Paul Wicks

List of Publications by Year
in descending order

129 papers	5,083 citations	81900 39 h-index	106344 65 g-index
150 all docs	150 docs citations	150 times ranked	6732 citing authors

#	Article	IF	Citations
1	Sharing Health Data for Better Outcomes on PatientsLikeMe. Journal of Medical Internet Research, 2010, 12, e19.	4.3	514
2	Accelerated clinical discovery using self-reported patient data collected online and a patient-matching algorithm. Nature Biotechnology, 2011, 29, 411-414.	17.5	306
3	National randomized controlled trial of virtual house calls for Parkinson disease. Neurology, 2017, 89, 1152-1161.	1.1	169
4	Adaptation and validation of the Treatment Burden Questionnaire (TBQ) in English using an internet platform. BMC Medicine, 2014, 12, 109.	5.5	163
5	Improving clinical trial outcomes in amyotrophic lateral sclerosis. Nature Reviews Neurology, 2021, 17, 104-118.	10.1	152
6	The power of social networking in medicine. Nature Biotechnology, 2009, 27, 888-890.	17.5	133
7	Patient-reported Outcomes as a Source of Evidence in Off-Label Prescribing: Analysis of Data From PatientsLikeMe. Journal of Medical Internet Research, 2011, 13, e6.	4.3	130
8	Time to deliver patient centred care. BMJ, The, 2015, 350, h530.	6.0	129
9	Concordance between site of onset and limb dominance in amyotrophic lateral sclerosis. Journal of Neurology, Neurosurgery and Psychiatry, 2011, 82, 853-854.	1.9	114
10	â€˜Trust but verifyâ€™ â€" five approaches to ensure safe medical apps. BMC Medicine, 2015, 13, 205.	5.5	112
11	Perceived benefits of sharing health data between people with epilepsy on an online platform. Epilepsy and Behavior, 2012, 23, 16-23.	1.7	109
12	How accurate are digital symptom assessment apps for suggesting conditions and urgency advice? A clinical vignettes comparison to GPs. BMJ Open, 2020, 10, e040269.	1.9	106
13	Innovations in e-health. Quality of Life Research, 2014, 23, 195-203.	3.1	105
14	Prevalence of depression in a 12-month consecutive sample of patients with ALS. European Journal of Neurology, 2007, 14, 993-1001.	3.3	100
15	Increasing Patient Involvement in Drug Development. Value in Health, 2016, 19, 869-878.	0.3	86
16	Beyond the hype of big data and artificial intelligence: building foundations for knowledge and wisdom. BMC Medicine, 2019, 17, 143.	5.5	85
17	Patient-Reported Outcome Measures in Safety Event Reporting: PROSPER Consortium Guidance. Drug Safety, 2013, 36, 1129-1149.	3.2	84
18	How common are ALS plateaus and reversals?. Neurology, 2016, 86, 808-812.	1.1	78

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19	Patients' Utilization and Perception of an Artificial Intelligence–Based Symptom Assessment and Advice Technology in a British Primary Care Waiting Room: Exploratory Pilot Study. JMIR Human Factors, 2020, 7, e19713.	2.0	78
20	SOD1 and cognitive dysfunction in familial amyotrophic lateral sclerosis. Journal of Neurology, 2009, 256, 234-241.	3.6	76
21	Patients' roles and rights in research. BMJ: British Medical Journal, 2018, 362, k3193.	2.3	76
22	Measuring function in advanced ALS: validation of ALSFRS€X extension items. European Journal of Neurology, 2009, 16, 353-359.	3.3	74
23	Evidence of Human-Level Bonds Established With a Digital Conversational Agent: Cross-sectional, Retrospective Observational Study. JMIR Formative Research, 2021, 5, e27868.	1.4	71
24	Online assessment of ALS functional rating scale compares well to in-clinic evaluation: A prospective trial. Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders, 2012, 13, 210-216.	2.1	70
25	Patient-Centeredness in the Design of Clinical Trials. Value in Health, 2014, 17, 471-475.	0.3	70
26	Research led by participants: a new social contract for a new kind of research. Journal of Medical Ethics, 2016, 42, 216-219.	1.8	67
27	Evaluation of an Online Platform for Multiple Sclerosis Research: Patient Description, Validation of Severity Scale, and Exploration of BMI Effects on Disease Course. PLoS ONE, 2013, 8, e59707.	2.5	65
28	Use of an Online Community to Develop Patient-Reported Outcome Instruments: The Multiple Sclerosis Treatment Adherence Questionnaire (MS-TAQ). Journal of Medical Internet Research, 2011, 13, e12.	4.3	65
29	Clinical trials from the patient perspective: survey in an online patient community. BMC Health Services Research, 2017, 17, 166.	2.2	59
30	Subjects no more: what happens when trial participants realize they hold the power?. BMJ, The, 2014, 348, g368-g368.	6.0	57
31	Neuronal loss associated with cognitive performance in amyotrophic lateral sclerosis: An (^{11}C)–flumazenil PET study. Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders, 2008, 9, 43-49.	2.1	56
32	Virtual visits for Parkinson disease. Neurology: Clinical Practice, 2014, 4, 146-152.	1.6	52
33	Changes in memory for emotional material in amyotrophic lateral sclerosis (ALS). Neuropsychologia, 2005, 43, 1107-1114.	1.6	51
34	Prevalence of depression in amyotrophic lateral sclerosis and other motor disorders. European Journal of Neurology, 2010, 17, 1047-1053.	3.3	51
35	Digital Trespass: Ethical and Terms-of-Use Violations by Researchers Accessing Data From an Online Patient Community. Journal of Medical Internet Research, 2019, 21, e11985.	4.3	48
36	National Randomized Controlled Trial of Virtual House Calls for People with Parkinson's Disease: Interest and Barriers. Telemedicine Journal and E-Health, 2016, 22, 590-598.	2.8	47

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37	ALS patients request more information about cognitive symptoms. European Journal of Neurology, 2008, 15, 497-500.	3.3	46
38	Opportunities and counterintuitive challenges for decentralized clinical trials to broaden participant inclusion. Npj Digital Medicine, 2022, 5, 58.	10.9	45
39	The multiple sclerosis rating scale, revised (MSRS-R): Development, refinement, and psychometric validation using an online community. Health and Quality of Life Outcomes, 2012, 10, 70.	2.4	44
40	Patients report worse MS symptoms after menopause: Findings from an online cohort. Multiple Sclerosis and Related Disorders, 2015, 4, 18-24.	2.0	44
41	Patient perspectives on neuromyelitis optica spectrum disorders: Data from the PatientsLikeMe online community. Multiple Sclerosis and Related Disorders, 2017, 17, 116-122.	2.0	43
42	Severe Loss of Appetite in Amyotrophic Lateral Sclerosis Patients: Online Self-Assessment Study. Interactive Journal of Medical Research, 2013, 2, e8.	1.4	42
43	Patients optimizing epilepsy management via an online community. Neurology, 2015, 85, 129-136.	1.1	38
44	Preferred Features of Oral Treatments and Predictors of Non-Adherence: Two Web-Based Choice Experiments in Multiple Sclerosis Patients. Interactive Journal of Medical Research, 2015, 4, e6.	1.4	35
45	Quantifying Short-Term Dynamics of Parkinson's Disease Using Self-reported Symptom Data From an Internet Social Network. Journal of Medical Internet Research, 2013, 15, e20.	4.3	34
46	Can We Use Social Media to Support Content Validity of Patient-Reported Outcome Instruments in Medical Product Development?. Value in Health, 2015, 18, 1-4.	0.3	33
47	Stakeholder engagement in patient-centered outcomes research: high-touch or high-tech?. Expert Review of Pharmacoeconomics and Outcomes Research, 2014, 14, 335-344.	1.4	32
48	Three soccer playing friends with simultaneous amyotrophic lateral sclerosis. Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders, 2007, 8, 177-179.	2.1	31
49	PatientsLikeMe® Online Epilepsy Community: Patient characteristics and predictors of poor health-related quality of life. Epilepsy and Behavior, 2016, 63, 20-28.	1.7	31
50	Scaling PatientsLikeMe via a "Generalized Platform" for Members with Chronic Illness: Web-Based Survey Study of Benefits Arising. Journal of Medical Internet Research, 2018, 20, e175.	4.3	30
51	The real-world patient experience of fingolimod and dimethyl fumarate for multiple sclerosis. BMC Research Notes, 2016, 9, 434.	1.4	29
52	Pathological gambling amongst Parkinson's disease and ALS patients in an online community (PatientsLikeMe.com). Movement Disorders, 2009, 24, 1085-1088.	3.9	28
53	Exploring Concordance of Patient-Reported Information on PatientsLikeMe and Medical Claims Data at the Patient Level. Journal of Medical Internet Research, 2016, 18, e110.	4.3	28
54	Perceived stigma and adherence in epilepsy: Evidence for a link and mediating processes. Epilepsy and Behavior, 2014, 41, 227-231.	1.7	26

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55	Quality of Life in Organ Transplant Recipients Participating in an Online Transplant Community. Patient, 2014, 7, 73-84.	2.7	25
56	Patients' motivations and interest in research: characteristics of volunteers for patient-led projects on PatientsLikeMe. Research Involvement and Engagement, 2016, 2, 33.	2.9	25
57	Mining Online Social Network Data for Biomedical Research: A Comparison of Clinicians' and Patients' Perceptions About Amyotrophic Lateral Sclerosis Treatments. Journal of Medical Internet Research, 2012, 14, e90.	4.3	25
58	Absence of cognitive, behavioral, or emotional dysfunction in progressive muscular atrophy. Neurology, 2006, 67, 1718-1719.	1.1	22
59	Patient assessment of physician performance of epilepsy quality-of-care measures. Neurology: Clinical Practice, 2012, 2, 335-342.	1.6	21
60	New approach for analyzing self-reporting of insomnia symptoms reveals a high rate of comorbid insomnia across a wide spectrum of chronic diseases. Sleep Medicine, 2015, 16, 1332-1341.	1.6	21
61	Concept Elicitation Within Patient-Powered Research Networks: A Feasibility Study in Chronic Lymphocytic Leukemia. Value in Health, 2016, 19, 42-52.	0.3	21
62	Women's experiences of menopause in an online MS cohort: A case series. Multiple Sclerosis and Related Disorders, 2016, 9, 56-59.	2.0	21
63	How the Social Web Supports patient experimentation with a new therapy: The demand for patient-controlled and patient-centered informatics. AMIA ... Annual Symposium proceedings, 2008, , 217-21.	0.2	20
64	ALS Untangled No. 20: The Deanna Protocol. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2013, 14, 319-323.	1.7	19
65	It's a long shot, but it just might work! Perspectives on the future of medicine. BMC Medicine, 2016, 14, 176.	5.5	17
66	Understanding How Chorea Affects Health-Related Quality of Life in Huntington Disease: An Online Survey of Patients and Caregivers in the United States. Patient, 2018, 11, 547-559.	2.7	17
67	Modifiable barriers to enrollment in American ALS research studies. Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders, 2010, 11, 502-507.	2.1	16
68	Reassessing received wisdom in ALS – pain is common when studied systematically. European Journal of Neurology, 2012, 19, 531-532.	3.3	15
69	DigitalMe: a journey towards personalized health and thriving. BioMedical Engineering OnLine, 2018, 17, 119.	2.7	15
70	Lunasin does not slow ALS progression: results of an open-label, single-center, hybrid-virtual 12-month trial. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2019, 20, 285-293.	1.7	15
71	Safety of Triage Self-assessment Using a Symptom Assessment App for Walk-in Patients in the Emergency Care Setting: Observational Prospective Cross-sectional Study. JMIR MHealth and UHealth, 2022, 10, e32340.	3.7	15
72	The ALS Ice Bucket Challenge – Can a splash of water reinvigorate a field?. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2014, 15, 479-480.	1.7	14

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73	Could digital patient communities be the launch pad for patient-centric trial design?. Trials, 2014, 15, 172.	1.6	14
74	Patient, study thyself. BMC Medicine, 2018, 16, 217.	5.5	14
75	Excessive yawning is common in the bulbarâ€ onset form of ALS. Acta Psychiatrica Scandinavica, 2007, 116, 76-76.	4.5	13
76	Hypothesis: Higher prenatal testosterone predisposes ALS patients to improved athletic performance and manual professions. Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders, 2012, 13, 251-253.	2.1	12
77	Resilient design: decentralized trials recovered faster from the impact of COVID-19 than traditional site-based designs. Expert Review of Medical Devices, 2021, 18, 1-4.	2.8	12
78	The Potential Research Impact of Patient Reported Outcomes on Osteogenesis Imperfecta. Clinical Orthopaedics and Related Research, 2010, 468, 2581-2585.	1.5	10
79	ALSUntangled No. 16: Cannabis. Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders, 2012, 13, 400-404.	2.1	9
80	Improving Emergency Department Patient-Physician Conversation Through an Artificial Intelligence Symptom-Taking Tool: Mixed Methods Pilot Observational Study. JMIR Formative Research, 2022, 6, e28199.	1.4	9
81	E-mental health: A medium reaches maturity. Journal of Mental Health, 2012, 21, 332-335.	1.9	8
82	Data Donation Could Power the Learning Health Care System, Including Special Access Programs. American Journal of Bioethics, 2014, 14, 27-29.	0.9	8
83	Feasibility of a Web-Based Survey of Hallucinations and Assessment of Visual Function in Patients With Parkinsonâ€™s Disease. Interactive Journal of Medical Research, 2014, 3, e1.	1.4	8
84	Report of the independent panel considering the retraction of two articles in The BMJ. BMJ, The, 2014, 349, g5176-g5176.	6.0	7
85	Commentary: Measuring what matters: the case for patient generated PROMS. BMJ, The, 2015, 350, h54.	6.0	7
86	ALSUntangled No. 30: Methylcobalamin. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2015, 16, 536-539.	1.7	7
87	Increasing patient participation in drug development. Nature Biotechnology, 2015, 33, 134-135.	17.5	7
88	Beyond the Therapistâ€™s Office: Merging Measurement-Based Care and Digital Medicine in the Real World. Digital Biomarkers, 2021, 5, 176-182.	4.4	7
89	Quality of condition suggestions and urgency advice provided by the Ada symptom assessment app evaluated with vignettes optimised for Australia. Australian Journal of Primary Health, 2021, 27, 377.	0.9	7
90	ALS Untangled No. 17: â€œWhen ALS Is Lymeâ€. Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders, 2012, 13, 487-491.	2.1	6

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91	ALSUntangled 15: Coconut Oil. Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders, 2012, 13, 328-330.	2.1	6
92	Optimization of Patient Flow in Urgent Care Centers Using a Digital Tool for Recording Patient Symptoms and History: Simulation Study. JMIR Formative Research, 2021, 5, e26402.	1.4	6
93	The Virtuous Circle of the Quantified Self: A Human Computational Approach to Improved Health Outcomes. , 2013, , 105-129.		6
94	ALSUntangled #64: butyrates. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2022, 23, 638-643.	1.7	6
95	Letter to the Editor: Quality of mental health information on Wikipedia. Psychological Medicine, 2012, 42, 891-891.	4.5	5
96	ALSUntangled No. 19: Sodium chlorite. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2013, 14, 236-238.	1.7	5
97	ALS Untangled No. 21: Fecal transplants. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2013, 14, 482-485.	1.7	5
98	It's time to stop saying â€œthe mind is unaffectedâ€•in ALS. Neurology, 2018, 91, 679-681.	1.1	4
99	A RAPID SCREENING BATTERY TO IDENTIFY FRONTAL DYSFUNCTION IN PATIENTS WITH ALS. Neurology, 2007, 69, 118-120.	1.1	3
100	ALSUntangled No. 9: Blue-green algae (Spirulina) as a treatment for ALS. Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders, 2011, 12, 153-155.	2.1	3
101	ALSUntangled No. 8: Low dose naltrexone for ALS. Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders, 2011, 12, 76-78.	2.1	3
102	Medicine and the future of health: reflecting on the past to forge ahead. BMC Medicine, 2016, 14, 169.	5.5	3
103	Getting stem cell patients 'on the grid'. Nature Biotechnology, 2016, 34, 1228-1230.	17.5	3
104	Rethinking the locked-in state for people with ALS. Neurology, 2019, 93, 419-420.	1.1	3
105	Going on up to the SPIRIT in AI: will new reporting guidelines for clinical trials of AI interventions improve their rigour?. BMC Medicine, 2020, 18, 272.	5.5	3
106	ALSUntangled #63: ketogenic diets. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2023, 24, 159-163.	1.7	3
107	ALSUntangled No. 11: Nu Tech Mediworld. Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders, 2011, 12, 309-311.	2.1	2
108	ALSUntangled No. 10: Luteolin and Lutimax. Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders, 2011, 12, 235-237.	2.1	2

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109	ALSUntangled No. 14: Mototab. Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders, 2012, 13, 161-164.	2.1	2
110	Comparison of rates of nausea side effects for prescription medications from an online patient community versus medication labels: an exploratory analysis. AAPS Open, 2017, 3, .	1.3	2
111	ALSUntangled No. 18: Apoaequorin (Prevagen). Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2013, 14, 78-79.	1.7	1
112	Crowdsourcing Advancements in Health Care Research. , 2016, , 307-329.		1
113	A millennial discharge summary. BMJ, The, 2016, , i6607.	6.0	1
114	The quality of diagnosis and triage advice provided by free online symptom checkers and apps in Australia. Medical Journal of Australia, 2021, 214, 143.	1.7	1
115	ALSUntangled 59: Tamoxifen. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2021, 22, 595-598.	1.7	1
116	ALSUntangled #62: vitamin C. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2021, , 1-4.	1.7	1
117	Conversational Agents in Health Care. JAMA - Journal of the American Medical Association, 2020, 324, 2444.	7.4	1
118	Sharing access might increase engagement. BMJ: British Medical Journal, 2010, 341, c7209-c7209.	2.3	1
119	A Modular Health-Related Quality of Life Instrument for Electronic Assessment and Treatment Monitoring: Web-Based Development and Psychometric Validation of Core Thrive Items. Journal of Medical Internet Research, 2019, 21, e12075.	4.3	1
120	Sharing information with patients like me. British Journal of Neuroscience Nursing, 2009, 5, 132-133.	0.2	0
121	ALSUntangled 13: Bee Venom. Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders, 2011, 12, 471-472.	2.1	0
122	Information wants to be free, but when it comes to clinical trials can we afford to let it be?. Clinical Investigation, 2012, 2, 125-127.	0.0	0
123	Correction: The multiple sclerosis rating scale, revised (MSRS-R): development, refinement, and psychometric validation using an online community. Health and Quality of Life Outcomes, 2013, 11, 60.	2.4	0
124	ALSUntangled No. 22: Propofol. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2013, 14, 640-642.	1.7	0
125	Measuring the burden of treatment. BMJ, The, 2014, 349, g7322-g7322.	6.0	0
126	Close the loop to show patients the value of taking part in research. BMJ, The, 2015, 351, h4313.	6.0	0

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127	Clinical Trial Blinding in the Age of Social Media. , 2016, , 97-106.		0
128	ALSUntangled #60: light therapy. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2021, , 1-5.	1.7	0
129	Experiences With Assessments and Procurement of Their First Power Wheelchair Among Members of an Online Patient Community. American Journal of Occupational Therapy, 2019, 73, 7311510234p1-7311510234p1.	0.3	0