

AD, Data Partnerships - Rare Disease

Job ID

REQ-10086801

Sep 01, 2026

LOC_US

About the Role

Key Responsibilities:

- Implement the organization's rare disease data partnership strategy, including the identification of critical data needs across US Commercial rare disease brands, functions, and priority use cases.
- Establish, manage, and strengthen strategic rare disease data partnerships with external data providers, platforms, and vendors to maximize the value of external rare disease data assets.
- Apply deep understanding of rare disease data sources, vendor capabilities, data limitations, patient identification challenges, and fit-for-purpose use cases to guide partnership decisions and business recommendations.
- Monitor adherence to data quality, security, privacy, and compliance standards for external rare disease data sources, platforms, and vendors, ensuring alignment with regulatory requirements and internal data management policies.
- Collaborate with data vendors, business stakeholders, analytics teams, field enablement, access, patient services, and cross-functional rare disease teams to address data quality issues and communicate corresponding changes.
- Implement oversight mechanisms for external rare disease data partnerships, ensuring compliance with data standards, data-sharing agreements, governance expectations, and internal policies.
- Implement data stewardship practices across platforms, vendors, and technology solutions to verify that rare disease data is properly managed, governed, and leveraged throughout the partnership lifecycle.
- Track rare disease data partnerships and spend, provide performance metrics and governance reporting to senior leadership, and identify opportunities for operational efficiencies, improved governance, and enhanced collaboration.
- Work closely with internal stakeholders to understand rare disease business needs, recommend relevant data sets, and guide teams on how to extract actionable insights from available data sources.
- Provide ongoing data advisory support to internal stakeholders, including guidance on recurring deliverables, interpretation of data outputs, data availability, limitations, and appropriate use of rare disease data to support business decisions.

Experience:

Novartis seeks an individual with extensive experience establishing and managing rare disease data partnerships. The ideal candidate will have a deep understanding of healthcare and rare disease data, including the strengths, limitations, governance considerations, and business applications of external data assets. Prior experience working with or for a data vendor is strongly preferred, as this role requires the ability to assess vendor capabilities, challenge data assumptions, manage partnership performance, and translate rare disease business needs into practical data solutions. A proven ability to navigate data-related risks, including privacy, security, quality, compliance, and small patient population considerations, while building mutually beneficial vendor partnerships is essential. The successful candidate will be committed to continuous improvement in the organization's rare disease data partnership strategy, leveraging data insights, vendor expertise, and industry trends to strengthen collaboration and maximize the value of external data assets.

Essential Requirements:

- Education: Bachelor's or Master's degree in Information Management, Computer Science, Business Administration, or related field.
- Minimum 6 years of experience establishing and managing data partnerships, with a strong focus on rare disease, healthcare data, data governance, data management, or related roles.
- Prior experience working with or for a data vendor, data provider, healthcare data platform, or analytics organization is strongly preferred.

- Deep understanding of rare disease data assets, including data sourcing, patient identification, data coverage, refresh cadence, linkage, quality considerations, and fit-for-purpose business use cases.
- Expert understanding of data partnership principles, frameworks, and best practices, with a proven ability to forge strategic collaborations with external data providers and vendors.
- Familiarity with regulatory requirements and industry standards related to healthcare data privacy, security, quality, compliance, and appropriate use of rare disease data.
- Excellent leadership, communication, stakeholder management, influencing, and change management skills in a complex organizational environment.
- Strong analytical and problem-solving skills, with the ability to assess vendor data quality, identify data gaps, manage risks associated with external data partnerships, and ensure the integrity, security, and quality of shared data.
- Experience working with IQVIA, Komodo, MMIT, Symphony, Definitive Healthcare, Veeva, claims/EHR data providers, patient services data, specialty pharmacy data, or similar healthcare and rare disease data sources is highly desirable.
- Ability to translate rare disease business needs into data solutions and guide teams in selecting and leveraging the right data sets to support decision-making.

Novartis Compensation Summary:

The salary for this position is expected to range between \$145,600.00 and \$270,400.00 per year.

The final salary offered is determined based on factors like, but not limited to, relevant skills and experience, and upon joining Novartis will be reviewed periodically. Novartis may change the published salary range based on company and market factors.

Your compensation will include a performance-based cash incentive and, depending on the level of the role, eligibility to be considered for annual equity awards.

US-based eligible employees will receive a comprehensive benefits package that includes health, life and disability benefits, a 401(k) with company contribution and match, and a variety of other benefits. In addition, employees are eligible for a generous time off package including vacation, personal days, holidays and other leaves.

Role Requirements

Division

DIV_IU

Business Unit

General Management

Location

LOC_US

Site

Remote Position (USA)

Company / Legal Entity

U014 (FCRS = US014) Novartis Pharmaceuticals Corporation

Functional Area

FCT_MM

Job Type

Full time

Employment Type

Regular

Shift Work

No

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