

## E-Rare-3 Call for Proposals 2018 for

**"Transnational research projects on hypothesis-driven use of multi-omic integrated approaches for discovery of diseases causes and/or functional validation in the context of rare diseases."**

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### Call text

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**submission deadline for pre-proposals: February 6, 2018**

**Submission deadline for full proposals: June 19, 2018**

The links to pre-proposal template, electronic proposal submission, guidelines for applicants and further information including "Looking for collaborations module" and Interactive FAQ can be found at the E-Rare website

[www.e-rare.eu](http://www.e-rare.eu)

or contact the Joint Call Secretariat at ZonMw, The Netherlands:

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## 1. MOTIVATION

There are at least 7000 distinct rare diseases, the great majority being of genetic origin. Although individually rare, taken together rare diseases affect at least 26-30 million people in Europe. Moreover, they represent a major issue in health care: a large number of these diseases have an early or very early onset and/or lead to a significant decrease of life expectancy. Moreover, most of them cause chronic illnesses with a large impact on quality of life and the health care system.

Therefore, research on rare diseases is needed to provide knowledge for prevention, diagnosis and better care of patients. Yet, research is hampered by lack of resources at several levels: (1) Few scientists work on any given specific disease, (2) There are few patients per disease and they are scattered over large geographic areas, causing difficulties to assemble the necessary cohorts, (3) Existing databases and bio-material collections are usually local, small, and not accessible or standardised, (4) The complex clinical phenotypes of these diseases require interdisciplinary cooperation to improve research and treatment.

The specificities of rare diseases - limited number of patients, scarcity of relevant knowledge and expertise, and fragmentation of research - single them out as a distinctive domain of very high European added-value. Rare diseases are therefore a prime example of a research area that necessitates collaboration/coordination on a transnational scale.

In this context, the ERA-NET “E-Rare” for research programmes on rare diseases has been extended to a third phase “E-Rare-3” (2014-2019) to further 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).

The following funding organisations:

- Austrian Science Fund (FWF), Austria
- Research Foundation Flanders (FWO), Belgium, Flanders
- Fund for Scientific Research - FNRS (F.R.S.-FNRS), Belgium, French-speaking community
- Canadian Institutes of Health Research – Institute of Genetics (CIHR-IG), Canada
- Fonds de recherche du Québec-Santé (FRQS), Québec (Canada)
- Ministry of Education, Youth and Sports (MEYS), Czech Republic
- Academy of Finland (AKA), Finland
- French National Research Agency (ANR), France
- Federal Ministry of Education and Research (BMBF), Germany
- German Research Foundation (DFG), Germany
- General Secretariat for Research and Technology (GSRT), Greece
- National Research, Development and Innovation Office (NKFIH), Hungary
- Chief Scientist Office of the Ministry of Health (CSO-MOH), Israel
- Italian Ministry of Health (MoH-IT), Italy
- State Education Development Agency (VIAA), Latvia
- National Centre for Research and Development (NCBR), Poland
- Executive Agency for Higher Education, Research, Development and Innovation Funding (UEFISCDI), Romania
- National Institute of Health Carlos III (ISCIII), Spain
- Swiss National Science Foundation (SNSF), Switzerland
- Netherlands Organization for Health Research and Development (ZonMw), The Netherlands
- The Scientific and Technological Research Council of Turkey (TUBITAK), Turkey

have decided to open the **tenth E-Rare Joint Transnational Call (JTC 2018)** for funding multilateral research projects on rare diseases. The call is being opened simultaneously by the above mentioned funding organisations in their respective countries.

In addition, Patient Organisations (PO) - represented in this call mostly by EURORDIS - may also co-fund selected projects based on their mandate and research topic interest (see section 6.3 for details).

## 2. AIM OF THE CALL

The 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 translational research approach.

**Topics: The research projects have to focus on hypothesis-driven use of multi-omic integrated approaches for discovery of disease causes and/or on functional validation in the context of rare diseases.**

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

- a. Combined multi-omics approaches (e.g. epigenomics, transcriptomics, metabolomics, proteomics, etc.) that complement genomics-based gene discovery strategies and that are driven by a lead hypothesis. These multi-omics approaches should extend beyond descriptive “-omics” data gathering, such as simple whole exome/genome sequencing for disease gene discovery. For transcriptomic and proteomic data, a strong rationale for physiological relevance of the collected sample/tissue/dataset must be available;
- b. Functional validation of clinical or biological inferences obtained from “-omics” results, e.g. by
  - developing new computational, statistical and experimental methods for analysis and interpretation of existing multi-omic datasets or for the identification of relevant biomarkers;
  - integrating the already obtained “-omics” results to generate and test new biological models;
- c. Application of “-omics” approaches to rare diseases for which the gene(s) is/are known to enable insight into disease pathophysiology. Emphasis will be given to approaches that transcend a single “-omics” approach to illuminate pathomechanism. Projects that generate “-omics” data with limited integration and interpretation will be considered lower priority;
- d. Development and application of concepts and methods for pathogenic read-outs of disease groups which can be used as “blue print” to discover new disease genes and inform pathomechanism. Projects on “simple” or “pure” gene hunts will be discouraged if they can be rationally performed at a single institution or by existing international resource centers, with the exception of studies that inform fundamentally new genetic paradigms.

Furthermore, additional elements must be taken care of in the application:

- Proposed projects should rest on an excellent lead hypothesis for the intended activities;
- Proposed projects that focus only on data sets from genomic approaches (e.g. exome/genome sequencing of a cohort) will have low priority;

- Proposed projects *have to* show multi-dimensional approaches and strong knowledge of interpretation of such data, ideally combining rigorous statistical methods with biological/experimental verification;
- A core set of “-omics” results should already be present; and serve as a justification to perform other “-omics” experiments;
- The design of the study (sample collection, statistical power, interpretation, relevant models for hypothesis validation) must be well justified and should be part of the proposal;
- Appropriate bioinformatics and statistical skills should constitute, whenever justified, an integral part of the proposal;
- The new research data resulting from the project should be treated permissible according to the FAIR<sup>1</sup> principles, and deposited and shared, according to the national rules of the countries involved. It is strongly advised to make data accessible through RD-Connect (<http://rd-connect.eu/> - connecting databases, patient registries, biobanks and clinical bioinformatics data into a central resource for researchers worldwide) and through Elixir (<https://www.elixir-europe.org/platforms/data/elixir-deposition-databases> - compiling a list of resources for the deposition of experimental, biomolecular data). To make research data findable, accessible, interoperable and re-usable (FAIR), a data management strategy for the proposed full project is mandatory in the full proposal stage. Some countries involved in E-Rare JTC 2018 will also ask for a data management plan (DMP) at national level at the stage of full proposal or after granting of the project.

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

- a. Approaches concerning rare infectious diseases or rare cancers;
- b. Approaches concerning rare adverse drug events/medical complications in treatments of common diseases;
- c. Interventional clinical trials.

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 10000 persons in the European Community, EC associated states and Canada.

**The research projects submitted within this call must be based on novel ideas stemming from consolidated previous results and must be clearly endowed with a strong translational research orientation**, i.e. studies allowing a rapid implementation into public health-related decisions or into the clinics. To achieve this goal, the necessary expertise and resources should be brought together from academia, clinical/public health sector and private companies. The research teams within a consortium should include investigators from all scientific disciplines, research areas and expertise necessary to achieve the proposed objectives.

The research proposals must demonstrate complementary and synergistic interaction among the partner teams. There should be clear added value in the transnational collaboration over the individual projects, in terms of:

- i) Gathering a critical mass of subjects/patients and or subjects/patients databases and corresponding biological materials that would not be possible otherwise;

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<sup>1</sup> FAIR: Findable, Accessible, Interoperable, Reusable (for more information: see “The FAIR Guiding Principles for scientific data management and stewardship” (<https://www.nature.com/articles/sdata201618>))

- ii) Sharing of resources (biobanks, models, databases, diagnostic tools, etc.), of specific know-how and/or innovative technologies including “-omics”, and of expertise. The projects should clearly demonstrate the potential health impact.

The use of **existing European health research infrastructures** and/or **IRDiRC recognized resources** is strongly encouraged when appropriate, e.g. research infrastructures established as an European Research Infrastructure Consortium (ERIC) or identified on the roadmap of the European Strategy Forum on Research Infrastructures (ESFRI). Projects are invited to identify the existing European research data infrastructures that may be used and how these may be mobilised, in particular for long-term data curation and preservation (in accordance with EU and IRDiRC recommendations ([www.irdirc.org](http://www.irdirc.org))).

The following ESFRI European Research Infrastructures and European/international projects were identified as potentially useful for this kind of studies:

- Biobanking and Biomolecular Resources Research Infrastructure (BBMRI) - <http://bbmri-eric.eu/about>
- The European Life Sciences Infrastructure for Biological Information (ELIXIR) - <http://www.elixir-europe.org/>
- European Infrastructure for Phenotyping, Archiving and Distribution of Mouse Models (INFRAFRONTIER) - <https://www.infrafrontier.eu/>
- Integrated Structural Biology Infrastructure for Europe (INSTRUCT) - <http://www.structuralbiology.eu/>
- An integrated platform connecting databases, registries, biobanks and clinical bioinformatics for rare disease research (RD-Connect) - <http://rd-connect.eu/>
- IRDiRC recognized resources - <http://www.irdirc.org/activities/irdirc-recognized-resources/>
- Horizon 2020 FAIR Data Management Plan - Annex 1 in [http://ec.europa.eu/research/participants/data/ref/h2020/grants\\_manual/hi/oa\\_pilot/h2020-hi-oa-data-mgt\\_en.pdf](http://ec.europa.eu/research/participants/data/ref/h2020/grants_manual/hi/oa_pilot/h2020-hi-oa-data-mgt_en.pdf)

The aim of the call is in compliance with the goals set by the International Rare Diseases Research Consortium (IRDiRC) which fosters international collaboration in rare diseases research. For more information see IRDiRC website: <http://www.irdirc.org/>

### 3. MANAGEMENT BOARDS

Two boards, the Call Steering Committee (**CSC**) and the Scientific Evaluation Committee (**SEC**), will manage the evaluation process of the call with support of the Joint Call Secretariat (**JCS**) (set up at ZonMw, The Netherlands). SEC and CSC members will not submit or participate in proposals within this call. The process includes the evaluation procedure of pre- and full-proposals and the final selection and award of research projects.

- **The Call Steering Committee (CSC)** is composed of a single representative from each country/region funding organisation. The CSC will supervise the progress of the call and the evaluation of proposals. The CSC will make the final funding recommendation to the national/regional funding organisations on the proposals to be funded, based on the final ranking list provided by the SEC. All decisions concerning the call procedures will be taken by the CSC.
- **The Scientific Evaluation Committee (SEC)** is a panel of internationally recognised scientific experts responsible for the evaluation of submitted proposals. SEC members must sign a confidentiality form and a statement to confirm that they do not have any conflicts of interest.

## 4. APPLICATION

### 4.1. Funding recipients/Eligibility

Joint research proposals may be submitted by applicants belonging to one of the following categories (according to country/regional regulations):

- academia (research teams working in universities, other higher education institutions or research institutes)
- clinical/public health sector (research teams working in hospitals/public health and/or other health care settings and health organisations)
- enterprise (all sizes of private companies). Participation of small and medium-size enterprises (SMEs) is encouraged when allowed by national/regional regulations

➤ Please note that the inclusion of a non-eligible partner in a proposal **leads to the rejection of the entire proposal without further review**. Whilst applications will be submitted jointly by research partners from several countries, individual groups will be funded by the individual funding organisation of their country/region that is participating in the E-Rare-3 JTC 2018. The applications are therefore subjected to **eligibility criteria of individual funding organisations**. Applicants are **strongly advised** to contact their corresponding national/regional representative and confirm eligibility with their respective funding organisations in advance of submitting an application (see national/regional contact details and Annex). **The adherence to the national/regional regulations in the “Guidelines for applicants” document is mandatory.**

Only transnational projects will be funded. Each consortium submitting a proposal must involve a **minimum of three eligible** and a **maximum of six eligible partners** from **at least three different countries** participating to the call (see list above). No more than two eligible partners from the same country participating in the call will be accepted in one consortium.

The Joint Call Secretariat and national/regional funding organisations will perform cross-checks in parallel submissions to other joint transnational calls (e.g. NEURON, JPND, EuroNanoMed, ERA PerMed and others) and national calls. Applicants shall avoid applying for same research activities to different calls. Double funding is not allowed.

**The consortium coordinator must always be eligible to receive funding from the funding organisations participating in the call.**

Only groups that contribute substantially to at least one of the work packages are considered as partners and should be indicated in the project.

Applicants are encouraged to **include partners from the participating underrepresented countries** (Czech Republic, Hungary, Latvia, Poland, Romania and Turkey). If they include such partners, the maximum number of partners can be increased to **eight** (see tables below).

To collect the necessary patient data and/or samples for the proposed study, a consortium may need to collaborate with other centres. If the unique role of those centres is providing patients data and/or samples for the study only, they will not be considered as partners of the consortium but can be included otherwise, e.g. via cooperation agreements or subcontracting.

Additional partners that secure their **own funding** may join consortia. However, their number is **limited to two**. They must state clearly in the proposal if these funds are already secured or if not, how they plan to obtain funding in advance of the project start, as well as what the



concrete amount of contributed funding will be. It will be required to document the availability of their funds before October 1, 2018. In the (pre)proposal form these partners are mentioned in the category «Associated research partners not asking for funding».

Number of partners requesting funding	Possible number of additional partners with own funding
3	2
4	
5	
6	
7 (only possible with inclusion of 1 Eastern European partner)	1
8 (only possible with inclusion of 2 Eastern European partners)	0

Each transnational proposal must nominate a **project consortium coordinator** among the project partner principal investigators. The coordinator must be a project partner from an E-Rare-3 JTC 2018 funding country/region. The project coordinator will represent the consortium externally and towards the JCS and CSC, and will be responsible for its internal scientific management (such as controlling, reporting, intellectual property rights issues and contact with the JCS). Each project partner will be represented by a single principal investigator. Within a joint proposal, the principal investigator of each project partner will be the contact person for the relevant country/regional funding organisation.

Consortia of projects funded in previous E-Rare Joint Transnational Calls can apply for funding for an extension of their cooperation. These consortia must clearly demonstrate the success of the current project and innovative scientific aims for their future collaboration. Their applications will compete with applications for new research projects.

The duration of the projects can be up to 3 years. Nevertheless, a partner can receive funding for less than 3 years according to E-Rare-3 JTC 2018 funding organisations eligibility criteria and regulations.

#### **4.2. Submission of joint proposals**

There will be a **two-stage submission procedure for joint applications**: pre-proposals and full proposals. In both cases, one joint proposal document (in English) shall be prepared by the partners of a joint transnational proposal, and must be submitted to the JCS by uploading it on the electronic submission system by one spokesperson, the coordinator.

Joint **pre-proposals** (in English) must be received by the JCS in an electronic version no later than **February 6, 2018 at 05 p.m. Central European Time (CET)**. The pre-proposals should strictly follow the “Guidelines for applicants”.

The decision on selection of applications for invitation to full proposal will be communicated in the second week of May 2018.

Please note that **joint full proposals will be accepted only from those applicants who were explicitly invited by the JCS to submit them**. Full proposals (in English) must be received by the JCS in an electronic version no later than **June 19, 2018 at 05 p.m. Central European Summer Time (CEST)**.

In general, no fundamental changes between the pre- and full proposals concerning the composition of the consortia, objectives of the project or requested budget will be accepted. The CSC, however, may allow such changes only in exceptional cases, if detailed justification is provided to the JCS<sup>2</sup>.

E-Rare is aware of the importance of international collaboration and capacity building, especially in the countries presenting lower success rate. Thus, if a country, involved in E-Rare JTC 2018, is not represented by any national research team in the pre-proposals that are invited to write a full proposal (after the first evaluation by the Scientific Evaluation Committee), the funding organisation in this country may be given an opportunity to propose research teams that could be of added value for the projects to be evaluated in the 2<sup>nd</sup> stage and/or the coordinator/partners of the project(s) invited to the 2<sup>nd</sup> stage of evaluation can inquire themselves to find suitable partners from among listed countries (see section 6.2 for details).

The selection on full proposals will be communicated to applicants as soon as possible and before the end of October 2018.

Further information on how to submit pre-proposals and full proposals electronically will be made available through the E-Rare website ([www.e-rare.eu](http://www.e-rare.eu)) and in the "Guidelines for applicants". The forms that have to be used for submission of pre-proposals and full proposals are available on the E-Rare website. Applicants should take note of individual national/regional rules, and should contact their national/regional contact person for any questions (see "contact information" section).

For applicants from some countries/regions it might also be necessary to submit the proposals and/or other information directly to the country/regional funding organisations.

### **4.3. Further information**

Applicants must contact their corresponding national/regional representative and confirm eligibility with their respective funding organisations in advance of submitting an application (see national/regional contact details and Annex). If you need additional information, please contact the JCS. **The adherence to the national/regional regulations in the "Guidelines for applicants" document is mandatory.**

## **5. EVALUATION**

### **5.1. Evaluation criteria**

Pre-proposals and full proposals will be assessed according to specific evaluation criteria (see below), using a common evaluation form. A scoring system from 0 to 5 will be used to evaluate the proposal's performance with respect to the different evaluation criteria.

#### **Scoring system:**

**0: Failure.** The proposal fails to address the criterion in question, or cannot be judged because of missing or incomplete information.

**1: Poor.** The proposal shows serious weaknesses in relation to the criterion in question.

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<sup>2</sup> One of the exceptional circumstances may be that a preproposal has been opened for a research team from a country that joins E-Rare JTC 2018, but was not represented in the chosen preproposals to be elaborated into a full proposal (See "6.2. Opening of pre-proposals after the first evaluation round for involvement of researchers from countries joining E-Rare JTC 2018 but not represented in full proposals").



**2: Fair.** The proposal generally addresses the criterion, but there are significant weaknesses that need corrections.

**3: Good.** The proposal addresses the criterion in question well but certain improvements are necessary.

**4: Very good.** The proposal addresses the criterion very well, but small improvements are possible.

**5: Excellent.** The proposal successfully addresses all aspects of the criterion in question.

### Evaluation criteria:

#### 1. Excellence

- a. Clarity and pertinence of the objectives;
- b. Credibility of the proposed approach and methodology;
- c. Soundness of the concept;
- d. Innovative potential;
- e. Feasibility of the project (adequate requested resources, time schedule);
- f. Competence and experience of participating research partners in the field(s) of the proposal (previous work in the field, specific technical expertise).

#### 2. Impact

- a. Potential of the expected results for future clinical, public health and/or other socio-economic health relevant applications, including patients' needs;
- b. Added-value of transnational collaboration: gathering a critical mass of patients/biological material, sharing of resources (models, databases, diagnosis, etc.), harmonization of data, sharing of specific know-how and/or innovative technologies, etc.;
- c. Effectiveness of the proposed measures to exploit and disseminate the project results (including management of IPR), to communicate the project, and to manage research data. A data management strategy in the full proposal is mandatory;
- d. Involvement of patient organisation, patient representatives or industry (when appropriate/applicable/available).

#### 3. Quality and efficiency of the implementation

- a. Coherence and effectiveness of the work plan, including appropriateness of the allocation of tasks, resources and time-frame;
- b. Complementarity of the participants within the consortium;
- c. Appropriateness of the management structures and procedures, including risk and innovation management;
- d. Concept for sustainability of infrastructures initiated by the project;
- e. Budget and cost-effectiveness of the project (rational distribution of resources in relation to project's activities, partners responsibilities and time frame).

Sub-criteria 2a and 2b will be prioritized for assessing the impact of proposals (pre- and full proposal stage).

Sub-criteria 2c, 2d, 3c, 3d and 3e will be taken into account only for the full proposal evaluation step.

Evaluation scores will be awarded for the 3 main criteria, and not singularly for the different aspects listed below the criteria. Each criterion will be scored out of 5. The threshold for individual criteria will be 3. The overall threshold, applying to the sum of the three individual scores, will be 12. The maximum score that can be reached from all three criteria together is 15 points.

## **5.2. Eligibility check of pre-proposals and first step peer review**

### **5.2.1. Eligibility check**

The JCS will check all pre-proposals to ensure that they meet the call's formal criteria (date of submission; number and country distribution of participating research partners; inclusion of all necessary information in English, page length of each section). The JCS will forward the proposals to the CSC members who will perform a check for compliance to country/regional rules as described in the "Guidelines for applicants".

Please note that proposals not meeting the formal criteria or the national/regional eligibility criteria and requirements **will be declined without further review.**

### **5.2.2. Peer review of pre-proposals**

Pre-proposals passing the eligibility check (call secretariat and country/region) will be forwarded to the SEC members for a first evaluation (see evaluation criteria above). The SEC members will perform the assessment of the pre-proposal and fill the evaluation forms with scores and comments for each criterion. Each pre-proposal will be assessed by 2 SEC members. The SEC members will meet to establish a ranking of the pre-proposals. The CSC will meet to decide which pre-proposals will be accepted for the full proposal submission based on the SEC recommendations. The summary review report and eventual recommendations of the SEC will be forwarded to all applicants.

At this stage research teams of underrepresented countries may join successful pre-proposals (see 6.2 for more details).

## **5.3. Evaluation of full proposals with right to reply (rebuttal stage)**

### **5.3.1. Formal criteria check**

The JCS will check the full proposals to ensure that they meet the call's formal criteria.

### **5.3.2. External reviewer's evaluation**

Each proposal will be allocated to at least two external reviewers who fit the profile of the application.

### **5.3.3. Rebuttal stage**

Before the SEC members see the reviews from external reviewers, each project coordinator will be provided with the opportunity of studying the assessments and commenting on the arguments and evaluations of the external reviewers, which remain anonymous. This stage allows applicants to comment on factual errors or misunderstandings that may have been committed by the external reviewers while assessing their proposal and to reply to reviewers'

questions. However, issues which are not related with reviewers' comments or questions cannot be addressed and the work plan cannot be modified at this stage.

The applicants will have up to one week (in the third/fourth week of July 2018) for this **optional** response to the reviewers' comments.

#### **5.3.4. SEC evaluation**

The JCS will send full proposals, reviews and rebuttals to the SEC members. The SEC will meet to discuss each proposal and, after consideration of the evaluation criteria, external reviews, rebuttals and their own discussions, the SEC will make a classification of the proposals and rank proposals recommended for funding. The final summary review report prepared by the SEC members will be sent to all applicants.

#### **5.4. Funding decision**

Based on the ranking list established by the SEC and on available funding the CSC will suggest the projects to be funded to the national/regional funding organisations. Based on these recommendations, final decisions will be made by the national/regional funding organisations and will be subject to budgetary considerations.

If necessary, the CSC will determine a priority order for proposals, which have been awarded the same score within a ranked list. The following approach will be applied successively for every group of *ex aequo* proposals requiring prioritization, starting with the highest scored group, and continuing in descending order:

- Availability of national funding;
- Maximization of use of national funding;
- Proposals with participation of underrepresented countries;
- Proposals that address diseases not otherwise covered by more highly-ranked proposals.

The Joint Call Secretariat will communicate to all project coordinators the final decisions together with the consensus report of the evaluation from the SEC.

## **6. FINANCIAL AND LEGAL ISSUES**

### **6.1. Funding model**

The E-Rare-3 JTC 2018 Funding Partners have agreed to launch a joint call using the "virtual common pot" funding mode. This means that national/regional funding will be made available through national/regional funding organisations according to national/regional funding regulations.

Each country/region funds only its national/regional component of the transnational research project. Eligible costs and funding rates may vary according to the corresponding national/regional funding organisation regulations. Prior to submitting a proposal, applicants should verify their eligibility and financial support and thus must contact their national/regional contact person (see national/regional contact details). Funding is granted for a maximum of three years according to national/regional regulations.

## **6.2. Opening of pre-proposals after the first evaluation round for involvement of researchers from countries joining E-Rare JTC 2018 but not represented in full proposals**

If a country, involved in the E-Rare JTC 2018, is not represented by any national research team in the pre-proposals invited to the full proposal stage (after the first evaluation by the SEC), an opportunity will be given to involve a research team from that country with added value for the projects to be evaluated in the 2<sup>nd</sup> stage. This inclusion will not be considered as a fundamental change between pre- and full proposal (see 4.2 page 8).

How does it work?

Step 1. A list of countries eligible for this “widening procedure” will be published on E-Rare website after completion of the 1<sup>st</sup> stage of evaluation.

Step 2. Two inclusion options will be available:

A. The concerned national funding agency(ies) may investigate whether there is/are national team(s) that could provide additional expertise to projects. A list of such teams will be sent to the Joint Call secretariat. The Joint Call Secretariat will contact the coordinator(s) of projects invited to the 2<sup>nd</sup> stage of evaluation and propose them to consider the addition of such new research team. In any case, the final decision to take a new research team on board will be taken by the project consortium.

B. The coordinator/partners of the project(s) invited to the 2<sup>nd</sup> stage of evaluation can inquire themselves to find suitable partners from among listed countries. Again, the decision on taking on board a new team will be taken by the project consortium.

**IMPORTANT: Inclusion of new research teams is not mandatory. The new teams included should bring an added value and expertise to the projects.**

## **6.3. Involvement of patients organisations**

EURORDIS is a non-governmental patient-driven alliance of patient organisations representing 765 rare disease patient organisations in 69 countries. Through their involvement and coordination, interested patient organisations with research funding mandates will have access to the proposals so that they can evaluate the relevance to their mandate or pre-determined area of research interest. Patient organisations will develop an agreement with the funding agencies to potentially co-fund selected proposals. The applicants will have the possibility to indicate if they are interested in the potential co-funding by Patients Organisations and if they agree to share the proposals content with Patients Organisations.

## **6.4. Funding contracts**

Each project includes several consortium members called research partners and one project coordinator. Each research partner (including the project coordinator) will have a separate funding contract/letter of grant according to national/regional regulations with the appropriate national/regional funding institutions.

Changes to the composition of research consortia or in budget cannot occur during the contract/letter of grant, unless there is a good justification. Any minor changes have to be well justified and the relevant funding organisations will decide upon the proper action to be taken. However, in case of major changes, an independent expert can be consulted to help with the final decision of the funding organisations. The research partners shall inform the JCS and the respective funding bodies of any event that might affect the implementation of the project.

## **6.5. Research consortium agreement and ownership of intellectual property rights**

The project consortium partners have to sign a consortium agreement (CA) for cooperation addressing the issues given in “Guidelines for applicants” on consortium agreements (available on the E-Rare website). It is recommended that the research consortium signs this CA before the official project start date, and in any case the CA should be signed no later than six months after the official project start date. Please note that national/regional regulations may apply concerning the requirement for a CA (please contact your national/regional contact point or check the country-specific information in the guidelines). Upon request, this consortium agreement must be made available to the concerned E-Rare-3 JTC 2018 funding organisations.

Results and new Intellectual Property Rights (IPR) resulting from projects funded through the E-Rare-3 Joint Transnational Call 2018 will be owned by the researchers’ organisations according to national/regional rules on IPR. If several participants have jointly carried out work generating new IPR, they shall agree amongst themselves (Consortium Agreement) as to the allocation of ownership of IPR, taking into account their contributions to the creation of those IPR as well as the relevant guidelines on IPR issues.

The results of the research project and IPR created should be actively exploited and made available for use, whether for commercial gain or not, in order for public benefit to be obtained from the knowledge created.

The funding partners shall have the right to use documents, information and results submitted by the research partners and/or to use the information and results for their own purposes, provided that the owner’s rights are kept and taking care to specify their origin.

## **6.6. IRDiRC policies and guidelines**

The project partners are expected to follow IRDiRC policies and guidelines and to participate in IRDiRC working groups. For more information see <http://www.irdirc.org/>.

## **6.7. Respect for relevant European and international standards**

The submitted proposals have to respect relevant European and international standards like:

- The new EC Regulation (EC 2016/679) on the protection of natural persons with regard to the processing of personal data and on the free movement of such data. This Regulation will apply in all Member States from May 25, 2018 and thus also for the E-Rare JTC 2018 granted projects (<https://publications.europa.eu/en/publication-detail/-/publication/3e485e15-11bd-11e6-ba9a-01aa75ed71a1/language-en>).
- European Research Council Guidelines on Implementation of Open Access to Scientific Publications and Research Data (referred to in [http://ec.europa.eu/research/participants/docs/h2020-funding-guide/cross-cutting-issues/open-access-data-management/open-access\\_en.htm](http://ec.europa.eu/research/participants/docs/h2020-funding-guide/cross-cutting-issues/open-access-data-management/open-access_en.htm))
- To make research data findable, accessible, interoperable and re-usable (FAIR), a data management strategy is mandatory in the full proposal. For an example of questions for a data management strategy, see Annex 1 in [http://ec.europa.eu/research/participants/data/ref/h2020/grants\\_manual/hi/oa\\_pilot/h2020-hi-oa-data-mgt\\_en.pdf](http://ec.europa.eu/research/participants/data/ref/h2020/grants_manual/hi/oa_pilot/h2020-hi-oa-data-mgt_en.pdf).

A data management strategy/plan should include information on:

- the handling of research data during & after the end of the project;
- what data will be collected, processed and/or generated and/or reused;
- which methodology & standards will be applied;
- whether data will be shared/made open access;
- how data will be curated & preserved (including after the end of the project).

Some funding parties involved in E-Rare JTC 2018 may ask for a data management plan (DMP) at national level at the stage of full proposal or after granting of the project.

## 7. RESPONSIBILITIES, REPORTING REQUIREMENTS AND DISSEMINATION

The **coordinators** of all funded projects must submit **brief annual scientific project reports and a final scientific project report** (the latter should be submitted within six months of the end of the project) to FNRS, Belgium, which is responsible for monitoring the funded projects. All reports must be in English and use a common electronic reporting form that will be provided. The research partners are jointly responsible for delivery of the reports, and FNRS will only accept reports delivered on behalf of the consortium, via the project coordinator.

If required, each participant should submit financial and scientific reports to their **national/regional funding organisations**, according to national/regional regulations. The progress and final results of each individual contract/letter of grant will be monitored by the respective national/regional funding organisations.

The coordinators and/or national/regional group leaders will be asked to present the results of their projects at an **intermediate and a final status symposium** organized by E-Rare. The presence of at least one representative per project will be mandatory. Therefore, expenses related to these events should be foreseen accordingly in the budget of the project.

Funding recipients must ensure that all outcomes (publications, etc.) of transnational E-Rare-3 projects include a proper acknowledgement of ERA-NET E-Rare-3 and the respective national/regional funding partner organisations.

## 8. CONTACT AND FURTHER INFORMATION

The JCS is set up at ZonMw (Netherlands Organization for Health Research and Development) to assist the CSC and the national/regional funding bodies during the implementation of the call. FNRS, Belgium, will be responsible for the follow-up phase until the funded research projects have ended. The JCS will be responsible for the administrative management of the call. It will be the primary point of contact referring to the call procedures between the research consortia, the funding organisations (CSC) and the peer reviewers. The project coordinator will be the person contacted by the JCS during the application procedure, so he/she must forward this information to the other participants.

Further information on the E-Rare-3 Project, the Call and the follow-up is available at the E-Rare website ([www.e-rare.eu](http://www.e-rare.eu)). It is strongly advised to contact the national/regional contact person for any questions regarding the Call (please see national/regional contact details below).

## 9. ANNEXES I-III on the next pages



**ANNEX I. National/regional contact details**

Country/Region	Institution	Website	National/regional contact
Austria	FWF	<a href="http://www.fwf.ac.at">www.fwf.ac.at</a>	Stephanie Resch Phone: +43 (1) 505 67 40-8201 Email: <a href="mailto:stephanie.resch@fwf.ac.at">stephanie.resch@fwf.ac.at</a>  Anita Stürtz Phone: +43 (1) 505 67 40-8206 E-mail: <a href="mailto:anita.stuertz@fwf.ac.at">anita.stuertz@fwf.ac.at</a>
Belgium/Flanders	FWO	<a href="http://www.fwo.be">www.fwo.be</a>	Alain Deleener Phone: +32 2 550 15 95 Email: <a href="mailto:eranet@fwo.be">eranet@fwo.be</a>  Toon Monbaliu Phone: +32 2 550 15 70 Email: <a href="mailto:eranet@fwo.be">eranet@fwo.be</a>
Belgium/French speaking community	FNRS	<a href="http://www.frs-fnrs.be/">www.frs-fnrs.be/</a>	Florence Quist Phone: +32 2 504 93 51 Email: <a href="mailto:florence.quist@frs-fnrs.be">florence.quist@frs-fnrs.be</a>  Joël Groeneveld Phone: +32 2 504 92 70 E-mail: <a href="mailto:joel.groeneveld@frs-fnrs.be">joel.groeneveld@frs-fnrs.be</a>
Canada	CIHR-IG	<a href="http://www.cihr-irsc.gc.ca">www.cihr-irsc.gc.ca</a>	Adrian Puga Phone: +1 613 952 5728 Email: <a href="mailto:adrian.puga@cihr-irsc.gc.ca">adrian.puga@cihr-irsc.gc.ca</a>
Canada (Québec)	FRQS	<a href="http://www.frqs.gouv.qc.ca">www.frqs.gouv.qc.ca</a>	Fonds de recherche du Québec-Santé (FRQS)  Maxime Beaudoin Phone: +1 514 873 2114, ext 1369 Email: <a href="mailto:maxime.beaudoin@frq.gouv.qc.ca">maxime.beaudoin@frq.gouv.qc.ca</a>  Anne-Cécile Desfaits Phone: +1 514 873 2114, ext 1368 <a href="mailto:annececile.desfaits@frq.gouv.qc.ca">annececile.desfaits@frq.gouv.qc.ca</a>
Czech Republic	MEYS	<a href="http://www.msmt.cz">www.msmt.cz</a>	Ministry of Education Youth and Sports Renata Hrubá (MSMT) Phone: +420 234 811 504 Mobile: +420 770 145 082 E-mail: <a href="mailto:renata.hrubá@msmt.cz">renata.hrubá@msmt.cz</a>
Finland	AKA	<a href="http://www.aka.fi">www.aka.fi</a>	Heikki Vilen Phone: +358 29 5335 135 Email: <a href="mailto:heikki.vilen@aka.fi">heikki.vilen@aka.fi</a>

Country/Region	Institution	Website	National/regional contact
France	ANR	<a href="http://www.agence-nationale-recherche.fr">www.agence-nationale-recherche.fr</a>	<p>Ingrid Pfeifer Phone: + 33) (0)1 78 09 80 22 Daria Julkowska Phone: + 33) (0)1 78 09 80 78 Email: <a href="mailto:E-RareCalls@agencerecherche.fr">E-RareCalls@agencerecherche.fr</a></p> <p>Agence Nationale de la Recherche – ANR Health &amp; Biology Department 50 Avenue Daumesnil 75012 Paris, France</p>
Germany	BMBF/ PT-DLR	<a href="http://www.gesundheitsforschung-g-bmbf.de">www.gesundheitsforschung-g-bmbf.de</a>	<p>Katarzyna Saedler Phone: +49 (0)228 3821 1947 Email: <a href="mailto:Katarzyna.Saedler@dlr.de">Katarzyna.Saedler@dlr.de</a></p> <p>Michaela Fersch Phone: +49 (0)228 3821 1268 Email: <a href="mailto:Michaela.Fersch@dlr.de">Michaela.Fersch@dlr.de</a></p> <p>Ralph Schuster Phone: +49 (0)228 3821 1233 Email: <a href="mailto:Ralph.Schuster@dlr.de">Ralph.Schuster@dlr.de</a></p> <p>Project Management Agency of the German Aerospace Centre (PT-DLR) -Health Research-</p>
Germany	DFG	<a href="http://www.dfg.de">www.dfg.de</a>	<p>Dr. Katja Großmann Email: <a href="mailto:katja.grossmann@dfg.de">katja.grossmann@dfg.de</a> Phone: +49 (0) 228 885 2565 Fax: +49 (0) 228) 885 2777 Kennedyallee 40 53175 Bonn</p>
Greece	GSRT	<a href="http://www.gsrt.gr">www.gsrt.gr</a>	<p>Sofia DIMITROPOULOU Phone: +30 2107 458 187 Email: <a href="mailto:s.dimitropoulou@gsrt.gr">s.dimitropoulou@gsrt.gr</a> Ministry of Education, Research &amp; Religious Affairs General Secretariat for Research &amp; Technology International S&amp;T Cooperation Directorate Division of Bilateral &amp; Multilateral Relations</p>
Hungary	NKFIH	<a href="http://www.nkfi.gov.hu">www.nkfi.gov.hu</a>	<p>National Research, Development and Innovation Office Department of Research and Development</p> <p>Előd Nemerkenyi Phone: +36 1 8963987 Email: <a href="mailto:elod.nemerkenyi@nkfi.gov.hu">elod.nemerkenyi@nkfi.gov.hu</a></p> <p>Gábor Tóth Phone: +36 1 8961727 Email <a href="mailto:gabor.toth@nkfi.gov.hu">gabor.toth@nkfi.gov.hu</a></p>

Country/Region	Institution	Website	National/regional contact
Israel	CSO-MOH	<a href="http://www.health.gov.il">www.health.gov.il</a>	Irit Allon Phone: +972-2-5082167 Email: <a href="mailto:Irit.allon@moh.health.gov.il">Irit.allon@moh.health.gov.il</a>
Italy	MoH-It	<a href="http://www.salute.gov.it">www.salute.gov.it</a>	Dr. Giselda Scalera Phone: +39 065994 2596 Email: <a href="mailto:g.scalera@sanita.it">g.scalera@sanita.it</a> research.EU.dgri@sanita.it  Head Office 5 (Health Research IRCCS), Directorate General for Research and Innovation I Healthcare Ministry of Health, Viale Giorgio Ribotta, 5 -00144 Rome, Italy  Dr. Raffaele Ruocco Phone +39 065994 3233 Email : <a href="mailto:r.ruocco@sanita.it">r.ruocco@sanita.it</a>
Latvia	VIAA	<a href="http://www.viaa.gov.lv">www.viaa.gov.lv</a>	Dr Maija Bundule Phone: +371- 67785423 E-Mail: <a href="mailto:Maija.Bundule@viaa.gov.lv">Maija.Bundule@viaa.gov.lv</a>  Dr Uldis Berkis Phone:+371 67785487; +371 29472349 Email: <a href="mailto:Uldis.Berkis@viaa.gov.lv">Uldis.Berkis@viaa.gov.lv</a>
Poland	NCBR	<a href="http://www.ncbr.gov.pl/en/">www.ncbr.gov.pl/en/</a>	Marcin Chmielewski Section for Research Projects BIOMED, Nowogrodzka Str. 47a, 00-695 Warsaw, Poland, Phone: +48 22 39 07 109 Email: <a href="mailto:marcin.chmielewski@ncbr.gov.pl">marcin.chmielewski@ncbr.gov.pl</a>
Romania	UEFISCDI	<a href="http://uefiscdi.gov.ro/">http://uefiscdi.gov.ro/</a>	Executive Agency for Higher Education, Research, Development and Innovation Funding  Mihaela Manole Phone: +40 21 3023 863 Email: <a href="mailto:mihaela.manole@uefiscdi.ro">mihaela.manole@uefiscdi.ro</a>  Nicoleta Dumitrache Phone: +40 21 3023 886 Email: <a href="mailto:nicoleta.dumitrache@uefiscdi.ro">nicoleta.dumitrache@uefiscdi.ro</a>
Spain	ISCIII	<a href="http://www.isciii.es">www.isciii.es</a>	María Druet SG de Programas Internacionales de Investigación Phone: +34 9182 22530 E-mail: <a href="mailto:mdruet@isciii.es">mdruet@isciii.es</a>

Country/Region	Institution	Website	National/regional contact
Switzerland	SNSF	<a href="http://www.snf.ch">www.snf.ch</a>	Raphael Banz Division of Biology and Medicine Swiss National Science Foundation Phone: +41 31 308 21 82 Email: <a href="mailto:raphael.banz@snf.ch">raphael.banz@snf.ch</a>
The Netherlands	ZonMw	<a href="http://www.zonmw.nl">www.zonmw.nl</a>	Nika Ritsema Phone: +31 (0)70 349 54 85 Email: <a href="mailto:ritsema@zonmw.nl">ritsema@zonmw.nl</a>  Harald Moonen Phone: +31-(0)70 349 53 49 Email: <a href="mailto:moonen@zonmw.nl">moonen@zonmw.nl</a>  Sonja van Weely Email: <a href="mailto:weely@zonmw.nl">weely@zonmw.nl</a>  The Netherlands Organization for Health Research and Development (ZonMw)
Turkey	TUBITAK	<a href="http://www.tubitak.gov.tr">www.tubitak.gov.tr</a>	Jale Şahin Phone: +90- 312- 298 17 96 Email: <a href="mailto:e-rare@tubitak.gov.tr">e-rare@tubitak.gov.tr</a>  The Scientific and Technological Research Council of Turkey (TUBITAK) International Cooperation Department Division of Bilateral and Multilateral Relations

## ANNEX II. Indicative funding commitments of the participating organisations of the E-Rare-3 JTC 2018

Country/Region	Participating organisation	Envisioned amount of funding (M€ for 3 years)	Anticipated number of fundable research partners
Austria	Austrian Science Fund (FWF)	0.7	2
Belgium/Flanders	Research Foundation Flanders (FWO)	0.2	1
Belgium/French speaking community	Fund for Scientific Research - FNRS (F.R.S.-FNRS)	0.2	1
Canada	Canadian Institutes of Health Research, Institute of Genetics (CIHR-IG) <sup>3</sup>	1.0	3-4
Canada	Fonds de recherche du Québec-Santé (FRQS)	0.36	1-2
Czech Republic	Ministry of Education, Youth and Sports (MEYS)	0.5	2-3
Finland	Academy of Finland (AKA)	0.6	2-3
France	French National Research Agency (ANR) <sup>4</sup>	2.0	6
Germany	German Federal Ministry of Education and Research (BMBF), German Research Foundation (DFG)	BMBF: 3 DFG: 3	BMBF: 10-15 DFG: tbd
Greece	General Secretariat for Research and Technology (GSRT) <sup>5</sup>	0.5	2-3
Hungary	National Research, Development and Innovation Office (NKFIH)	0.15	1-2
Israel	Chief Scientist Office of the Ministry of Health (CSO/MOH)	Up to 0.3	Up to 2
Italy	Ministry of Health (MoH-IT)	1	4-6
Latvia	State Education Development Agency (VIAA)	0.42	2
Poland	National Centre for Research and Development (NCBR)	0.6 Up to 0.2 per project, regardless of the number of Polish research groups in the project consortium	1-3

<sup>3</sup> CIHR-IG will fund to a maximum of \$1.5 million Canadian over three years (currently equivalent to 1 Mio €) to support operational research costs only. The Canadian amount will not be adjusted to reflect conversion rate changes.

<sup>4</sup> Maximum funding of 300 000 € for a French coordinator and 250 000 € for a French partner.

<sup>5</sup> GSRT will fund up to 3 projects. The funding commitment is up to 200,000-250,000 € per project

Romania	Executive Agency for Higher Education, Research, Development & Innovation Funding (UEFISCDI)	0.5	1-2
Spain	National Institute of Health Carlos III (ISCIII)	0.25	2-3
Switzerland	Swiss National Science Foundation (SNSF) <sup>6</sup>	0.86	3-4
The Netherlands	The Netherlands Organisation for Health Research and Development (ZonMw) <sup>7</sup>	1.8	8-12
Turkey	The Scientific and Technological Research Council of Turkey (TUBITAK)	0.6	3-4

<sup>6</sup> SNSF has earmarked a budget of 1.0 million Swiss Francs over three years (currently equivalent to 0.86 Mio €).

<sup>7</sup> Maximum funding of 250,000 € for Dutch participation per project



### ANNEX III. Eligibility of beneficiary institutions for the participating organisations of the E- Rare-3 JTC 2018

Country/Region	Institution	Eligible beneficiary institution		
		Academia	Clinical/public health	Company
Austria	Austrian Science Fund (FWF)	Yes <sup>(3)</sup>	Yes <sup>(3)</sup>	Yes <sup>(3)</sup>
Belgium/Flanders	Research Foundation Flanders (FWO)	Yes	Yes <sup>(1,2)</sup>	No
Belgium/French speaking community	Fund for Scientific Research - FNRS (F.R.S.-FNRS)	Yes <sup>(6)</sup>	Yes <sup>(7,8)</sup>	No
Canada	Canadian Institutes of Health Research, Institute of Genetics (CIHR-IG)	Yes	Yes	No
Canada (Québec)	Fonds de recherche du Québec-Santé (FRQS)	Yes	Yes	No
Czech Republic	Ministry of Education, Youth and Sports (MEYS)	Yes	Yes	No
Finland	Academy of Finland (AKA)	Yes	Yes	Yes
France	French National Research Agency (ANR)	Yes	Yes	Yes <sup>(1)</sup>
Germany	German Federal Ministry of Education and Research (BMBF)	Yes	Yes	Yes <sup>(1)</sup>
Germany	German Research Foundation (DFG)	Yes <sup>(10)</sup>	Yes <sup>(11)</sup>	No
Greece	General Secretariat of Research and Technology (GSRT)	Yes	Yes	Yes <sup>(1)</sup>
Hungary	National Research, Development and Innovation Office (NKFIH)	Yes	Yes	No
Israel	Chief Scientist Office of the Ministry of Health (CSO/MOH)	Yes	Yes	No
Israel	Israel Innovation Authority	No	No	Yes
Italy	Ministry of Health (MoH-IT)	No	Yes <sup>(4)</sup>	No
Latvia	State Education Development Agency (VIAA)	Yes	Yes	Yes <sup>(1)</sup>
Poland	National Centre for Research and Development (NCBR)	Yes	Yes	Yes
Romania	Executive Agency for Higher Education, Research, Development & Innovation Funding (UEFISCDI),	Yes	Yes	Yes <sup>(1)</sup>
Spain	National Institute of Health Carlos III (ISCIII)	Yes <sup>(12)</sup>	Yes	No
Switzerland	Swiss National Science Foundation (SNSF)	Yes <sup>(9)</sup>	Yes <sup>(9)</sup>	No
The Netherlands	The Netherlands Organisation for Health Research and Development (ZonMw)	Yes	Yes	Yes <sup>(5)</sup>
Turkey	The Scientific and Technological Research Council of Turkey (TUBITAK)	Yes	Yes	Yes <sup>(1)</sup>

**Please note that the information on this table is only indicative**

- (1) The eligibility of companies and institutions is subjected to different conditions in each country/region. Further details regarding the eligible beneficiaries and other national/regional eligibility criteria and requirements are available on the “guidelines for applicants” and the E-Rare website ([www.e-rare.eu](http://www.e-rare.eu)).
- (2) Only clinics associated with Flemish universities are eligible for the FWO.
- (3) Applications for projects from FWF (Austria) may only be submitted by single natural persons. Affirmation of the research institution (academia, clinical/public health, enterprise) of the applicant is mandatory.
- (4) Research Hospital: Istituti di ricovero e cura a carattere scientifico (IRCCS). Only IRCCS (The Italian Scientific Institutes for Health Research and Health Care). The list of the IRCCS by Region and City is available here:  
<http://www.salute.gov.it/ricercaSanitaria/paginaInternaMenuRicercaSanitaria.jsp?id=1064&menu=strumentieservizi>.
- (5) For universities, research institutes affiliated to universities, university medical centers, research hospitals and for health promoting institutes and knowledge institutes the several ZonMw grant terms and conditions (as of 1 July 2013) apply. Companies are eligible for funding of ZonMw in this call under strict conditions (see the separate document on Guidelines). Co-financing by companies or in kind contribution of companies is encouraged.
- (6) The institution must belong to the French speaking community
- (7) Clinical studies can be funded as long as they are addressing scientific questions without any link to industry of private sector.
- (8) Schools of public health are eligible if they are linked or associated with an institution from the French speaking community.
- (9) SNSF has formal and material eligibility criteria. Applicants must show that they have successfully carried out research work for several years, and must be capable of running a project under their sole responsibility and leading the project team engaged for the (sub) project. Proposals that are manifestly inadequate to be forwarded to external experts for review or show obvious substantial insufficiencies in any of the SNSF scientific assessment criteria are rejected and not forwarded to external review.
- (10) For some non-university academic institutions a duty to cooperate with university institutions may exist. See guideline 55.01 ([http://www.dfg.de/formulare/55\\_01/](http://www.dfg.de/formulare/55_01/))
- (11) Only non-profit clinics and institutions are eligible.
- (12) Academic institutions are eligible if there is another Spanish beneficiary in the consortium from a Hospital or health care setting belonging to the National Health System or from Health Research Institutes (IIS) or from CIBER/CIBERNED. The last two could only participate as coordinators of the E-Rare project.

**Applicants need to contact their national/regional contact points for further information and refer to the national/regional information in the “Guidelines for applicants” document**