RD Connect

An EU FP7 success story

RD-Connect is a global platform that facilitates research on rare diseases by connecting databases, patient registries, biobanks and clinical bioinformatics data into a central resource for researchers worldwide.

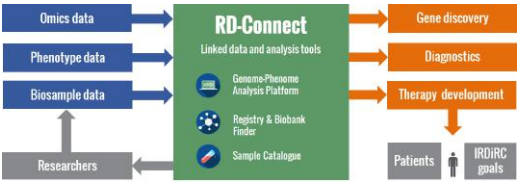
Although individually uncommon, rare diseases (RDs) collectively affect 6-8% of the population; around 30M people in the EU. RD research faces specific challenges. Since patients, clinical expertise and research communities are scarce and fragmented, data sharing between researchers is crucial.

To address this, the **European Commission** awarded a six-years (2012-2018) €12M FP7 grant to RD-Connect to create an integrated platform bringing together analysis tools and different types of data into a common resource for clinicians and researchers worldwide.

RD-Connect is also a flagship project of the ***International Rare Diseases Research Consortium (IRDiRC)*** implementing IRDiRC policies and guidelines on data sharing.

RD-Connect has built three integrated online systems open to any rare disease:

- **Genome-Phenome Analysis Platform (GPAP)** for analysis and sharing of omics data to diagnose patients and discover new disease genes
- **Registry & Biobank Finder,** a global directory of rare disease patient registries and biobanks
- **Sample Catalogue,** which helps researchers find rare biosamples stored in biobanks



In addition, RD-Connect has several clinical bioinformatic tools and developed solutions for linking data across resources.

RD-Connect ethical and legal experts developed guidelines for researchers and optimal models for data sharing, while the engagement of patients and patient representatives at every level of the project's work ensured patient-centred approach.

Funded by the European Union

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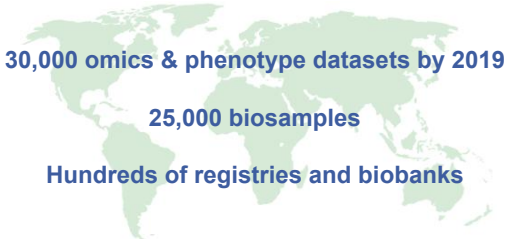
The main achievements

RD-Connect has built a unique RD community integrating various stakeholders, who otherwise would have limited opportunities to work together.



Genome-Phenome Analysis Platform was used as the primary analysis tool by the 17 projects funded in the 2016 ***BBMRI-LPC*** call and by the ***Solve-RD*** project to diagnose 19,000 unsolved cases from the European Reference Networks.

Registry & Biobank Finder includes hundreds of databases and covers over 2000 RDs.

Sample Catalogue already holds data on 25,000 samples from *EuroBioBank*, the RD-Connect's first *de facto* biobank. This number will increase.

The project has helped move the RD field forward by advancing research and data sharing.

Successful collaborations

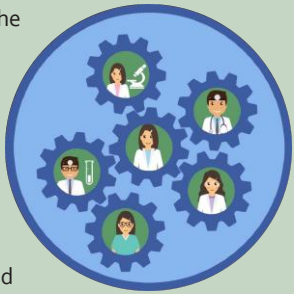
Collaboration with two EU research projects ***NeurOmics*** and ***EURenOmics*** helped to develop the RD-Connect tools and optimise them for the needs of RD researchers.

Collaboration with the **European Reference Networks** will ensure the impact of RD-Connect on improving RD patients' quality of life.

RD-Connect is embedded in the EU and international efforts, including **BBMRI**, **Elixir** and **IRDiRC**.

International recognition

The value of RD-Connect has been highlighted by the ***IRDiRC Recognized Resource*** label awarded to three project outputs: *The International Charter of principles for sharing bio-specimens and data* (2015), *Guidelines for the informed consent process* (2016), Genome-Phenome Analysis Platform (2018); and for the *FAIR Guiding Principles* (2017), which were developed with significant involvement of the RD-Connect partners.



The role of **data sharing** has been reflected in two major 2018 RD research calls by the German Federal Ministry of Education and Research and by *E-Rare*. Both mandate the use of infrastructure like RD-Connect for omics sharing and analysis.

Further information

If you have any further questions or would be interested in collaboration, please e-mail:

info@rd-connect.eu

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