

Jane Kaye

List of Publications by Year in Descending Order

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The third column is the impact factor (IF) of the journal, and the fourth column is the number of citations of the article.

113
papers

4,882
citations

33
h-index

68
g-index

120
ext. papers

5,756
ext. citations

8.1
avg, IF

5.61
L-index

#	Paper	IF	Citations
113	Processes Underlying Glycemic Deterioration in Type 2 Diabetes: An IMI DIRECT Study. <i>Diabetes Care</i> , 2021 , 44, 511-518	14.6	6
112	Reflections on dynamic consent in biomedical research: the story so far. <i>European Journal of Human Genetics</i> , 2021 , 29, 649-656	5.3	9
111	'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 ^{5.3}	5.3	7
110	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	4.4	2
109	Governance mechanisms for sharing of health data: An approach towards selecting attributes for complex discrete choice experiment studies. <i>Technology in Society</i> , 2021 , 66, 101625	6.3	1
108	Toward better governance of human genomic data. <i>Nature Genetics</i> , 2021 , 53, 2-8	36.3	14
107	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	1.2	9
106	Landscape of Participant-Centric Initiatives for Medical Research in the United States, the United Kingdom, and Japan: Scoping Review. <i>Journal of Medical Internet Research</i> , 2020 , 22, e16441	7.6	1
105	Dynamic Consent: An Evaluation and Reporting Framework. <i>Journal of Empirical Research on Human Research Ethics</i> , 2020 , 15, 175-186	1.6	12
104	Governance of research consortia: challenges of implementing Responsible Research and Innovation within Europe. <i>Life Sciences, Society and Policy</i> , 2020 , 16, 13	3.2	4
103	A Factorial Survey Investigating the Effect of Disclosing Parental Intellectual Disability on Risk Assessments by Children's Social Workers in Child Safeguarding Scenarios. <i>British Journal of Social Work</i> , 2020 , 50, 1185-1200	1.2	3
102	Clinical Decision Support Systems and Medico-Legal Liability in Recall and Treatment: A Fresh Examination. <i>Journal of Law & Medicine</i> , 2020 , 28, 132-144	0.3	
101	Don Chalmers: His Contributions to Legal Research and Education, Health Law, and Research Ethics, Locally and Globally. <i>Journal of Law & Medicine</i> , 2020 , 28, 289-297	0.3	
100	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	5.3	14
99	Consent insufficient for data release. <i>Science</i> , 2019 , 364, 445-446	33.3	8
98	Health Data Linkage for UK Public Interest Research: Key Obstacles and Solutions. <i>International Journal of Population Data Science</i> , 2019 , 4, 1093	1.4	6
97	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, 332-334	8	19

96	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	8.1	21
95	Dynamic consent ¶Improving translational research. <i>Pathology</i> , 2018 , 50, S31	1.6	1
94	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	3	47
93	Desiderata for digital consent in genomic research. <i>Journal of Community Genetics</i> , 2018 , 9, 191-194	2.5	4
92	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	1.9	5
91	Making the most of the waiting room: Electronic patient engagement, a mixed methods study. <i>Digital Health</i> , 2018 , 4, 2055207617751304	4	3
90	Including all voices in international data-sharing governance. <i>Human Genomics</i> , 2018 , 12, 13	6.8	33
89	Equitable Participation in Biobanks: The Risks and Benefits of a "Dynamic Consent" Approach. <i>Frontiers in Public Health</i> , 2018 , 6, 253	6	25
88	The governance structure for data access in the DIRECT consortium: an innovative medicines initiative (IMI) project. <i>Life Sciences, Society and Policy</i> , 2018 , 14, 20	3.2	5
87	Returning Results in Biobank Research: Global Trends and Solutions. <i>Genetic Testing and Molecular Biomarkers</i> , 2017 , 21, 128-131	1.6	11
86	The RUDY study: using digital technologies to enable a research partnership. <i>European Journal of Human Genetics</i> , 2017 , 25, 816-822	5.3	29
85	The European General Data Protection Regulation: challenges and considerations for iPSC researchers and biobanks. <i>Regenerative Medicine</i> , 2017 , 12, 693-703	2.5	31
84	Marketing of unproven stem cell-based interventions: A call to action. <i>Science Translational Medicine</i> , 2017 , 9,	17.5	104
83	Dynamic Consent: a potential solution to some of the challenges of modern biomedical research. <i>BMC Medical Ethics</i> , 2017 , 18, 4	2.9	129
82	Exploring the potential duty of care in clinical genomics under UK law. <i>Medical Law International</i> , 2017 , 17, 158-182	0.7	14
81	Participant-Centric Initiatives and Medical Research: Scoping Review Protocol. <i>JMIR Research Protocols</i> , 2017 , 6, e245	2	1
80	Citizen science or scientific citizenship? Disentangling the uses of public engagement rhetoric in national research initiatives. <i>BMC Medical Ethics</i> , 2016 , 17, 33	2.9	95
79	Using digital technologies to engage with medical research: views of myotonic dystrophy patients in Japan. <i>BMC Medical Ethics</i> , 2016 , 17, 51	2.9	13

78	Personalized assent for pediatric biobanks. <i>BMC Medical Ethics</i> , 2016 , 17, 59	2.9	4
77	Access Governance for Biobanks: The Case of the BioSHaRE-EU Cohorts. <i>Biopreservation and Biobanking</i> , 2016 , 14, 201-6	2.1	13
76	Biobank Report: United Kingdom. <i>Journal of Law, Medicine and Ethics</i> , 2016 , 44, 96-105	1.2	2
75	eRegistries: Electronic registries for maternal and child health. <i>BMC Pregnancy and Childbirth</i> , 2016 , 16, 11	3.2	38
74	New technologies for DNA analysis--a review of the READNA Project. <i>New Biotechnology</i> , 2016 , 33, 311-304	3.4	10
73	Governance Through Privacy, Fairness, and Respect for Individuals. <i>EGEMS (Washington, DC)</i> , 2016 , 4, 1207	2.2	17
72	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	7.6	82
71	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	4.2	28
70	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	4.2	27
69	Challenges and opportunities for ELSI early career researchers. <i>BMC Medical Ethics</i> , 2016 , 17, 37	2.9	5
68	eRegistries: governance for electronic maternal and child health registries. <i>BMC Pregnancy and Childbirth</i> , 2016 , 16, 279	3.2	10
67	Has the biobank bubble burst? Withstanding the challenges for sustainable biobanking in the digital era. <i>BMC Medical Ethics</i> , 2016 , 17, 39	2.9	63
66	Consent for Biobanking: The Legal Frameworks of Countries in the BioSHaRE-EU Project. <i>Biopreservation and Biobanking</i> , 2016 , 14, 195-200	2.1	18
65	Feedback of Individual Genetic Results to Research Participants: Is It Feasible in Europe?. <i>Biopreservation and Biobanking</i> , 2016 , 14, 241-8	2.1	16
64	StemBANCC: Governing Access to Material and Data in a Large Stem Cell Research Consortium. <i>Stem Cell Reviews and Reports</i> , 2015 , 11, 681-7	6.4	36
63	The UK10K project identifies rare variants in health and disease. <i>Nature</i> , 2015 , 526, 82-90	50.4	776
62	Marking Shifts in Human Research Ethics in the Development of Biobanking. <i>Public Health Ethics</i> , 2015 , 8, 63-71	1.8	11
61	'Pop-Up' Governance: developing internal governance frameworks for consortia: the example of UK10K. <i>Life Sciences, Society and Policy</i> , 2015 , 11, 10	3.2	4

60	Towards 'Engagement 2.0': Insights from a study of dynamic consent with biobank participants. <i>Digital Health</i> , 2015 , 1, 2055207615605644	4	25
59	Direct-to-consumer genetic testing for predicting sports performance and talent identification: Consensus statement. <i>British Journal of Sports Medicine</i> , 2015 , 49, 1486-91	10.3	81
58	Dynamic consent: a patient interface for twenty-first century research networks. <i>European Journal of Human Genetics</i> , 2015 , 23, 141-6	5.3	355
57	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	3.6	65
56	The Tension Between Data Sharing and the Protection of Privacy in Genomics Research. <i>The International Library of Ethics, Law and Technology</i> , 2015 , 101-120	0.5	6
55	Data sharing policy design for consortia: challenges for sustainability. <i>Genome Medicine</i> , 2014 , 6, 4	14.4	37
54	Building a data sharing model for global genomic research. <i>Genome Biology</i> , 2014 , 15, 430	18.3	27
53	Managing clinically significant findings in research: the UK10K example. <i>European Journal of Human Genetics</i> , 2014 , 22, 1100-4	5.3	33
52	A dynamic model of patient consent to sharing of medical record data. <i>BMJ, The</i> , 2014 , 348, g1294	5.9	16
51	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	0.7	9
50	Spies, data and research. <i>EMBO Reports</i> , 2014 , 15, 200	6.5	
49	Health database: Restore public trust in care.data project. <i>Nature</i> , 2014 , 508, 458	50.4	4
48	The emerging need for family-centric initiatives for obtaining consent in personal genome research. <i>Genome Medicine</i> , 2014 , 6, 118	14.4	13
47	The evolution of withdrawal: negotiating research relationships in biobanking. <i>Life Sciences, Society and Policy</i> , 2014 , 10, 16	3.2	16
46	A review of the key issues associated with the commercialization of biobanks. <i>Journal of Law and the Biosciences</i> , 2014 , 1, 94-110	4.1	66
45	Can I access my personal genome? The current legal position in the UK. <i>Medical Law Review</i> , 2014 , 22, 64-86	0.8	13
44	Implementing a successful data-management framework: the UK10K managed access model. <i>Genome Medicine</i> , 2013 , 5, 100	14.4	33
43	A P3G generic access agreement for population genomic studies. <i>Nature Biotechnology</i> , 2013 , 31, 384-5	44.5	21

42	Ownership of Biomedical Information in Biobanks 2013 , 77-86		
41	Legislation on direct-to-consumer genetic testing in seven European countries. <i>European Journal of Human Genetics</i> , 2012 , 20, 715-21	5.3	100
40	The tension between data sharing and the protection of privacy in genomics research. <i>Annual Review of Genomics and Human Genetics</i> , 2012 , 13, 415-31	9.7	152
39	Toward a roadmap in global biobanking for health. <i>European Journal of Human Genetics</i> , 2012 , 20, 1105-13	5.3	113
38	From patients to partners: participant-centric initiatives in biomedical research. <i>Nature Reviews Genetics</i> , 2012 , 13, 371-6	30.1	197
37	Consent and research governance in biobanks: evidence from focus groups with medical researchers. <i>Public Health Genomics</i> , 2012 , 15, 232-42	1.9	33
36	Research priorities. ELSI 2.0 for genomics and society. <i>Science</i> , 2012 , 336, 673-4	33.3	30
35	ELSI challenges and strategies of national biobank infrastructures. <i>Norsk Epidemiologi</i> , 2012 , 21,	2.8	5
34	Embedding biobanks as tools for personalised medicine. <i>Norsk Epidemiologi</i> , 2012 , 21,	2.8	6
33	Assessing the privacy risks of data sharing in genomics. <i>Public Health Genomics</i> , 2011 , 14, 17-25	1.9	81
32	From consent to institutions: designing adaptive governance for genomic biobanks. <i>Social Science and Medicine</i> , 2011 , 73, 367-74	5.1	114
31	From single biobanks to international networks: developing e-governance. <i>Human Genetics</i> , 2011 , 130, 377-82	6.3	87
30	Towards a data sharing Code of Conduct for international genomic research. <i>Genome Medicine</i> , 2011 , 3, 46	14.4	79
29	From genomic databases to translation: a call to action. <i>Journal of Medical Ethics</i> , 2011 , 37, 515-6	2.5	7
28	Consent forms in genomics: the difference between law and practice. <i>European Journal of Health Law</i> , 2011 , 18, 491-519	0.2	13
27	Ethical implications of the use of whole genome methods in medical research. <i>European Journal of Human Genetics</i> , 2010 , 18, 398-403	5.3	82
26	Building a foundation for biobanking: the 2009 OECD guidelines on human biobanks and genetic research databases (HBGRDs). <i>European Journal of Health Law</i> , 2010 , 17, 187-90	0.2	22
25	Revoking consent: A Blind spot in data protection law?. <i>Computer Law and Security Review</i> , 2010 , 26, 273-283	3	13

24	8.2 Data Sharing in Genomics: Is It Lawful? 2010 , 245-247		2
23	Broad Consent in Biobanking: Reflections on Seemingly Insurmountable Dilemmas. <i>Medical Law International</i> , 2009 , 10, 85-100	0.7	71
22	Public access to genome-wide data: five views on balancing research with privacy and protection. <i>PLoS Genetics</i> , 2009 , 5, e1000665	6	60
21	Prepublication data sharing. <i>Nature</i> , 2009 , 461, 168-70	50.4	197
20	Planning for translational research in genomics. <i>Genome Medicine</i> , 2009 , 1, 87	14.4	5
19	Sample, data use and protection in biobanking in Europe: legal issues. <i>Pharmacogenomics</i> , 2008 , 9, 773-81.6	31.6	36
18	The path forward for DNA data. <i>Science</i> , 2008 , 322, 1186-7	33.3	
17	Research ethics recommendations for whole-genome research: consensus statement. <i>PLoS Biology</i> , 2008 , 6, e73	9.7	174
16	The regulation of direct-to-consumer genetic tests. <i>Human Molecular Genetics</i> , 2008 , 17, R180-3	5.6	94
15	Public Health Genomics (PHG) and Public Participation: Points to Consider. <i>Journal of Deliberative Democracy</i> , 2008 , 5,	0.7	6
14	Patents and translational research in genomics. <i>Nature Biotechnology</i> , 2007 , 25, 739-41	44.5	13
13	Governing Genetic Databases: Challenges Facing Research Regulation and Practice. <i>Journal of Law and Society</i> , 2007 , 34, 163-189	0.8	35
12	Governing Genetic Databases: Collection, Storage and Use. <i>Kings Law Journal</i> , 2007 , 18, 201-208	1.2	15
11	Genetic testing without consent: the implications of the new Human Tissue Act 2004. <i>Journal of Medical Ethics</i> , 2006 , 32, 690-2	2.5	6
10	Do we need a uniform regulatory system for biobanks across Europe?. <i>European Journal of Human Genetics</i> , 2006 , 14, 245-8	5.3	48
9	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, 103-33	0.2	12
8	Governing UK Biobank: the importance of ensuring public trust. <i>Trends in Biotechnology</i> , 2004 , 22, 284-5	15.1	53
7	Genetic research on the UK population--do new principles need to be developed?. <i>Trends in Molecular Medicine</i> , 2001 , 7, 528-30	11.5	8

6	Safeguards for research using large scale DNA collections. <i>BMJ: British Medical Journal</i> , 2000 , 321, 1146-9	33
5	Regulating human genetic databases in Europe91-96	1
4	The legal jigsaw governing population genetic databases: concluding remarks on the ELSAGEN legal findings141-146	
3	PGP-UK: a research and citizen science hybrid project in support of personalized medicine	1
2	Publics preferences for sharing health data: a discrete choice experiment (Preprint)	1
1	Publics preferences for sharing health data: a discrete choice experiment (Preprint). <i>JMIR Medical Informatics</i> ,	3.6 2