

A European Partnership on Rare Diseases

2024-2031

What are European Partnerships?

European Partnerships bring the European Commission and private and/or public partners together to address some of Europe's most pressing challenges through concerted research and innovation initiatives.

Those partnerships are key **implementation tools of Horizon Europe**, and aim to contribute to achieving the EU's political priorities.

During the strategic planning of Horizon Europe, **rare diseases** were identified as one of the topics to be addressed as a Partnership.

One of the ultimate objectives of the EU Partnerships is to avoid the duplication of investments and contribute to reducing the fragmentation of the RD research and innovation landscape in the EU.

Different types and natures of EU Partnerships exist: co-funded, co-programmed, institutionalized.

The RD Partnership will fall under the **co-funded partnership scheme**. These are partnerships involving **EU countries, with research funders and other public authorities at the core of the consortium**.

Rare Disease Partnership Goal

The main goal of the RD partnership is to improve the life of patients living with a rare disease by developing diagnostics and treatments through multidisciplinary research and innovation programmes.

The RD partnership will coordinate national, local and European research and innovation programmes. It will combine research funding and implementation of research supportive activities such as training, data access infrastructures, data standards, etc.

RD Partnership development status

In Spring 2021, the Commission services asked potential partners to further elaborate proposals for the candidate European Partnerships (49) planned to be launched in 2023 and 2024. The RD Partnership itself is planned to be launched in 2024.

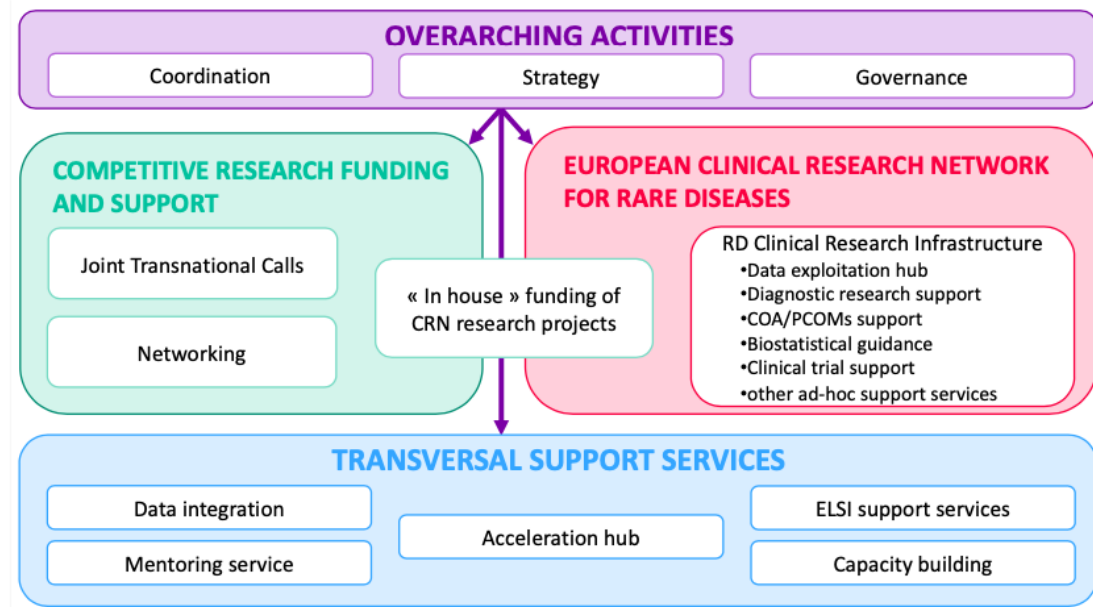
A Concept Paper has been developed by partners based on guidance and template received from the EC. This has been done considering the initial concepts developed by the Commission and also thanks to the feedbacks received from Member States during early consultation.

This draft is [released](#) to ensure transparency of information on the current status of preparation. It is an **informal document** that does not reflect the final views of the Commission, nor pre-empt the formal decision-making on the establishment of the RD Partnership.

In **March 2022**, calls are planned with EU Member States relevant organisations and agencies in order to ensure: i) that they are fully aware about the ongoing developments of the RD Partnership; ii) they can exchange on the RD Partnership concept and identify needs and strengths in view of their country participation; iii) they are best placed to decide and influence when their country will be consulted to commit to the RD Partnership in the next weeks.

By **30 April**, Member States must send a Letter of Commitment to the EC where they express their engagement to support the European Partnerships they wish to co-fund. The Commission will decide which Partnership to fund based on the EU countries that have expressed themselves favorably in support of them.

RD Partnership foreseen implementation



The RD Partnership implementation concept

RD Partnership Investment

Building upon the experience of the EJP RD co-fund where the EU (via Horizon 2020) and Member States jointly co-fund activities, the RD Partnership is primarily a co-fund where **EU public** (via Horizon Europe) and **national** (sometimes even regional) public Ministries/agencies jointly finance the activities. In addition, cooperation with private actors (NGOs, charities, industry etc.) might also be sought on specific aspects.

The RD Partnership's ambition will **only be possible with a strong political engagement and high investments from all stakeholders** (participating countries, public and private funders, European Commission).

An overview of the estimated costs of the Rare Diseases Partnership is summarized below.

- **Competitive research funding and support** (funding clinical research projects, collaborative research projects and networks): 349 300 000 €
- **European Clinical Research Network for Rare Diseases** (infrastructure supporting the Clinical Research Networks, national registries, data sources, data analysis and exploitation): 42 000 000 €
- **Transversal activities** (mentoring, data coordination, training, management, communication, ethics and legal support): 128 952 000 €
- **Governance and strategy** (National Mirror Groups, monitoring, sustainability, IRDiRC support, Governance and meetings): 16 763 800 €
- The overall estimated budget to reach the RD Partnership goal and ambition is **537 015 800 €**

With a limited budget, the RD Partnership will not be able to achieve its goals and ambition, and the proposed activities will merely focus on the funding of joint transnational calls with some limited support services.

More information

The full concept paper is available for anyone who would like to consult it: https://ec.europa.eu/info/sites/default/files/research_and_innovation/funding/documents/ec_rtd_he-partnerships-rare-diseases.pdf

Recommended to read ahead of our call: p.19 - p.32-35 - p.47-50.