

# RD-Connect

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## Research Areas



**Data-Sharing Enabler**

## At a Glance

- Status: **Active Consortium**
- Year Launched: **2013**
- Initiating Organization: **RD-Connect**
- Initiator Type: **Third-party organization**
- **Rare** disease
- Location: **Europe**

## Abstract

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RD-Connect is a unique global infrastructure project that links databases, registries, biobanks, and clinical bioinformatics data used in rare disease research into a central resource for researchers worldwide. In a six-year project funded by the European Union but uniting researchers across the world, it will develop an integrated research platform in which complete clinical profiles are combined with “-omics” data and sample availability for rare disease research, in particular research funded under the International Rare Diseases Research Consortium (IRDiRC).

## Mission

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RD-Connect’s primary objectives are as follows:

## Structure & Governance

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RD-Connect is led by coordinator Hanns Lochmüller of Newcastle University.

The project's Governing Board, consisting of one representative from each partner institution, is responsible for setting annual objectives and policy in accordance with the rules of the EC contract. The Governing Board provides legal and strategic oversight and ratifies any necessary changes to the consortium and workplan.

For operational management, the coordinator is supported by the Executive Management Committee and the coordination team in Newcastle.

## Patent Engagement

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The Patient Advisory Council (PAC) examines ethical, social, and participatory questions linked to research taking place in the context of RD-Connect, NeurOmics, and EURenOmics. This will ensure that all project activities have a patient-centric approach throughout. EURORDIS coordinates activities in respective projects with the PAC as well as invites its patient representatives to meetings and discussions.

Issues, concerns, or dilemmas brought forth by the PAC are addressed by the Rare Disease Patient and Ethics Council (RD-PEC) as well as all project partners. The PAC is composed of a multidisciplinary group of patients, parents, representatives of patients' organizations, clinicians, legal academics, sociologists, scientists, and ethicists.

## Data Sharing

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All data- and material-sharing agreements should be ethically robust and mindful of the responsibilities owed to the donors to make best ethical use of the samples and data consistent with their consent.

The international charter of principles for sharing biospecimens and data provides guidance for effective legally and ethically grounded sharing and can be found on the RD-Connect website.

The charter is inspired by the following principles:

## Links/Social Media Feed

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Twitter <https://twitter.com/ConnectRD>  
Homepage <http://rd-connect.eu/>

## Points of Contact

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RD-Connect Coordination Team  
Institute of Genetic Medicine  
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## Sponsors & Partners

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Aix-Marseille University Medical School  
Association Francaise contre les Myopathies  
Banco Nacional de ADN-University of Salamanca  
CARE4RARE  
Centro de Investigacion Biomedica En Red de Enfermedades  
Raras (CIBERER)  
Centro Nacional de Analisis Genomico  
Centro Nacional de Investigaciones Oncologicas  
Charles University  
Children's National Medical Center  
Consiglio Nazionale delle Ricerche  
EuroBioBank  
European Bioinformatics Institute  
European HD Network  
European Organisation for Rare Diseases

Finovatis  
Fondation maladies rares  
Fondazione Telethon  
Foundation for Research and Technology – Hellas  
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Glaxo SmithKline  
Innolyst, Inc. Patient Crossroads  
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Interactive Biosoftware  
Istituto Superiore di Sanita  
Karolinska Institutet  
Leiden University Medical Center  
LYSOGENE  
Medical University of Graz  
Murdoch University  
National Center for Neurology & Psychiatry  
National Institute of Environmental Health  
National Institutes of Health, Office of Rare Diseases Research  
NGRL Manchester  
Office of Population Health Genomics  
Orphan Europe Recordati Group  
Orphanet  
PhenoTips  
Telethon Network of Genetic Biobanks  
University Hospital of Ulm  
University Medical Center Groningen  
University of Aveiro  
University of Gottingen  
University of Leicester  
University of Malta  
University of Newcastle upon Tyne  
University of Paris Diderot – Paris 7  
University of Patras

University of Washington GeneReviews

University of Zurich

Uppsala University

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