

Cloud-Based Rare Disease Family Registry Industry Analysis Report 2025: Key Trends, Drivers, and Forecast Insights

The Business Research Company's Cloud-Based Rare Disease Family Registry Global Market Report 2025 – Market Size, Trends, And Global Forecast 2025-2034

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The Business
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Cloud-Based Rare Disease Family Registry Industry
Analysis Report 2025

[Cloud-Based Rare Disease Family Registry Market](#) Growth Forecast: What To Expect By 2025?

The market for a cloud-based registry for families suffering from rare diseases has seen significant expansion in the past few years. The forecast predicts an increase from \$1.19 billion in 2024 to \$1.40 billion in 2025, demonstrating a compound annual growth rate (CAGR) of 17.8%. Key factors contributing to this historical growth have included an increase in drug approvals, growing demand for digitization in healthcare, an escalated use of sophisticated data analytics, expanded use of provider-entered (site-based) registry, and a rising demand for real-world evidence (RWE).

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The market for cloud-based family registries dedicated to

rare diseases is projected to experience considerable expansion in the upcoming years. The expected market value by 2029 is \$2.68 billion, with a compound annual growth rate (CAGR) of 17.6%. This upward trajectory during the predictive period can be credited to factors such as the rise in AI-fueled analytics integration, greater utilization of registry by pharmaceutical companies for post-marketing surveillance, growing demand for specialty-tailored, modular registries, higher patient interaction through portals and remote instruments, and increased health information exchange (HIE) and interoperability standards. Main trends in the projected period

includes the incorporation of wearable technology and internet of things (IoT) devices, secure data sharing through blockchain development, advancement in telehealth and remote monitoring, innovation in EHR-registry interoperability, investment in standardizing procedures, and data collection driven by patients.

Download a free sample of the cloud-based rare disease family registry market report:

<https://www.thebusinessresearchcompany.com/sample.aspx?id=28178&type=smp>

What Are Key Factors Driving The Demand In The Global Cloud-Based Rare Disease Family Registry Market?

The progressive emphasis on precision medicine is projected to drive the expansion of the market for cloud-based rare disease family registries. This medical approach individualizes prevention and treatment plans based on each person's genetic, environmental, and lifestyle characteristics. Advancements in genomic sequencing, which provide a more precise understanding of a patient's genetic profile, are contributing to the rise of precision medicine. The registries for rare diseases, housed on cloud platforms, aid this approach by gathering and centralizing comprehensive patient data, including genetic, clinical, and treatment specifics. For example, the Personalized Medicine Coalition, a non-profit organization based in the US, announced in February 2024 that the FDA, a US federal agency, authorized 16 new personalized treatments for rare disease patients in 2023. This was a significant increase from the six approvals in the previous year. Among the newly permitted treatments, seven are aimed at cancer, and three address other diseases and conditions. Consequently, the escalating emphasis on precision medicine is fueling the growth of the cloud-based rare disease family registry market.

Who Are The Leading Players In The Cloud-Based Rare Disease Family Registry Market?

Major players in the Cloud-Based Rare Disease Family Registry Global Market Report 2025 include:

- Thermo Fisher Scientific Inc.
- IQVIA Holdings Inc.
- ICON plc
- Syneos Health Inc.
- Parexel International Corp.
- Medidata Solutions Inc.
- FIGMD Inc.
- OM1 Inc.
- Mission Health Labs Inc.
- TREAT-NMD Global Registries Platform.

What Are The Major Trends That Will Shape The Cloud-Based Rare Disease Family Registry Market In The Future?

Leading organizations in the cloud-based rare disease family registry sector are promoting progressive technological advancements, like bilingual federated registries. These new systems

supply patients, their families, and scientists with safe, widely spread data platforms that enhance involvement and back real-time data compiling and assessment. A bilingual federated registry is a cloud-powered structure that permits data to stay at localized sites, facilitating several languages while adhering to regional consent and privacy regulations. For example, in June 2025, the U.S. nonprofit, the National Organization for Rare Disorders (NORD), scheduled the initiation of two Canadian patient registries for PKU and MPS. These registries, created in partnership with Canadian patient advocacy groups, researchers, and clinicians, represent the first in the IAMRARE Program to be hosted outside the U.S. They are structured to meet provincial consent requirements, foster collaborative real-time data compilation and study, and aid in expediting research, enhancing understanding of rare metabolic disorders, and helping in the discovery of participants for clinical trials.

Analysis Of Major Segments Driving The [Cloud-Based Rare Disease Family Registry Market Growth](#)

The cloud-based rare disease family registry market covered in this report is segmented as

- 1) By Component: Software, Services
- 2) By Deployment Mode: Public Cloud, Private Cloud, Hybrid Cloud
- 3) By Application: Patient Data Management, Research, Clinical Trials, Genetic Data Collection, Other Applications
- 4) By End-User: Hospitals And Clinics, Research Institutes, Pharmaceutical And Biotechnology Companies, Patient Advocacy Groups, Other End-Users

Subsegments:

- 1) By Software: Electronic Data Capture, Data Management Platform, Analytics And Reporting Tools, Patient Engagement Tools, Clinical Trial Management System
- 2) By Services: Implementation And Integration, Training And Support, Data Hosting And Security, Consulting Services, Maintenance And Upgrades

View the full cloud-based rare disease family registry market report:

<https://www.thebusinessresearchcompany.com/report/cloud-based-rare-disease-family-registry-global-market-report>

Which Region Is Expected To Lead The Cloud-Based Rare Disease Family Registry Market By 2025?

In the 2024 Cloud-Based Rare Disease Family Registry Global Market Report, North America emerged as the most dominant region. However, it is projected that the Asia-Pacific region will experience the fastest growth in the forecast period. The report includes a comprehensive coverage of various regions including Asia-Pacific, Western Europe, Eastern Europe, North America, South America, Middle East, and Africa.

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