**Main Mission**

- Within the framework of the execution and monitoring of the European program "European Rare Diseases Research Alliance (ERDERA)" (link), funded through "Horizon Europe" HORIZONHLTH-2023-DISEASE-07 as a COFUND Action, we at *Inserm* are recruiting a Senior Scientific Project Manager for Rare Diseases for activities related to the Data Services Hub (Work Packages 13, 14, 15, and 16 of ERDERA) and the Expertise Services Hub (Work Packages 17, 18, and 19).

- This mission will be carried out within the ERDERA coordination team.
  - They will contribute to the implementation of the planned activities for research data management.
  - They will contribute to the implementation of the planned activities for providing scientific methodology expertise, regulatory expertise, and mentoring research projects.
  - They will propose the action schedule, prepare the required documents, and organize meetings.
  - They will support the teams, ensure coordination between different stakeholders, and guarantee the successful execution of activities.
  - They will provide necessary support to the leaders of various data management and expertise activities and initiatives.

**Main Activities**

- Organize activities in accordance with the ERDERA coordination team.
- Ensure the traceability of decisions (including, but not limited to, drafting meeting minutes and activity reports) and organize shared documents.
- Identify and monitor the execution of decisions until their completion.
- Participate in the preparation of periodic and final reports for the European Commission.
- Participate in organizing scientific conferences.
- Act as an interface between the various project partners and the European Commission.
- Monitor and evaluate the impact of the activities of the Data Services Hub and the Expertise Services Hub (using existing performance and impact indicators and developing new ones as needed).

- In the context of the Data Services Hub, provide support and contribute to the coordination of the following activities:
  - Development and maintenance of data infrastructures for the discovery, collection, storage, sharing, reuse, and analysis of rare disease research data (example: https://vp.ejprarediseases.org/).
  - Implementation of FAIR (Findable, Accessible, Interoperable, Reusable) principles for research data.
  - Identification of researchers' needs for data processing and development of suitable solutions.
  - Supervision of data integration from various sources, including clinical and genomic data.
  - Establishment of data security protocols to ensure the confidentiality and integrity of information.
  - Development and updating of documentation.
  - Organization of training sessions on best practices in data processing.
In the context of the Expertise Services Hub, provide support and contribute to the coordination of the following activities:

- Regulatory and methodological monitoring.
- Providing advice and responding to scientific, technical, and regulatory inquiries from researchers and project teams (for funded research and internally within the Clinical Research Network).
- Monitoring the development and correct application of innovative methods in research projects.
- Ensuring the compliance of research projects with regulatory requirements.
- Identifying research findings with potential for translation into clinical and therapeutic applications.
- Mentoring research projects, including consultation with international experts for translating research results.
- Developing and maintaining the knowledge base resulting from the above activities.

Monitor and keep track of the activities of related projects and networks (especially those listed in the Strategic Research and Innovation Agenda (link)).

Inform the ERDERA communications manager about communication and dissemination needs for activities and results.

Contribute to the establishment of standard operating procedures and the operation of the ERDERA Helpdesk.

You may be required to engage in other ERDERA actions, contribute to the cross-cutting activities of Inserm's Thematic Institute of Genetics, Genomics, and Bioinformatics, and tasks related to this position may evolve over time.

Occasional international travel is expected.

**Specificity and work environment**

**English environment:** bilingual or minimum C1 level in English (CEFRL)

**Numerous interactions:**
- **Internal:**
  - works under the responsibility of the Deputy Director of IT GGB and the ERDERA coordination delegates.
- **External:**
  - with national authorities (ministries, strategic institutions, etc.) of the EU 27, the European Commission, and program partners.

ERDERA offers a collaborative and dynamic work environment, bringing together internationally renowned experts in the field of rare diseases. Team members benefit from an innovative platform that promotes knowledge exchange and innovation. Working within ERDERA means engaging in projects with significant social impact while operating in an international framework with opportunities for collaboration with prestigious institutions, leading researchers, and patient organizations. The environment is enriched by a culture of mutual support, continuous professional development, and the use of cutting-edge technologies to achieve ambitious research and training goals.

**Knowledge**

- Knowledge of project management methods for complex projects.
- **IT Knowledge:**
  - Understanding of semantic and syntactic technologies and standards.
  - Understanding of ontologies and data and metadata models.
  - Understanding of IT architecture, particularly federated architectures.
- Knowledge of the institutional and political research environment, as well as national and international scientific and technical communities in the field.
- Regulatory knowledge in scientific research is a plus.
- Knowledge of research methodologies (preclinical and clinical) is a plus.

**Skills**

- Identify the goals and objectives of projects.
- Proficiency in computer tools (Excel, Word, PowerPoint, collaborative platforms like Microsoft Teams & SharePoint, Slack, generative AI tools, etc.).
  - Knowledge of data processing software and tools is a significant plus, for example:
    - Databases (SQL, MongoDB, etc.).
- Data management and analysis tools (R, Python with libraries such as Pandas, NumPy, SciPy, etc.).
- Data visualization tools (Power BI, Tableau, Matplotlib, or Seaborn for Python).
- Data environments and platforms (Jupyter Notebook, etc.).
- Version control and code management software (GitHub, etc.).
- Development and continuous integration tools (Docker, etc.).

- Establish various specifications.
- Plan the means for project realization and follow-up.
- Negotiate contracts with national and international service providers.
- Turn a request into a study problem and follow it through to resolution.
- Research and select strategic information.
- Evaluate the reliability and validity of sources and information.
- Conduct systematic reviews and write summary documents.
- Define the production and information processing procedures tailored to the needs of the concerned interlocutor and/or organization.
- Respect and/or enforce ethical and deontological principles related to the field.
- Explain the meaning of a policy, regulation, or given action to the actors concerned through written or oral communication actions.
- Master oral and written presentation techniques.
- Use various pedagogical methods to convey knowledge to diverse audiences.
- Be highly proficient in English (oral/written).
- Have excellent writing skills.
- Write educational support materials.

| Abilities | • Ability to work in a multicultural context with a variety of partners.  
• Be reactive and proactive.  
• Demonstrate rigor and organization.  
• Be autonomous, methodical, and organized.  
• Be a source of proposals.  
• Willingness for continuous improvement and skill acquisition that benefits the work and the team.  
• Strong analytical and synthesis skills.  
• Excellent writing skills.  
• Good interpersonal skills and team spirit.  
• Open-mindedness and diplomatic sense.  
• Good listening skills.  
• Ability to report effectively. |
|-----------|-----------------------------------------------------------------------------------|

| Desired Experience(s) | • Minimum of 3 years of experience required in managing European/international projects with an IT development component.  
• Experience in the research sector at the international level.  
• Experience in the field of rare disease research would be a plus. |
|------------------------|-----------------------------------------------------------------------------------------------|

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<th>Degree Level and Training(s)</th>
<th>• Master’s degree in science or a Doctorate in biology/health/medicine/pharmacy with additional training in data science.</th>
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### General Information

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<th>Start Date</th>
<th>01/09/2024</th>
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| Duration (Fixed-term contracts and secondments) | 12 months  
Renewable: ☑ YES ☐ NO |
| Working Hours | • Full-time  
• 38.5 hours per week  
• 45 days of Annual Leave and Time Off in Lieu (RTT) |
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<th><strong>Remote work</strong></th>
<th>☒ YES ☐ NO</th>
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**Salary**
- *Contractual employees:* Between 2 651.49 € and 3 949.21 € gross monthly depending on professional experience in positions of equivalent level.

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<th><strong>Application Procedures</strong></th>
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<td><strong>Application deadline</strong></td>
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| **Contractual employees** | • Send CV and cover letter to Daria JULKOWSKA ([recrutement@ejprarediseases.org](mailto:recrutement@ejprarediseases.org))  
  • Specify your salary expectations. |