

Bartha M Knoppers

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.

228
papers

6,735
citations

45
h-index

74
g-index

245
ext. papers

7,924
ext. citations

9.3
avg, IF

6.23
L-index

#	Paper	IF	Citations
228	The international data governance landscape.. <i>Journal of Law and the Biosciences</i> , 2022 , 9, Isac005	4.1	1
227	The Serious Factor in Expanded Prenatal Genetic Testing.. <i>American Journal of Bioethics</i> , 2022 , 22, 23-25	1.1	3
226	Re-contact Following Withdrawal of Minors from Research. <i>Canadian Journal of Bioethics</i> , 2022 , 5, 45	0.5	0
225	GA4GH: International policies and standards for data sharing across genomic research and healthcare.. <i>Cell Genomics</i> , 2021 , 1, 100029-100029		20
224	Computational tools for genomic data de-identification: facilitating data protection law compliance. <i>Nature Communications</i> , 2021 , 12, 6949	17.4	
223	A centralized rare disease database and whole-genome sequencing as a standard of care: two essential implementations for the future of health. <i>Facets</i> , 2021 , 6, 1831-1834	2.3	1
222	AI in Cardiovascular Imaging: "Unexplainable" Legal and Ethical Challenges?. <i>Canadian Journal of Cardiology</i> , 2021 ,	3.8	3
221	Parental Access to Children's Raw Genomic Data in Canada: Legal Rights and Professional Responsibility. <i>Frontiers in Genetics</i> , 2021 , 12, 535340	4.5	1
220	Coming Out to Play: Privacy, Data Protection, Children's Health, and COVID-19 Research. <i>Frontiers in Genetics</i> , 2021 , 12, 659027	4.5	2
219	The Equitable Implementation of Cystic Fibrosis Personalized Medicines in Canada. <i>Journal of Personalized Medicine</i> , 2021 , 11,	3.6	1
218	Three decades of genetic privacy: a metaphoric journey. <i>Human Molecular Genetics</i> , 2021 , 30, R156-R160	5.6	1
217	Personalized Risk Assessment for Prevention and Early Detection of Breast Cancer: Integration and Implementation (PERSPECTIVE I&I). <i>Journal of Personalized Medicine</i> , 2021 , 11,	3.6	13
216	A policy Delphi study to validate the key implications of data sharing (KIDS) framework for pediatric genomics in Canada. <i>BMC Medical Ethics</i> , 2021 , 22, 71	2.9	0
215	Longitudinal Health Studies: Secondary Uses Serving the Future. <i>Biopreservation and Biobanking</i> , 2021 , 19, 404-413	2.1	2
214	Risk-Stratified Approach to Breast Cancer Screening in Canada: Women's Knowledge of the Legislative Context and Concerns about Discrimination from Genetic and Other Predictive Health Data. <i>Journal of Personalized Medicine</i> , 2021 , 11,	3.6	1
213	Raising standards for global data-sharing-Response. <i>Science</i> , 2021 , 371, 134-135	33.3	
212	Frontline Ethico-Legal Issues in Childhood Cancer Genetics Research 2021 , 387-414		0

211	Women's Views on Multifactorial Breast Cancer Risk Assessment and Risk-Stratified Screening: A Population-Based Survey from Four Provinces in Canada. <i>Journal of Personalized Medicine</i> , 2021 , 11,	3.6	4
210	Of Screening, Stratification, and Scores. <i>Journal of Personalized Medicine</i> , 2021 , 11,	3.6	3
209	Ethical and Analytic Challenges With Genomic Sequencing of Relapsed Hematologic Malignancies Following Allogeneic Hematopoietic Stem-Cell Transplantation.. <i>JCO Precision Oncology</i> , 2021 , 5, 1339-1347	3.6	0
208	A marathon, not a sprint - neuroimaging, Open Science and ethics. <i>NeuroImage</i> , 2021 , 236, 118041	7.9	2
207	Should Age-Dependent Absolute Risk Thresholds Be Used for Risk Stratification in Risk-Stratified Breast Cancer Screening?. <i>Journal of Personalized Medicine</i> , 2021 , 11,	3.6	3
206	Toward better governance of human genomic data. <i>Nature Genetics</i> , 2021 , 53, 2-8	36.3	14
205	The Genetic Family as Patient?. <i>American Journal of Bioethics</i> , 2020 , 20, 77-80	1.1	5
204	International mHealth Research: Old Tools and New Challenges. <i>Journal of Law, Medicine and Ethics</i> , 2020 , 48, 178-186	1.2	3
203	How Can We Not Waste Legacy Genomic Research Data?. <i>Frontiers in Genetics</i> , 2020 , 11, 446	4.5	6
202	Doping controls and the Mature Minor Elite athlete: towards clarification?. <i>International Journal of Sport Policy and Politics</i> , 2020 , 12, 179-187	1.6	2
201	The Provision of Genetic Testing and Related Services in Quebec, Canada. <i>Frontiers in Genetics</i> , 2020 , 11, 127	4.5	1
200	Pandemics, privacy, and public health research. <i>Canadian Journal of Public Health</i> , 2020 , 111, 454-457	3.2	6
199	Genomics: data sharing needs an international code of conduct. <i>Nature</i> , 2020 , 578, 31-33	50.4	17
198	Oversight, governance, and policy for making decisions about return of individual genomic findings 2020 , 29-41		1
197	Bringing Code to Data: Do Not Forget Governance. <i>Journal of Medical Internet Research</i> , 2020 , 22, e18087.6	7.6	2
196	How to fix the GDPR's frustration of global biomedical research. <i>Science</i> , 2020 , 370, 40-42	33.3	16
195	The Right to Benefit from Science and Its Implications for Genomic Data Sharing. <i>European Journal of International Law</i> , 2020 , 31, 665-691	0.4	4
194	Ethical, Legal, and Social Issues (ELSI) of Responsible Data Sharing Involving Children in Genomics: A Systematic Literature Review of Reasons. <i>AJOB Empirical Bioethics</i> , 2020 , 11, 233-245	3	3

193	Of the Rights and Best Interests of Future Generations. <i>American Journal of Bioethics</i> , 2020 , 20, 38-40	1.1	
192	Modeling consent in the time of COVID-19. <i>Journal of Law and the Biosciences</i> , 2020 , 7, lsa020	4.1	4
191	When information is the treatment? Precision medicine in healthcare. <i>Healthcare Management Forum</i> , 2020 , 33, 120-125	1.7	
190	Biobanking for Genomic and Personalized Health Research: Participant Perceptions and Preferences. <i>Biopreservation and Biobanking</i> , 2020 , 18, 204-212	2.1	2
189	'Serious' factor-a relevant starting point for further debate: a response. <i>Journal of Medical Ethics</i> , 2020 , 46, 153-155	2.5	2
188	Reciprocity and the Quest for Meaningful Disclosure. <i>American Journal of Bioethics</i> , 2019 , 19, 36-38	1.1	2
187	Return of individual genomic research results: are laws and policies keeping step?. <i>European Journal of Human Genetics</i> , 2019 , 27, 535-546	5.3	46
186	Whose Commons? Data Protection as a Legal Limit of Open Science. <i>Journal of Law, Medicine and Ethics</i> , 2019 , 47, 106-111	1.2	7
185	Importance of Participant-Centricity and Trust for a Sustainable Medical Information Commons. <i>Journal of Law, Medicine and Ethics</i> , 2019 , 47, 12-20	1.2	14
184	Health professionals' perspectives on breast cancer risk stratification: understanding evaluation of risk versus screening for disease. <i>Public Health Reviews</i> , 2019 , 40, 2	4.3	12
183	Letter: Relearning the 3 R's? Reinterpretation, recontact, and return of genetic variants. <i>Genetics in Medicine</i> , 2019 , 21, 2401-2402	8.1	5
182	"CRISPR babies": What does this mean for science and Canada?. <i>Cmaj</i> , 2019 , 191, E91-E92	3.5	7
181	Genome-wide sequencing in acutely ill infants: genomic medicine's critical application?. <i>Genetics in Medicine</i> , 2019 , 21, 498-504	8.1	28
180	Development of a consent resource for genomic data sharing in the clinical setting. <i>Genetics in Medicine</i> , 2019 , 21, 81-88	8.1	12
179	Privacy-Preserving Linkage of Genomic and Clinical Data Sets. <i>IEEE/ACM Transactions on Computational Biology and Bioinformatics</i> , 2019 , 16, 1342-1348	3	13
178	Model consent clauses for rare disease research. <i>BMC Medical Ethics</i> , 2019 , 20, 55	2.9	8
177	Regulatory Landscape of International Direct-to-Participant (DTP) Genomic Research: Time to Untie the Gordian Knot?. <i>Journal of Law, Medicine and Ethics</i> , 2019 , 47, 336-341	1.2	1
176	The Human Right to Science and the Regulation of Human Germline Engineering. <i>CRISPR Journal</i> , 2019 , 2, 134-142	2.5	9

175	A Tale of Two Capacities: Including Children and Decisionally Vulnerable Adults in Biomedical Research. <i>Frontiers in Genetics</i> , 2019 , 10, 289	4.5	10
174	Canada's Pragmatic Reforms in Support of Research. <i>Frontiers in Medicine</i> , 2019 , 6, 157	4.9	5
173	Heritable Genome Editing: Who Speaks for "Future" Children?. <i>CRISPR Journal</i> , 2019 , 2, 285-292	2.5	10
172	Envisioning Implementation of a Personalized Approach in Breast Cancer Screening Programs: Stakeholder Perspectives. <i>Healthcare Policy</i> , 2019 , 15, 39-54	1.1	7
171	A response to "Personalised medicine and population health: breast and ovarian cancer". <i>Human Genetics</i> , 2019 , 138, 287-289	6.3	13
170	The 'serious' factor in germline modification. <i>Journal of Medical Ethics</i> , 2019 , 45, 508-513	2.5	11
169	Biotechnologies nibbling at the legal "human". <i>Science</i> , 2019 , 366, 1455-1457	33.3	9
168	Pre-implantation Genetic Diagnosis: The Road Forward in Canada. <i>Journal of Obstetrics and Gynaecology Canada</i> , 2019 , 41, 68-71	1.3	5
167	Organizational challenges to equity in the delivery of services within a new personalized risk-based approach to breast cancer screening. <i>New Genetics and Society</i> , 2019 , 38, 38-59	1.9	6
166	The Genomic Commons. <i>Annual Review of Genomics and Human Genetics</i> , 2018 , 19, 429-453	9.7	14
165	Key Implications of Data Sharing in Pediatric Genomics. <i>JAMA Pediatrics</i> , 2018 , 172, 476-481	8.3	22
164	Registered access: authorizing data access. <i>European Journal of Human Genetics</i> , 2018 , 26, 1721-1731	5.3	17
163	Responsible sharing of biomedical data and biospecimens via the "Automatable Discovery and Access Matrix" (ADA-M). <i>Npj Genomic Medicine</i> , 2018 , 3, 17	6.2	28
162	Overcoming barriers to facilitate the regulation of multi-centre regenerative medicine clinical trials. <i>Stem Cell Research and Therapy</i> , 2018 , 9, 307	8.3	16
161	Bridging stem cell research and medicine: a learning health system. <i>Regenerative Medicine</i> , 2018 , 13, 741-752	2.5	8
160	Research on Human Embryos and Reproductive Materials: Revisiting Canadian Law and Policy. <i>Healthcare Policy</i> , 2018 , 13, 10-19	1.1	7
159	BRCA Challenge: BRCA Exchange as a global resource for variants in BRCA1 and BRCA2. <i>PLoS Genetics</i> , 2018 , 14, e1007752	6	90
158	Genetic database software as medical devices. <i>Human Mutation</i> , 2018 , 39, 1702-1712	4.7	8

157	Ethical, Legal, and Regulatory Issues for the Implementation of Omics-Based Risk Prediction of Women's Cancer: Points to Consider. <i>Public Health Genomics</i> , 2018 , 21, 37-44	1.9	8
156	Genetically Enhanced Minors: Whose Responsibility?. <i>American Journal of Bioethics</i> , 2018 , 18, 1-3	1.1	1
155	Ethics, big data and computing in epidemiology and public health. <i>Annals of Epidemiology</i> , 2017 , 27, 297-301	4.1	49
154	International Cooperation to Enable the Diagnosis of All Rare Genetic Diseases. <i>American Journal of Human Genetics</i> , 2017 , 100, 695-705	11	200
153	"Matching" consent to purpose: The example of the Matchmaker Exchange. <i>Human Mutation</i> , 2017 , 38, 1281-1285	4.7	10
152	Reply to C Harling. <i>European Journal of Human Genetics</i> , 2017 , 25, 1030	5.3	
151	Comparative Approaches to Genetic Discrimination: Chasing Shadows?. <i>Trends in Genetics</i> , 2017 , 33, 299-302	3.9	48
150	Criminal Prohibition of Wrongful Re-identification: Legal Solution or Minefield for Big Data?. <i>Journal of Bioethical Inquiry</i> , 2017 , 14, 527-539	1.9	12
149	Data Sharing and Privacy 2017 , 143-160		1
148	The Gatekeeping Function in Personalized Medicine Initiatives. <i>Current Pharmacogenomics and Personalized Medicine</i> , 2017 , 14, 36-49	0.4	
147	Oversight of Genomic Data Sharing: What Roles for Ethics and Data Access Committees?. <i>Biopreservation and Biobanking</i> , 2017 , 15, 469-474	2.1	15
146	Mitochondrial Replacement Therapy: The Road to the Clinic in Canada. <i>Journal of Obstetrics and Gynaecology Canada</i> , 2017 , 39, 916-918	1.3	8
145	Ethics and Big Data in health. <i>Current Opinion in Systems Biology</i> , 2017 , 4, 53-57	3.2	55
144	Ethics approval in applications for open-access clinical trial data: An analysis of researcher statements to clinicalstudydatarequest.com. <i>PLoS ONE</i> , 2017 , 12, e0184491	3.7	5
143	Population Biobanks and the Principle of Reciprocity 2017 , 99-109		1
142	P3G: Towards an International Policy Platform for Population Genomics 2017 , 155-167		
141	Population genetic testing for cancer susceptibility: founder mutations to genomes. <i>Nature Reviews Clinical Oncology</i> , 2016 , 13, 41-54	19.4	67
140	Exposing participants? Population biobanks go geo. <i>European Journal of Human Genetics</i> , 2016 , 24, 155-65	5.3	5

139	Legal approaches regarding health-care decisions involving minors: implications for next-generation sequencing. <i>European Journal of Human Genetics</i> , 2016 , 24, 1559-1564	5.3	8
138	Are Data Sharing and Privacy Protection Mutually Exclusive?. <i>Cell</i> , 2016 , 167, 1150-1154	56.2	36
137	Data Sharing - Is the Juice Worth the Squeeze?. <i>New England Journal of Medicine</i> , 2016 , 375, 1608-1609	59.2	39
136	The discombobulation of de-identification. <i>Nature Biotechnology</i> , 2016 , 34, 1102-1103	44.5	15
135	Sharing health-related data: a privacy test?. <i>Npj Genomic Medicine</i> , 2016 , 1, 160241-160246	6.2	27
134	Access Governance for Biobanks: The Case of the BioSHaRE-EU Cohorts. <i>Biopreservation and Biobanking</i> , 2016 , 14, 201-6	2.1	13
133	A decision tool to guide the ethics review of a challenging breed of emerging genomic projects. <i>European Journal of Human Genetics</i> , 2016 , 24, 1099-103	5.3	
132	RESEARCH ETHICS. Ethics review for international data-intensive research. <i>Science</i> , 2016 , 351, 1399-400	33.3	32
131	The Adoption of Cloud Computing in the Field of Genomics Research: The Influence of Ethical and Legal Issues. <i>PLoS ONE</i> , 2016 , 11, e0164347	3.7	17
130	Influence des facteurs organisationnels sur l'implantation d'une approche personnalisèe de d'pistage du cancer du sein. <i>Sante Publique</i> , 2016 , 28, 353		1
129	Consent Codes: Upholding Standard Data Use Conditions. <i>PLoS Genetics</i> , 2016 , 12, e1005772	6	51
128	Precision medicine: a matter of regulation or collaboration?. <i>Journal of Law and the Biosciences</i> , 2016 , 3, 687-690	4.1	2
127	Don't Take It Personal: European Union Legal Aspects of Procuring and Protecting Environmental Exposure Data in Population Biobanks Through the Use of a Geo-Information-Systems Toolkit. <i>Biopreservation and Biobanking</i> , 2016 , 14, 217-23	2.1	3
126	How mutually recognizable is mutual recognition? An international terminology index of research ethics review policies in the USA, Canada, UK and Australia. <i>Personalized Medicine</i> , 2016 , 13, 101-105	2.2	4
125	Registered access: a 'Triple-A' approach. <i>European Journal of Human Genetics</i> , 2016 , 24, 1676-1680	5.3	27
124	A step forward for data protection and biomedical research. <i>Lancet, The</i> , 2016 , 387, 1374-1375	40	10
123	An International Framework for Data Sharing: Moving Forward with the Global Alliance for Genomics and Health. <i>Biopreservation and Biobanking</i> , 2016 , 14, 256-9	2.1	22
122	Facilitating a culture of responsible and effective sharing of cancer genome data. <i>Nature Medicine</i> , 2016 , 22, 464-71	50.5	63

121	Do It Yourself Newborn Screening. <i>JAMA Pediatrics</i> , 2016 , 170, 523-4	8.3	6
120	Clinical Sequencing Exploratory Research Consortium: Accelerating Evidence-Based Practice of Genomic Medicine. <i>American Journal of Human Genetics</i> , 2016 , 98, 1051-1066	11	107
119	Next-Generation Sequencing and the Return of Results. <i>Cold Spring Harbor Perspectives in Medicine</i> , 2016 , 6,	5.4	6
118	Return of genetic testing results in the era of whole-genome sequencing. <i>Nature Reviews Genetics</i> , 2015 , 16, 553-9	30.1	100
117	International Charter of principles for sharing bio-specimens and data. <i>European Journal of Human Genetics</i> , 2015 , 23, 721-8	5.3	98
116	CRISPR germline engineering--the community speaks. <i>Nature Biotechnology</i> , 2015 , 33, 478-86	44.5	91
115	Oversight of human inheritable genome modification. <i>Nature Biotechnology</i> , 2015 , 33, 454-5	44.5	13
114	Genomic cloud computing: legal and ethical points to consider. <i>European Journal of Human Genetics</i> , 2015 , 23, 1271-8	5.3	62
113	Data Safe Havens in health research and healthcare. <i>Bioinformatics</i> , 2015 , 31, 3241-8	7.2	41
112	The ethics weathervane. <i>BMC Medical Ethics</i> , 2015 , 16, 58	2.9	7
111	From the principles of genomic data sharing to the practices of data access committees. <i>EMBO Molecular Medicine</i> , 2015 , 7, 507-9	12	41
110	Ethical challenges and innovations in the dissemination of genomic data: the experience of the PERSPECTIVE project. <i>Advances in Genomics and Genetics</i> , 2015 , 283		1
109	INTRODUCTION: Harmonizing Privacy Laws to Enable International Biobank Research. <i>Journal of Law, Medicine and Ethics</i> , 2015 , 43, 673-4	1.2	9
108	Data analysis: Create a cloud commons. <i>Nature</i> , 2015 , 523, 149-51	50.4	71
107	Streamlining review of research involving humans: Canadian models. <i>Journal of Medical Genetics</i> , 2015 , 52, 566-9	5.8	5
106	Statement of principles on the return of research results and incidental findings in paediatric research: a multi-site consultative process. <i>Genome</i> , 2015 , 58, 541-8	2.4	22
105	Whole-genome sequencing in newborn screening? A statement on the continued importance of targeted approaches in newborn screening programmes. <i>European Journal of Human Genetics</i> , 2015 , 23, 1593-600	5.3	59
104	A human rights approach to an international code of conduct for genomic and clinical data sharing. <i>Human Genetics</i> , 2014 , 133, 895-903	6.3	72

103	Reporting results from whole-genome and whole-exome sequencing in clinical practice: a proposal for Canada?. <i>Journal of Medical Genetics</i> , 2014 , 51, 68-70	5.8	23
102	International ethics harmonization and the global alliance for genomics and health. <i>Genome Medicine</i> , 2014 , 6, 13	14.4	30
101	Building a data sharing model for global genomic research. <i>Genome Biology</i> , 2014 , 15, 430	18.3	27
100	Data protection and consent to biomedical research: a step forward?. <i>Lancet, The</i> , 2014 , 384, 855	40	10
99	Stem cell research funding policies and dynamic innovation: a survey of open access and commercialization requirements. <i>Stem Cell Reviews and Reports</i> , 2014 , 10, 455-71	6.4	4
98	Special Issue - From Biobanks to the Clinic. <i>Applied & Translational Genomics</i> , 2014 , 3, 21-2		1
97	Identifiability and privacy in pluripotent stem cell research. <i>Cell Stem Cell</i> , 2014 , 14, 427-30	18	29
96	Anonymity 2.0: direct-to-consumer genetic testing and donor conception. <i>Fertility and Sterility</i> , 2014 , 101, 630-2	4.8	17
95	FORGE Canada Consortium: outcomes of a 2-year national rare-disease gene-discovery project. <i>American Journal of Human Genetics</i> , 2014 , 94, 809-17	11	174
94	Population biobanking and international collaboration. <i>Pathobiology</i> , 2014 , 81, 276-285	3.6	7
93	Current trends in biobanking for rare diseases: a review. <i>Journal of Biorepository Science for Applied Medicine</i> , 2014 , 49		12
92	Return of whole-genome sequencing results in paediatric research: a statement of the P3G international paediatrics platform. <i>European Journal of Human Genetics</i> , 2014 , 22, 3-5	5.3	52
91	Does policy grow on trees?. <i>BMC Medical Ethics</i> , 2014 , 15, 87	2.9	2
90	Framework for responsible sharing of genomic and health-related data. <i>The HUGO Journal</i> , 2014 , 8, 3		153
89	The best interests of the child and the return of results in genetic research: international comparative perspectives. <i>BMC Medical Ethics</i> , 2014 , 15, 72	2.9	18
88	Towards an ethics safe harbor for global biomedical research. <i>Journal of Law and the Biosciences</i> , 2014 , 1, 3-51	4.1	29
87	Data sharing in large research consortia: experiences and recommendations from ENGAGE. <i>European Journal of Human Genetics</i> , 2014 , 22, 317-21	5.3	39
86	Beyond public health genomics: proposals from an international working group. <i>European Journal of Public Health</i> , 2014 , 24, 877-9	2.1	17

85	Data sharing, year 1--access to data from industry-sponsored clinical trials. <i>New England Journal of Medicine</i> , 2014 , 371, 2052-4	59.2	85
84	Attitudes of parents toward the return of targeted and incidental genomic research findings in children. <i>Genetics in Medicine</i> , 2014 , 16, 633-40	8.1	67
83	The challenge of informed consent and return of results in translational genomics: empirical analysis and recommendations. <i>Journal of Law, Medicine and Ethics</i> , 2014 , 42, 344-55	1.2	52
82	INTRODUCTION: From the Right to Know to the Right Not to Know. <i>Journal of Law, Medicine and Ethics</i> , 2014 , 42, 6-10	1.2	18
81	Management Strategies for Ethics in International Research. <i>Current Genetic Medicine Reports</i> , 2014 , 2, 255-260	2.2	1
80	An implementation framework for the feedback of individual research results and incidental findings in research. <i>BMC Medical Ethics</i> , 2014 , 15, 88	2.9	31
79	Whole-genome sequencing in newborn screening programs. <i>Science Translational Medicine</i> , 2014 , 6, 229am3	4.3	48
78	The ethical framing of personalized medicine. <i>Current Opinion in Allergy and Clinical Immunology</i> , 2014 , 14, 404-8	3.3	18
77	DataSHIELD: taking the analysis to the data, not the data to the analysis. <i>International Journal of Epidemiology</i> , 2014 , 43, 1929-44	7.8	116
76	Genotype-driven recruitment: a strategy whose time has come?. <i>BMC Medical Genomics</i> , 2013 , 6, 19	3.7	11
75	Recommendations for returning genomic incidental findings? We need to talk!. <i>Genetics in Medicine</i> , 2013 , 15, 854-9	8.1	246
74	An ethics safe harbor for international genomics research?. <i>Genome Medicine</i> , 2013 , 5, 99	14.4	17
73	Genomics: from persons to populations and back again. <i>Genome</i> , 2013 , 56, 537-9	2.4	3
72	Beyond ELSIs 2013 , 405-428		
71	Rare diseases and now rare data?. <i>Nature Reviews Genetics</i> , 2013 , 14, 372	30.1	15
70	Whole-genome sequencing in health care: recommendations of the European Society of Human Genetics. <i>European Journal of Human Genetics</i> , 2013 , 21, 580-4	5.3	262
69	Cohort profile of the CARTaGENE study: Quebec's population-based biobank for public health and personalized genomics. <i>International Journal of Epidemiology</i> , 2013 , 42, 1285-99	7.8	117
68	From tissues to genomes. <i>G3: Genes, Genomes, Genetics</i> , 2013 , 3, 1203-4	3.2	1

67	A P3G generic access agreement for population genomic studies. <i>Nature Biotechnology</i> , 2013 , 31, 384-5	44.5	21
66	Demystifying biobanks. <i>Hastings Center Report</i> , 2013 , 43, 4-5	3.3	2
65	Personalized medicine and access to health care: potential for inequitable access?. <i>European Journal of Human Genetics</i> , 2013 , 21, 143-7	5.3	33
64	Population studies: return of research results and incidental findings Policy Statement. <i>European Journal of Human Genetics</i> , 2013 , 21, 245-7	5.3	84
63	Pediatric research 'personalized'? International perspectives on the return of results. <i>Personalized Medicine</i> , 2013 , 10, 89-95	2.2	7
62	A new twist on an old problem: primary care physicians and results from direct-to-consumer genetic testing. <i>Personalized Medicine</i> , 2013 , 10, 827-833	2.2	3
61	Power to the people: a wiki-governance model for biobanks. <i>Genome Biology</i> , 2012 , 13, 158	18.3	28
60	Managing incidental findings and research results in genomic research involving biobanks and archived data sets. <i>Genetics in Medicine</i> , 2012 , 14, 361-84	8.1	365
59	Questioning the limits of genomic privacy. <i>American Journal of Human Genetics</i> , 2012 , 91, 577-8; author reply 579	11	14
58	Sampling populations of humans across the world: ELSI issues. <i>Annual Review of Genomics and Human Genetics</i> , 2012 , 13, 395-413	9.7	45
57	Disclosure and management of research findings in stem cell research and banking: policy statement. <i>Regenerative Medicine</i> , 2012 , 7, 439-48	2.5	27
56	Toward a roadmap in global biobanking for health. <i>European Journal of Human Genetics</i> , 2012 , 20, 1105-11	13	113
55	Paediatric research and the communication of not-so incidental findings. <i>Paediatrics and Child Health</i> , 2012 , 17, 190-2	0.7	15
54	Data sharing in the post-genomic world: the experience of the International Cancer Genome Consortium (ICGC) Data Access Compliance Office (DACO). <i>PLoS Computational Biology</i> , 2012 , 8, e1002549	5.9	81
53	International normative perspectives on the return of individual research results and incidental findings in genomic biobanks. <i>Genetics in Medicine</i> , 2012 , 14, 484-9	8.1	46
52	Research priorities. ELSI 2.0 for genomics and society. <i>Science</i> , 2012 , 336, 673-4	33.3	30
51	Editorial (An Idea Whose Time Has Come? An African Foresight Observatory on Genomics Medicine and Data-Intensive Global Science). <i>Current Pharmacogenomics and Personalized Medicine</i> , 2012 , 10, 7-15	0.4	7
50	Attitudes of Researchers to the Return of Incidental and Targeted Genomic Findings Obtained in a Research Setting to Participants. <i>Blood</i> , 2012 , 120, 2069-2069	2.2	

49	From banking to international governance: fostering innovation in stem cell research. <i>Stem Cells International</i> , 2011 , 2011, 498132	5	17
48	Harmonised consent in international research consortia: an impossible dream?. <i>Genomics Society and Policy</i> , 2011 , 7,		4
47	Introduction: return of research results: how should research results be handled?. <i>Journal of Law, Medicine and Ethics</i> , 2011 , 39, 574-6	1.2	8
46	Genomic databases access agreements: legal validity and possible sanctions. <i>Human Genetics</i> , 2011 , 130, 441-9	6.3	21
45	Publishing SNP genotypes of human embryonic stem cell lines: policy statement of the International Stem Cell Forum Ethics Working Party. <i>Stem Cell Reviews and Reports</i> , 2011 , 7, 482-4	6.4	13
44	Bridging consent: from toll bridges to lift bridges?. <i>BMC Medical Genomics</i> , 2011 , 4, 69	3.7	11
43	Towards a data sharing Code of Conduct for international genomic research. <i>Genome Medicine</i> , 2011 , 3, 46	14.4	79
42	Policy and data-intensive scientific discovery in the beginning of the 21st century. <i>OMICS A Journal of Integrative Biology</i> , 2011 , 15, 221-5	3.8	13
41	Sustained interaction: the new normal for stem cell repositories?. <i>Regenerative Medicine</i> , 2011 , 6, 783-92.5		14
40	From genomic databases to translation: a call to action. <i>Journal of Medical Ethics</i> , 2011 , 37, 515-6	2.5	7
39	Connective tissue: Cancer patients' attitudes towards medical research using excised (tumour) tissue. <i>BioSocieties</i> , 2011 , 6, 466-486	1.5	8
38	Retrospective access to data: the ENGAGE consent experience. <i>European Journal of Human Genetics</i> , 2010 , 18, 741-5	5.3	31
37	Consent to 'personal' genomics and privacy. Direct-to-consumer genetic tests and population genome research challenge traditional notions of privacy and consent. <i>EMBO Reports</i> , 2010 , 11, 416-9	6.5	26
36	Framing genomics, public health research and policy: points to consider. <i>Public Health Genomics</i> , 2010 , 13, 224-34	1.9	26
35	Quality, quantity and harmony: the DataSHaPER approach to integrating data across bioclinical studies. <i>International Journal of Epidemiology</i> , 2010 , 39, 1383-93	7.8	117
34	DataSHIELD: resolving a conflict in contemporary bioscience--performing a pooled analysis of individual-level data without sharing the data. <i>International Journal of Epidemiology</i> , 2010 , 39, 1372-82	7.8	102
33	Stem cell banking: between traceability and identifiability. <i>Genome Medicine</i> , 2010 , 2, 73	14.4	32
32	Use of umbilical cord blood for stem cell research. <i>Journal of Obstetrics and Gynaecology Canada</i> , 2010 , 32, 58-61	1.3	13

31	Response--Biobanks. <i>Science</i> , 2009 , 326, 799-799	33.3	1
30	Return of "accurate" and "actionable" results: yes!. <i>American Journal of Bioethics</i> , 2009 , 9, 107-9	1.1	21
29	Governing stem cell banks and registries: emerging issues. <i>Stem Cell Research</i> , 2009 , 3, 96-105	1.6	35
28	Genomics and policymaking: from static models to complex systems?. <i>Human Genetics</i> , 2009 , 125, 375-9	6.3	27
27	Prepublication data sharing. <i>Nature</i> , 2009 , 461, 168-70	50.4	197
26	The human embryo: ethical and legal aspects. <i>Methods in Molecular Biology</i> , 2009 , 550, 281-305	1.4	4
25	Health privacy in genetic research. <i>Politics and the Life Sciences</i> , 2009 , 28, 99-101	0.7	6
24	'Principled' personalized medicine?. <i>Personalized Medicine</i> , 2009 , 6, 663-667	2.2	4
23	The global emergence of epidemiological biobanks: opportunities and challenges 2009 , 77-99		2
22	Should physicians warn patients' relatives of genetic risks?. <i>Cmaj</i> , 2008 , 178, 593-5	3.5	26
21	Research ethics recommendations for whole-genome research: consensus statement. <i>PLoS Biology</i> , 2008 , 6, e73	9.7	174
20	DESCENDO A TOCA DO COELHO: TRANSFERÊNCIA DE TECNOLOGIA NO CAMPO DA PESQUISA EM CÉLULAS-TRONCO. <i>Revista Da Faculdade De Direito UFPR</i> , 2008 , 47,	0	1
19	Our social genome?. <i>Trends in Biotechnology</i> , 2007 , 25, 284-8	15.1	27
18	Genomic Databases and International Collaboration. <i>Kings Law Journal</i> , 2007 , 18, 291-311	1.2	21
17	Beyond the permissibility of embryonic and stem cell research: substantive requirements and procedural safeguards. <i>Human Reproduction</i> , 2006 , 21, 2474-81	5.7	33
16	The Babel of genetic data terminology. <i>Nature Biotechnology</i> , 2005 , 23, 925-7	44.5	52
15	Human genetic research: emerging trends in ethics. <i>Nature Reviews Genetics</i> , 2005 , 6, 75-9	30.1	192
14	Biobanking: international norms. <i>Journal of Law, Medicine and Ethics</i> , 2005 , 33, 7-14	1.2	71

13	Consent revisited: points to consider. <i>Health Law Review</i> , 2005 , 13, 33-8		22
12	Of biotechnology and man. <i>Public Health Genomics</i> , 2004 , 7, 176-81		4
11	Genetic information and the family: are we our brother's keeper?. <i>Trends in Biotechnology</i> , 2002 , 20, 85-6	15.1	47
10	Serious genetic disorders: can or should they be defined?. <i>American Journal of Medical Genetics Part A</i> , 2002 , 108, 29-35		53
9	Science and society: children and incompetent adults in genetic research: consent and safeguards. <i>Nature Reviews Genetics</i> , 2002 , 3, 221-5	30.1	34
8	Legal Aspects of Genetics, Work and Insurance in North America and Europe. <i>European Journal of Health Law</i> , 1996 , 3, 143-161	0.2	14
7	Unesco and population genetics. <i>Nature</i> , 1996 , 379, 11	50.4	4
6	Research and Stored Tissues. <i>JAMA - Journal of the American Medical Association</i> , 1995 , 274, 1806	27.4	21
5	The Human Genome Project: under an international ethical microscope. <i>Science</i> , 1994 , 265, 2035-6	33.3	56
4	Reproductive genetics: Canadian and European perspectives. <i>Fetal Diagnosis and Therapy</i> , 1993 , 8, 189-201	20.1	2
3	Recent Advances in Medically Assisted Conception: Legal, Ethical and Social Issues. <i>American Journal of Law and Medicine</i> , 1991 , 17, 329-361	0.5	37
2	The concept of humanity and biogenetics	223-243	
1	COVID-19 and beyond: a call for action and audacious solidarity to all the citizens and nations, it is humanity's fight. <i>F1000Research</i> , 9, 1130	3.6	2