

# Mark W Skinner

## List of Publications by Year in descending order

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Version: 2024-02-01

48  
papers

1,039  
citations

394421

19  
h-index

454955

30  
g-index

50  
all docs

50  
docs citations

50  
times ranked

854  
citing authors

#	ARTICLE	IF	CITATIONS
1	User-Centered Development and Testing of the Online Patient-Reported Outcomes, Burdens, and Experiences (PROBE) Survey and the myPROBE App and Integration With the Canadian Bleeding Disorder Registry: Mixed Methods Study. <i>JMIR Human Factors</i> , 2022, 9, e30797.	2.0	2
2	Association of factor expression levels with health-related quality of life and direct medical costs for people with haemophilia B. <i>Journal of Medical Economics</i> , 2022, 25, 386-392.	2.1	0
3	A preliminary application of a haemophilia value framework to emerging therapies in haemophilia. <i>Haemophilia</i> , 2022, 28, 9-18.	2.1	8
4	Non-severe haemophilia: Is it benign? Insights from the PROBE study. <i>Haemophilia</i> , 2021, 27, 17-24.	2.1	16
5	Evidence of a disability paradox in patient-reported outcomes in haemophilia. <i>Haemophilia</i> , 2021, 27, 245-252.	2.1	25
6	Vaccination against COVID-19: Rationale, modalities and precautions for patients with haemophilia and other inherited bleeding disorders. <i>Haemophilia</i> , 2021, 27, 515-518.	2.1	9
7	Patient-relevant health outcomes for hemophilia care: Development of an international standard outcomes set. <i>Research and Practice in Thrombosis and Haemostasis</i> , 2021, 5, e12488.	2.3	20
8	Evolution of haemophilia integrated care in the era of gene therapy: Treatment centre's readiness in United States and EU. <i>Haemophilia</i> , 2021, 27, 511-514.	2.1	13
9	The effect of emicizumab prophylaxis on long-term, self-reported physical health in persons with haemophilia A without factor VIII inhibitors in the HAVEN 3 and HAVEN 4 studies. <i>Haemophilia</i> , 2021, 27, 854-865.	2.1	21
10	Patient preferences and priorities for haemophilia gene therapy in the US: A discrete choice experiment. <i>Haemophilia</i> , 2021, 27, 769-782.	2.1	15
11	Evaluation of the sexual health in people living with hemophilia. <i>Haemophilia</i> , 2021, 27, 993-1001.	2.1	2
12	Identified unmet needs and proposed solutions in mild-to-moderate haemophilia: A summary of opinions from a roundtable of haemophilia experts. <i>Haemophilia</i> , 2021, 27, 25-32.	2.1	9
13	Integrated Hemophilia Patient Care via a National Network of Care Centers in the United States: A Model for Rare Coagulation Disorders. <i>Journal of Blood Medicine</i> , 2021, Volume 12, 897-911.	1.7	21
14	Eliminating Panglossian thinking in development of AAV therapeutics. <i>Molecular Therapy</i> , 2021, 29, 3325-3327.	8.2	12
15	Achieving the unimaginable: Health equity in haemophilia. <i>Haemophilia</i> , 2020, 26, 17-24.	2.1	54
16	Core data set on safety, efficacy, and durability of hemophilia gene therapy for a global registry: Communication from the SSC of the ISTH. <i>Journal of Thrombosis and Haemostasis</i> , 2020, 18, 3074-3077.	3.8	24
17	Gene therapy to cure haemophilia: Is robust scientific inquiry the missing factor?. <i>Haemophilia</i> , 2020, 26, 931-933.	2.1	24
18	Challenges and key lessons from the design and implementation of an international haemophilia registry supported by a pharmaceutical company. <i>Haemophilia</i> , 2020, 26, 966-974.	2.1	4

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19	The role of telemedicine in the delivery of health care in the COVID-19 pandemic. Haemophilia, 2020, 26, e230-e231.	2.1	57
20	World Federation of Hemophilia Gene Therapy Registry. Haemophilia, 2020, 26, 563-564.	2.1	28
21	The World Federation of Hemophilia Annual Global Survey 1999-2018. Haemophilia, 2020, 26, 591-600.	2.1	50
22	Examination and Validation of a Patient-Centric Joint Metric: "Problem Joint"; Empirical Evidence from the CHES US Dataset. Blood, 2020, 136, 25-26.	1.4	2
23	Hemophilia trials in the twenty-first century: Defining patient important outcomes. Research and Practice in Thrombosis and Haemostasis, 2019, 3, 184-192.	2.3	42
24	Exploring regional variations in the cross-cultural, international implementation of the Patient Reported Outcomes Burdens and Experience (PROBE) study. Haemophilia, 2019, 25, 365-372.	2.1	11
25	The 1st WFH Gene Therapy Round Table: Understanding the landscape and challenges of gene therapy for haemophilia around the world. Haemophilia, 2019, 25, 189-194.	2.1	31
26	Test-retest properties of the Patient Reported Outcomes, Burdens and Experiences (PROBE) questionnaire and its constituent domains. Haemophilia, 2019, 25, 75-83.	2.1	14
27	The Patient Reported Outcomes, Burdens and Experiences (PROBE) Project: development and evaluation of a questionnaire assessing patient reported outcomes in people with haemophilia. Pilot and Feasibility Studies, 2018, 4, 58.	1.2	34
28	Core outcome set for gene therapy in haemophilia: Results of the core HEM multistakeholder project. Haemophilia, 2018, 24, e167-e172.	2.1	74
29	Psychometric properties of the Patient Reported Outcomes, Burdens and Experiences (PROBE) questionnaire. BMJ Open, 2018, 8, e021900.	1.9	15
30	Genotypes, phenotypes and whole genome sequence: Approaches from the My Life Our Future haemophilia project. Haemophilia, 2018, 24, 87-94.	2.1	32
31	Establishing the appropriate primary endpoint in haemophilia gene therapy pivotal studies. Haemophilia, 2017, 23, 643-644.	2.1	18
32	Assessments of outcome in haemophilia – a patient perspective. Haemophilia, 2016, 22, e208-9.	2.1	8
33	NHF-McMaster Guideline on Care Models for Haemophilia Management. Haemophilia, 2016, 22, 6-16.	2.1	50
34	Improving comprehensive care in the haemophilia community: building on the HERO Study. Haemophilia, 2016, 22, e320-2.	2.1	3
35	Risk-based decision making and ethical considerations in donor compensation for plasma-derived medicinal products. Transfusion, 2016, 56, 2889-2894.	1.6	33
36	Test-Retest Reliability Analysis of the Patient Reported Outcomes Burdens and Experiences (PROBE). Blood, 2016, 128, 5964-5964.	1.4	0

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37	The national haemophilia program standards, evaluation and oversight systems in the United States of America. <i>Blood Transfusion</i> , 2014, 12 Suppl 3, e542-8.	0.4	3
38	Gene Therapy for Hemophilia: Addressing the Coming Challenges of Affordability and Accessibility. <i>Molecular Therapy</i> , 2013, 21, 1-2.	8.2	23
39	World Federation of Hemophilia: 50 years of advancing treatment for all. <i>Haemophilia</i> , 2013, 19, 475-480.	2.1	9
40	Ensuring maximum outcomes and benefits in comprehensive care for bleeding disorders through surveillance and data collection. <i>Hematology</i> , 2012, 17, s147-s149.	1.5	2
41	WFH: Closing the global gap – achieving optimal care. <i>Haemophilia</i> , 2012, 18, 1-12.	2.1	86
42	Haemophilia care – past, present and future from a patient perspective. <i>Haemophilia</i> , 2012, 18, 3-5.	2.1	11
43	Haemophilia: provision of factors and novel therapies: World Federation of Hemophilia goals and achievements. <i>British Journal of Haematology</i> , 2011, 154, 704-714.	2.5	28
44	Cell Phones and Landlines: The Impact of Gene Therapy on the Cost and Availability of Treatment for Hemophilia. <i>Molecular Therapy</i> , 2011, 19, 1749-1750.	8.2	16
45	Building our global family – achieving treatment for all. <i>Haemophilia</i> , 2010, 16, 1-10.	2.1	11
46	WFH – the cornerstone of global development: 45 years of progress. <i>Haemophilia</i> , 2008, 14, 1-9.	2.1	21
47	Treatment for all: a vision for the future. <i>Haemophilia</i> , 2006, 12, 169-173.	2.1	36
48	The Hemophilia Gene Therapy Patient Journey: Questions and Answers for Shared Decision-Making. <i>Patient Preference and Adherence</i> , 0, Volume 16, 1439-1447.	1.8	12