Resource Summary Report

Generated by kravitz2 on Sep 16, 2026

PatientCrossroads

RRID:SCR_006279
Type: Tool

Proper Citation

PatientCrossroads (RRID:SCR_006279)

Resource Information

URL: http://www.patientcrossroads.com/

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Description: A trusted third-party gatekeeper of patient data from participants in a rare disease ecosystem, collecting and managing the information in a scalable, cost-effective manner. Each patient registry provides critical disease knowledge which makes that disease easier to study, increasing the probability a treatment can be developed. PatientCrossroads takes a network approach to patient registry programs. Unlike companies that merely sell registry software, we offer a full range of administration, management, and genetic curation services. What does this consolidated, patient-centric approach to patient registries mean? * Patients can more easily find registries and provide their valuable data (including locations of blood and tissue samples as well as reports of diagnoses, disease symptoms, treatment usage, and lifestyle activities) * Patients can be confident in the privacy of their de-identified data and the knowledge that PatientCrossroads does not sell patient data * Researchers and pharmaceutical companies have a larger, more easily accessible pool of potential patients for research studies and clinical trials targeting specific rare diseases * Pharmaceutical companies can collect post-market surveillance data in a more scalable and cost-effective manner * Rare disease advocacy and research foundations can more easily organize their global patient populations for inclusion in trials and studies

Abbreviations: PatientCrossroads

Synonyms: Patient Crossroads

Resource Type: data or information resource, patient registry, people resource, portal, topical portal

Keywords: disease, treatment, clinical, patient, registry, drug discovery, clinical trial, research study, genetics, biorepository

Related Condition: Rare disease

Resource Name: PatientCrossroads

Resource ID: SCR_006279

Alternate IDs: nlx_151889

Record Creation Time: 20220129T080235+0000

Record Last Update: 20260912T195637+0000

Ratings and Alerts

No rating or validation information has been found for PatientCrossroads.

No alerts have been found for PatientCrossroads.

Data and Source Information

Source: SciCrunch Registry

Usage and Citation Metrics

We found 3 mentions in open access literature.

Listed below are recent publications. The full list is available at kravitz2 .

Osara Y, et al. (2017) Development of newborn screening connect (NBS connect): a self-reported patient registry and its role in improvement of care for patients with inherited metabolic disorders. Orphanet journal of rare diseases, 12(1), 132.

Balma??a J, et al. (2016) Conflicting Interpretation of Genetic Variants and Cancer Risk by Commercial Laboratories as Assessed by the Prospective Registry of Multiplex Testing. Journal of clinical oncology : official journal of the American Society of Clinical Oncology, 34(34), 4071.

, et al. (2012) Simons Variation in Individuals Project (Simons VIP): a genetics-first approach to studying autism spectrum and related neurodevelopmental disorders. Neuron, 73(6), 1063.