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Horizon 2020 Work Programme for Research & Innovation 2018-2020

Rare Disease European Joint Programme Cofund

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European Commission

Research and Innovation

Rare diseases activities at EU level

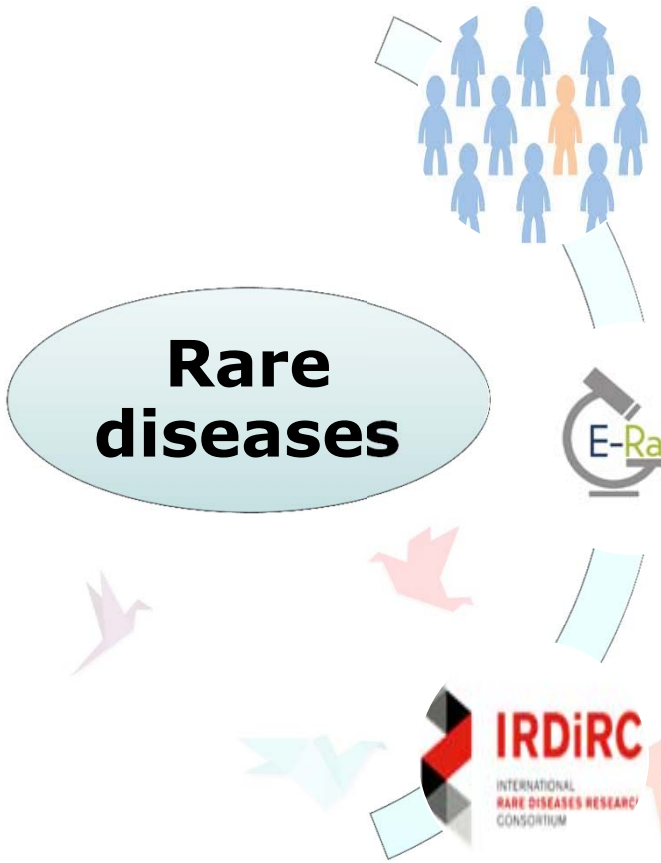
Research and Innovation

Coordination of research

National plans, information, codification, patient registries, access to best care and knowledge

EU funded rare diseases research

Research priorities



R&I funding

Linking major EU and national initiatives

International coordination: IRDIRC

Research Results

Close to € 900 million in more than 160 projects in FP7 and H2020 on: pathophysiology, natural history, delivered new diagnostics and therapies

E-RARE: research funders collaboration: more than € 90 million in more than 100 projects

IRDIRC: 200 new therapies and means to diagnose most rare diseases achieved in 2017: >50 international partners, policies and guidelines to implement goals

E-Rare-3: beyond Europe

28 partners in 20 countries

- ANR (France) – Coordination
- AKA (Finland)
- ASSR (Italy)
- CIHR (Canada)
- CSO/MOH (Israel)
- DLR/BMBF (Germany)
- DFG (Germany)
- FCT (Portugal)
- FNRS (Belgium)
- FWO (Belgium)
- FRQS (Canada-Quebec)
- FFG (Austria)
- FWF (Austria)
- GSRT (Greece)
- Genome Canada (Canada)
- ISCIII (Spain)
- ISS (Italy)
- IT MoH (Italy)
- MEYS (Czech Republic)
- NKFIH (Hungary)
- NCBR (Poland)
- RCL (Lithuania)
- SNSF (Switzerland)
- TUBITAK (Turkey)
- TRI (Japan)
- UEFISCDI (Romania)
- VIAA (Latvia)
- ZonMw (Netherlands)

IRDiRC

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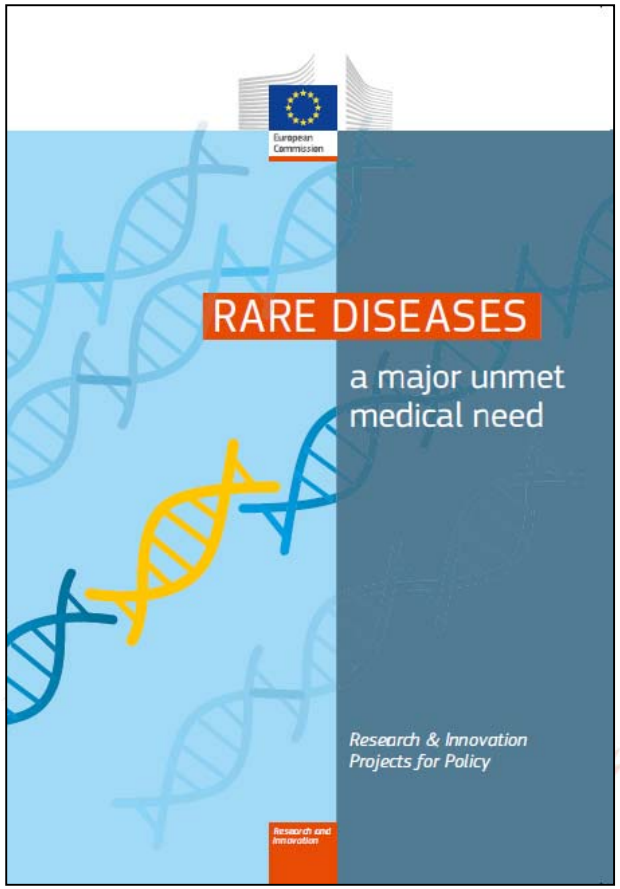
www.erare.eu

Projects for Policy (P4P) Report on Rare Diseases



CURRENT POLICY CHALLENGES

PORTFOLIO OF EU-FUNDED PROJECTS

IMPACT AND RESULTS OF EU FUNDING

POLICY RECOMMENDATIONS

https://ec.europa.eu/info/research-and-innovation/p4p_en

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Need for a coherent strategy – from bench to bedside

- More efficiently bring the results of research and innovation to the patient
- Programme to implement a research and innovation pipeline, from bench to bedside
- Integrative programme linking major EU and national initiatives – R&D, research infrastructures, registries
- **Bridging** to ERNs to help implementing research results and taking lessons learned from the clinic back to the bench

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Rare Disease European Joint Programme Cofund (SC1-BHC-04-2018) **Scope**

- Create research and innovation pipeline "from bench to bedside" ensuring rapid translation of research results into clinical applications and uptake in healthcare for the benefit of patients.
- Follow the policies and contribute to objectives of IRDiRC.
- Improve integration, efficacy, production and social impact of RD research through development and promotion of sharing of research and clinical data, knowledge and materials.
- Implement and further develop an efficient model of financial support for RD research including basic, clinical, epidemiological, social, economic and health service research.

Please check full topic text against published Work Programme

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Rare Disease European Joint Programme Cofund (SC1-BHC-04-2018)

Scope continued

Implement joint programme of activities including research, coordination, networking, training, demonstration and dissemination:

- Research and innovation programme encompassing various aspects of RD research to be funded through transnational calls resulting in financial support to third parties based on practices from ERA-NETs.
- Virtual platform for RD information, research data, samples, tools and standards building on existing resources; establish new connections across RD community in particular with ERNs; launch pilot actions to ensure usefulness of tools to be followed by upscaling in progressive manner.
- Capacity building including training and support activities to improve R&I potential of key stakeholders and enhance uptake of research results.
- Strategic coordination and management through annual programming. Appropriate considerations of ELSI aspects. Integration of the IRDiRC Secretariat.
- Participation of patient organisations should be encouraged in relevant activities.

Please check full topic text against published Work Programme

Rare Disease European Joint Programme Cofund (SC1-BHC-04-2018)

Expected Impact

- Improve lives of rare disease patients by providing new and optimised treatment options and diagnostic tools for these diseases.
- Decrease fragmentation of rare diseases expertise and research resources.
- Increase the EU's capacity to innovate in the field of rare diseases.
- Improve healthcare systems' capacity to take up research results.
- Reinforce the EU's role as a global leader for rare diseases.

Type of Action: COFUND (European Joint Programme)

Indicative EU contribution: € 50-55 million

Deadline: 18 April 2018

Please check full topic text against published Work Programme

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EJP Cofund – Eligibility and funding

Minimum five independent legal entities from different Member States or Associated Countries owning or managing national research and innovation programmes:

- **Programme owners**, typically national ministries/regional authorities responsible for defining, financing or managing programmes carried out at national or regional level.
- **Programme 'managers'** (such as research councils, funding agencies or governmental research performing organisations) or other entities that implement national or regional research and innovation programmes under the mandate of the programme owners.
- In addition to the minimum conditions, **other legal entities may participate if justified by the nature of the action**, in particular entities created to coordinate or integrate transnational research efforts, grouping funding from both national and private sources.
- **Funding**: The Horizon 2020 contribution will be limited to 70% of the total eligible costs of the action

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EJP Cofund on rare diseases - Timelines

October 19th 2016	Exploratory Meeting with MS
April 25th 2017	Workshop in Brussels with MS and experts
October 17th 2017	Funders' Meeting on EJP Cofund
November 7th 2017	Opening of call including EJP Cofund topic
April 18th 2018	Deadline for proposal submission
Q3-Q4 2018	Outcome of evaluation, grant preparation

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Thank you!

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Participant Portal www

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