



## European Joint Programme on Rare Diseases (EJP RD)

### Call for Proposals 2021

**"Social sciences and Humanities Research to improve health care implementation and everyday life of people living with a rare disease"**

### Early Announcement

**The content and procedures of the call described in this early announcement may be subject to change and are not legally binding.**

The **European Joint Programme on Rare Diseases (EJP RD)** has been established to help in coordinating the research efforts of European, Associated and non-European countries in the field of rare diseases and implement the objectives of the International Rare Disease Research Consortium (IRDiRC). Since 2019 it continues the funding effort of ERA-Net E-Rare that has successfully implemented ten Joint Transnational Calls for rare disease research projects between 2006 and 2018.

After the successful implementation of two **Joint Transnational Calls (JTCs 2019 and 2020)** focusing on basic and preclinical research, this year EJP RD fosters research projects on **Social Sciences and Humanities (SSH)** which are of major importance to better understand and improve healthcare implementation and everyday life of people living with a rare disease.



The following list of health-related Social sciences and Humanities (SSH) disciplines is used for definition (taken from the European Commission (EC) that was adapted from the UNESCO International Standard Classification of Education (ISCED 2011)):

- **Social sciences, business and law**
  - **Social and behavioural sciences:** economics, management, sociology, anthropology, demography, geography, psychology, neuropsychology, cognitive science, human rights, law, political sciences, communication, and social studies of science and technology.
  - **Education science:** educational research
  - **Governance:** public and institutional administration, social and health economic and systems, policy, and social policy
- **Humanities and the arts**
  - **Humanities:** cultural studies, linguistics, philosophy, ethics, and history.

## 1. AIM OF THE CALL

The general aim of the call is to enable scientists in different countries to build an effective collaboration on a common interdisciplinary research project based on complementarities and sharing of expertise, with a clear future benefit for patients.

**Topic: Social sciences and Humanities (SSH) Research to improve health care implementation and everyday life of people living with a rare disease**

**Transnational research proposals must cover at least one of the following areas, which are equal in relevance for this call:**

- ❖ **Health & social care services** research to improve patient and familial/household health outcomes
- ❖ **Economic Impact of Rare diseases**
- ❖ **Psychological and Social Impact of Rare diseases**
- ❖ Studies addressing the **impact/burden of the delay in diagnosis and of the lack of therapeutic intervention.**
- ❖ **e-Health in rare diseases:** Use of innovative technology systems for care practices in health and social services
- ❖ Development and enhancement of **health outcomes research methods** in rare diseases
- ❖ Effects of **pandemic crisis** and the **global outbreak alert** and response on the rare disease field, and the emergence of innovative care pathways in this regard.



Other research topics are possible as long as they focus on SSH research and are not in the excluded topics list.

**The following approaches and topics are excluded from the scope of the call:**

- a. Interventional clinical trials to prove efficacy of drugs, treatments, surgical procedures, medical technology procedures. This also includes studies comparing efficacy, e.g. B. two surgical techniques or therapies. Clinical phase IV pharmacovigilance studies cannot be funded either.
- b. Studies on the exclusive testing of the safety of medical devices.
- c. Health technology assessment reports (HTA) for a specific product
- d. Projects focussing on meta-analyses and systematic reviews
- e. Creation of new registers or establishment of new long-term cohorts and / or promotion of existing registers or long-term cohorts.
- f. Development of new digital or technological tools.
- g. Projects to accelerate diagnosis and/or explore disease progression and mechanisms of rare diseases as covered in [EJP RD JTC 2019](#).
- h. Development of new therapies as covered in [EJP RD JTC 2020](#).
- i. Projects focussing only on rare neurodegenerative diseases which are within the main focus of the Joint Programming Initiative on Neurodegenerative Disease Research (JPND; <http://www.neurodegenerationresearch.eu/>). These are: Alzheimer's disease and other dementias; Parkinson's disease (PD) and PD-related disorders; Prion disease; Motor Neuron Diseases; Huntington's disease; Spinal Muscular Atrophy and dominant forms of Spinocerebellar Ataxia. Interested researchers should refer to the relevant JPND calls.
- j. Rare infectious diseases, rare cancers and rare adverse drug events in treatments of common diseases.

## Consortium Makeup

Projects shall involve **a group of rare diseases or a single rare disease following the European definition** i.e. a disease affecting not more than **five in 10.000 persons** in the European Community, EC associated states and Canada.

**Consortia need to include clinical expertise and SSH expertise in their proposals. Partnering different groups, from different structures will allow a broader understanding of the cost of care, optimal care, and ultimately benefit patients.**

**Moreover, patient involvement is strongly encouraged for patient-centred successful applications.**

**The maximum duration of the project is three years.**

Only transnational projects will be funded. Each consortium submitting a proposal must involve at least **three** principal investigator partners from at least three different countries that are joining this Call JTC 2021. **No more than two eligible partners from the same country can be present in each consortium** (further national limits may apply).



### 3. PRELIMINARY TIMETABLE

There will be a **two-stage submission procedure** for joint applications: pre-proposals and full proposals. The call is scheduled to open in December, with a pre-proposal submission deadline in February.

Further information and the official publication of the call will soon be available on the website of the EJP RD

<http://www.ejprarediseases.org>

For general questions regarding the joint call please contact the Joint Call Secretariat at the FFRD, France:

E-Mail:

[JTC2021@ejprarediseases.org](mailto:JTC2021@ejprarediseases.org)

or individually:

Diana Désir-Parseille

[diana.desir-parseille@fondation-maladiesrares.com](mailto:diana.desir-parseille@fondation-maladiesrares.com)

+33 (0) 1 58 14 22 81

Laura Benkemoun

[laura.benkemoun@fondation-maladiesrares.com](mailto:laura.benkemoun@fondation-maladiesrares.com)

**The content and procedures of the call described in this early announcement may be subject to change and are not legally binding.**