of Human Genomics Research. , 2014, , 259-266.		0
115	Clinical Decision Support Systems and Medico-Legal Liability in Recall and Treatment: A Fresh Examination. <i>Journal of Law &amp; Medicine</i> , 2020, 28, 132-144.	0.0	0
116	Don Chalmers: His Contributions to Legal Research and Education, Health Law, and Research Ethics, Locally and Globally. <i>Journal of Law &amp; Medicine</i> , 2020, 28, 289-297.	0.0	0