

DRIVING GROWTH 

European Partnership on Rare Diseases

18 January 2023

HE Work Programme 2023-2024
National Info Day

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RESEARCH
& INNOVATION
FOUNDATION



CLUSTER 1: Health	CLUSTER 4: Digital, Industry & Space	CLUSTER 5: Climate, Energy & Mobility	CLUSTER 6: Food, Bioeconomy, Agriculture,...
Innovative Health Initiative	Key Digital Technologies	Clean Hydrogen	Circular Bio-based Europe
Global Health Partnership	Smart Networks & Services	Clean Aviation	Rescuing Biodiversity to Safeguard Life on Earth
Transforming Health Care Systems	High Performance Computing	Single European Sky ATM Research 3	Climate Neutral, Sustainable and Productive Blue Economy
Risk Assessment of Chemicals	European Metrology (Art. 185 of the TFEU)	Europe's Rail	Water4All "Water security for the planet"
ERA for Health	Artificial Intelligence, Data and Robotics	Cooperative, Connected and Automated Mobility (CCAM)	Animal Health and Welfare*
Rare Diseases*	Photonics	Batteries "Towards a competitive European industrial battery value chain"	Agroecology "Accelerating Farming Systems Transition"
One Health / Antimicrobial Resistance*	Made in Europe	Zero-emission Waterborne Transport	Agriculture of Data*
Personalised Medicine*	Clean Steel - Low Carbon Steelmaking	Zero-emission Road Transport (2ZERO)	Safe and Sustainable Food Systems*
Pandemic Preparedness* <i>Co-funded or co-programmed</i>	Processes4Planet	People-centric Sustainable Built Environment (Built4People)	
	Globally Competitive Space Systems**	Clean Energy Transition	
		Driving Urban Transitions to a Sustainable Future	

■ Institutionalised Partnerships (Art 185 or 187 of the TFEU)

■ Co-Programmed

■ Co-Funded

* Calls with opening dates in 2023-24

** Calls with opening dates not before 2022



► Rare Diseases Partnership - Overview

31 countries in this group: **EC group of National Delegates for the RD Partnership**

- **24 EU MS + 2 EEA countries** : EU Member States (AT, BE, BG, CY, CZ, DE, DK, EE, EL, ES, FR, IE, IT, LT, LU, LV, MT, NL, PL, PT, SE, SI, SK, RO) + EEA (NO and IS);
- Associated countries: Israel, Turkey, Georgia,
- Candidate Associated countries: Morocco, UK

Not yet on board but possibly interested:

- Other countries having expressed in the Partnership: North Macedonia, Tunisia
- Also interested: Canada, Australia?

HORIZON-HLTH-2023-DISEASE-07-01:
European Partnership on Rare Diseases

19 Sep 2023

Type of partnership	Co-funded
CY contribution for 2024	€3.000.000
Joint Call announcement	2024

What does the Commission expect regarding the RD Partnership? (presented on 10 Oct. 2022)

- Impact-driven;
- Improve the lives of people living with a rare disease by delivering on their unmet medical needs;
- Coordinate of national and regional research and innovation programmes on rare diseases & mobilise funds from Member States, regions, associated countries and the Commission;
- Align research and innovation priorities to overcome fragmentation, avoid duplication but enhance synergies within of the R&I landscape, through a multi-stakeholder approach;
- Consolidate an effective and inclusive research and innovation ecosystem;
- Strengthen the pipeline 'from bench to bedside' of publicly-funded research;
- Strengthen the EU-leadership;
- Contribute to IRDiRC's goals

What does the Commission expect regarding policy priorities? (presented on 10 Oct. 2022)

- Develop close synergies with national and regional programmes;
- Develop synergies with other Union's programmes:
 - EU4Health,
 - European Regional Development Fund (ERDF)
 - ...
- Contribute to the Pharmaceutical Strategy (in particular to the Regulation on Orphan medicinal products);
- Contribute to the EU's digital agenda

▶ MAIN OBJECTIVES (WP 2023-2024)

- Launch joint transnational calls for RD research and innovation priorities as defined in the SRIA, resulting in financial support to third parties, based on the annual work plans;
- Develop a European Clinical Research Network to accelerate the clinical trial readiness of the RD research community in Europe, to improve the research and innovation potential of RD stakeholders and facilitate the cost-effective clinical development of new therapies;
- Develop and consolidate the capacity building of the RD data ecosystem by supporting the federated access/sharing of FAIR research data, information resources to ensure the effective and fast translation of the research results to safe and effective health innovations;

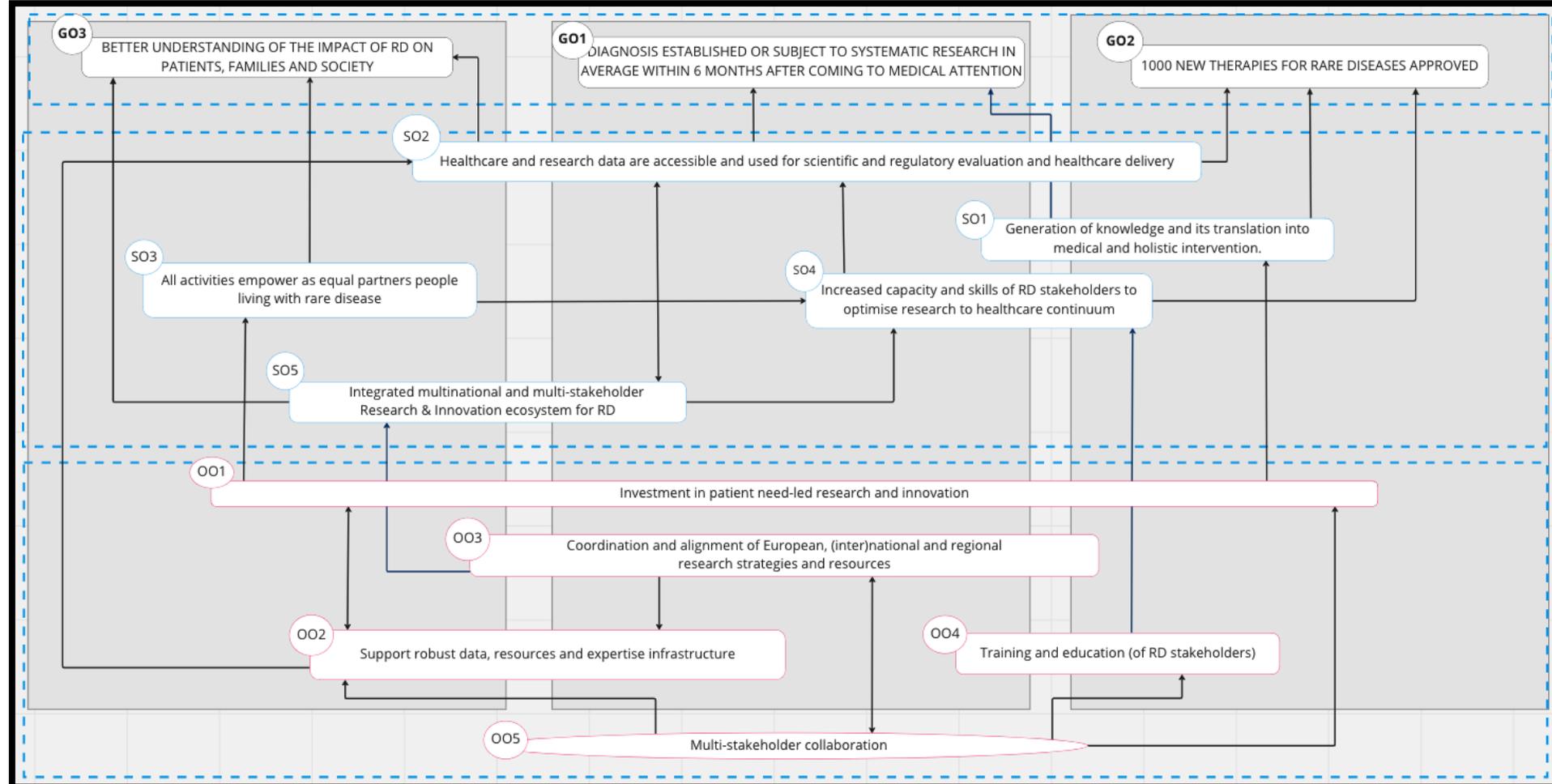
▶ **MAIN OBJECTIVES (WP 2023-2024)**

- Integrate basic, pre-clinical and clinical research to reduce the burden for people living with a rare disease.
- Support research in relevant medical fields and intervention areas (prevention, diagnosis, treatment), while improving the utilisation of existing health technologies in clinical practice;
- Support the scientific work of the International Rare Disease Research Consortium.

▶ EP RD proposed VISION

*“To improve the health and well-being of 30 million persons living with a rare disease in Europe, **by making Europe a world leader in RD research and innovation,** and delivering concrete health benefits to rare disease patients, through better prevention, diagnosis and treatment”*

Strategic Research & Innovation Agenda



Work in progress...

► Strategic Research & Innovation Agenda

General Objectives

- GO1 - Diagnosis established or subject to systematic research in average within 6 months after coming to medical attention
- GO2 - 1000 new therapies for Rare Diseases approved
- GO3 - Better understanding of the impact of RD on patients, families and society

► Strategic Research & Innovation Agenda

Operational Objectives

- OO1 - Investment in patient need-led research and innovation
- OO2 - Support robust data, resources and expertise infrastructure
- OO3 - Coordination and alignment of European, national and regional research strategies and resources
- OO4 - Training and education (of RD stakeholders)
- OO5 - Multi-stakeholder collaboration

► Strategic Research & Innovation Agenda

Specific Objectives

- SO1 - Generation of knowledge and its translation into medical and holistic intervention
- SO2 - Healthcare and research data are accessible and used for scientific and regulatory evaluation and healthcare delivery
- SO3 - All activities empower as equal partners people living with rare disease
- SO4 - Increased capacity and skills of RD stakeholders to optimize research to healthcare continuum
- SO5 - Integrated multi-national and multi-stakeholder Research and Innovation ecosystem for RD

▶ Thank you!

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