

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

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

RD-Connect’s primary objectives are as follows:

Structure & Governance

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

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

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

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

Points of Contact

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Sponsors & Partners

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
Genzyme Europe BV
Glaxo SmithKline
Innolyst, Inc. Patient Crossroads
Institut d'Investigacions Biomediques August Pi I Sunyer
Institute of Molecular Genetics and Genetic Engineering
University of Belgrade
Instituto de Salud Carlos III
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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