Resource Summary Report

Generated by RRID on Aug 4, 2026

PatientsLikeMe

RRID:SCR_003781
Type: Tool

Proper Citation

PatientsLikeMe (RRID:SCR_003781)

Resource Information

URL: http://www.patientslikeme.com/

Proper Citation: PatientsLikeMe (RRID:SCR_003781)

Description: A for-profit health data-sharing platform that can transform the way patients manage their conditions, change the way industry conducts research and improve patient care. PatientsLikeMe aligns patient and industry interests through data-sharing partnerships. They work with trusted nonprofit, research and industry Partners who use this health data to improve products, services and care for patients. They take the information patients share about their experience with the disease and sell it to their partners (i.e., companies that are developing or selling products to patients). These products may include drugs, devices, equipment, insurance, and medical services. Except for the restricted personal information entered when registering for the site, participants should expect that every piece of information submitted (even if it is not currently displayed) may be shared with their partners and any member of PatientsLikeMe, including other patients. They do not rent, sell or share personally identifiable information for marketing purposes or without explicit consent. Because they believe in transparency, they tell members exactly what they do and do not do with their data. Patients have the opportunity to share both personal stories and health data about their conditions to help uncover great ideas and new knowledge. By sharing information on the site, they can put their disease experiences in context and find answers to the questions they have. Every partnership we develop must bring them closer to aligning patient and industry interests. Their end goal is improved patient care and quality of life.

Resource Type: data or information resource

Keywords: patient, treatment, symptom, condition, health, data sharing, patient care, disease, community building portal, blog

Related Condition: Amyotrophic Lateral Sclerosis, Motor neuron degeneration, Primary Lateral Sclerosis, Progressive Muscular Atrophy, Parkinson's disease, Multiple Sclerosis, HIV, AIDS, Mood condition, Depressive Disorder, Anxiety, Bipolar Disorder, Obsessive-

Compulsive Disorder, Post-Traumatic Stress Disorder, Multiple System Atrophy, Progressive Supranuclear Palsy, Neuromyelitis Optica, Fibromyalgia, Chronic Fatigue, ME, Epilepsy, Organ Transplant

Availability: For-profit, Free to join but information is sold, The community can contribute to this resource

Resource Name: PatientsLikeMe

Resource ID: SCR_003781

Alternate IDs: nlx_143529

Record Creation Time: 20220129T080220+0000

Record Last Update: 20260801T190219+0000

Ratings and Alerts

No rating or validation information has been found for PatientsLikeMe.

No alerts have been found for PatientsLikeMe.

Data and Source Information

Source: SciCrunch Registry

Usage and Citation Metrics

We found 82 mentions in open access literature.

Listed below are recent publications. The full list is available at RRID .

Slade M, et al. (2025) Living with mental health issues: citizen science project on self-management strategies. Npj mental health research, 4(1), 50.

Guo S, et al. (2025) Extending Signaling Theory in Online Health Communities to Address Medical Information Asymmetry: Systematic Review With Narrative Synthesis. Journal of medical Internet research, 27, e73208.

Song S, et al. (2025) Participant Contributions to Person-Generated Health Data Research Using Mobile Devices: Scoping Review. Journal of medical Internet research, 27, e51955.

Rodriguez RD, et al. (2025) Mental Health Experiences and Challenges Among Individuals with Myasthenia Gravis: Insights from Patient-Centered, Qualitative Analyses. Advances in therapy, 42(12), 6209.

Shepherd JA, et al. (2024) Retrospective text and qualitative analyses of patient experience and management of vasomotor symptoms due to menopause: voices from the

PatientsLikeMe community. Menopause (New York, N.Y.), 31(9), 789.

Burger P, et al. (2023) GenIDA: an international participatory database to gain knowledge on health issues related to genetic forms of neurodevelopmental disorders. Journal of neural transmission (Vienna, Austria : 1996), 130(3), 459.

Arumugam A, et al. (2023) Patient and public involvement in research: a review of practical resources for young investigators. BMC rheumatology, 7(1), 2.

Brumm MC, et al. (2023) Updated Percentiles for the University of Pennsylvania Smell Identification Test in Adults 50 Years of Age and Older. Neurology, 100(16), e1691.

Yahya AA, et al. (2022) Social Media Analytics for Pharmacovigilance of Antiepileptic Drugs. Computational and mathematical methods in medicine, 2022, 8965280.

Lokmic-Tomkins Z, et al. (2022) Assessing the carbon footprint of digital health interventions: a scoping review. Journal of the American Medical Informatics Association : JAMIA, 29(12), 2128.

Yang J, et al. (2021) Understanding Continuance Intention Determinants to Adopt Online Health Care Community: An Empirical Study of Food Safety. International journal of environmental research and public health, 18(12).

Kiernan MC, et al. (2021) Improving clinical trial outcomes in amyotrophic lateral sclerosis. Nature reviews. Neurology, 17(2), 104.

Glinert LH, et al. (2021) Communicative and Discursive Perspectives on the Medication Experience. Pharmacy (Basel, Switzerland), 9(1).

Cortis K, et al. (2021) Over a decade of social opinion mining: a systematic review. Artificial intelligence review, 54(7), 4873.

García-Berná JA, et al. (2021) Energy efficiency in software: A case study on sustainability in personal health records. Journal of cleaner production, 282, 124262.

James G, et al. (2020) Characteristics, Symptom Severity, and Experiences of Patients Reporting Chronic Kidney Disease in the PatientsLikeMe Online Health Community: Retrospective and Qualitative Study. Journal of medical Internet research, 22(7), e18548.

Hixson JD, et al. (2020) Digital tools for epilepsy: Opportunities and barriers. Epilepsy research, 162, 106233.

Rifkin RM, et al. (2020) Treatment Satisfaction and Burden of Illness in Patients with Newly Diagnosed Multiple Myeloma. PharmacoEconomics - open, 4(3), 473.

Eyers T, et al. (2020) Ethics in Surgical Innovations from the Patient Perspective. Yearbook of medical informatics, 29(1), 169.

Mathur K, et al. (2020) Cannabidiol (CBD) Consumption and Perceived Impact on Extrahepatic Symptoms in Patients with Autoimmune Hepatitis. Digestive diseases and sciences, 65(1), 322.