



Towards an EU RD Partnership

CNA monthly call

03/03/2022

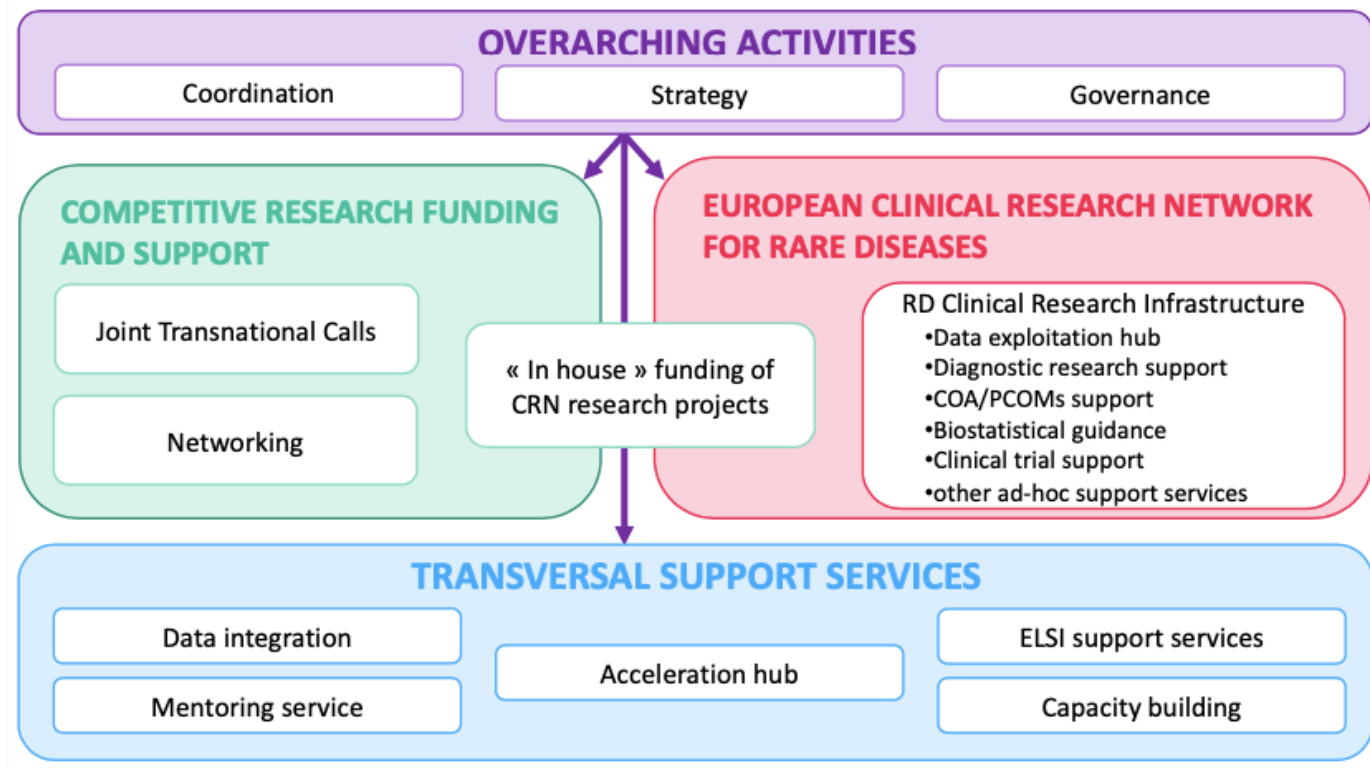
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A European Partnership for Rare Diseases

- EU Partnerships bring the EC **and** public and/or private partners together to address Europe's most pressing challenges
- **Concerted** research and innovation initiatives to **avoid duplication of investments and fragmentation** of research and innovation in the EU
- **Rare diseases** identified as one of the topics to be addressed as a Partnership
- Main goal of the RD partnership: improve the life of patients with a rare disease by:
 - Developing diagnostics and treatments through multidisciplinary research and innovation programmes
 - Coordinating national, local and European research and innovation programmes
 - Combining research funding and implementation of research supportive activities such as training, data access infrastructures, data standards, etc.
- Building upon EJP-RD
- To be launched in 2024

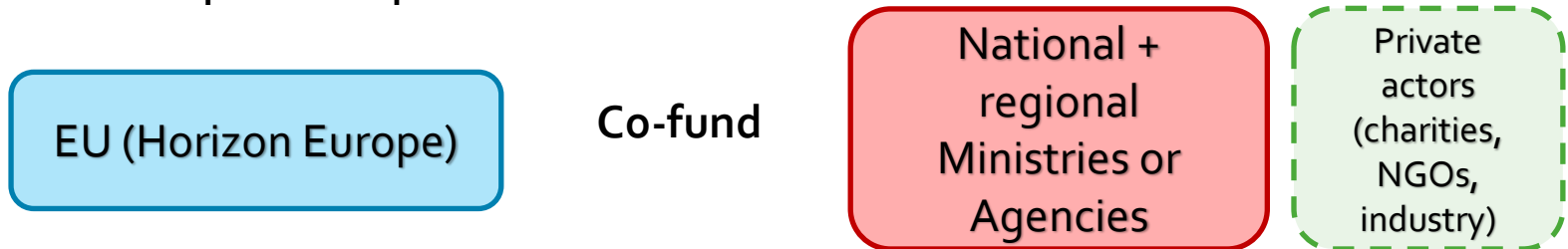
How the EU RD Partnership will work



The RD Partnership implementation concept

How the RD partnership will be funded

- Co-funded partnership scheme



- Overall estimated budget to reach the RD Partnership goal and ambition = **537 M€**
- **Competitive research funding and support = 350 M€**
- **European Clinical Research Network for Rare Diseases = 42 M€**
- **Transversal activities = 129 M€**
- **Governance and strategy = 16 M€**
- The RD Partnership's ambition will **only be possible with a strong political engagement and high investments from all stakeholders**

How can you help?

1) Help mobilise the national rare disease community and research contacts for the national meetings in March

EJP RD management team has already contacted their national reference and some meetings are being set up ...but it is not enough ! They are not sure to have contacted *all* the key stakeholders !

- Share contacts of key stakeholders with the EJP RD management (via EURORDIS) so that they can invite them to the March meetings
- Join the meetings: patients are key stakeholders !

2) Reach out to your Ministry/Research National Agency or the decision makers in your country!

- EURORDIS will draft a template letter
- Translate and adapt as you see fit and send! EURORDIS can co-sign if you wish



Thank you !

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