



## ERDERA Call for Proposals 2026

### Call Text

#### **“Resolving unsolved cases in rare genetic and non-genetic diseases”**

**For further information,**

An information webinar will be held on December 16th, 2026, 15.00-16.00 (CET). Register to participate in the webinar here:

[ERDERA JTC 2026 Information Webinar Registration](#)

Visit us on the web:

<https://erdera.org/>

**Submission deadline for pre-proposals: February 12th, 2026 at 2 PM (CET)**

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## 1. Background

There are at least 7000 distinct rare diseases (RD). Although individually rare, taken together RDs affect at least 26-30 million people in Europe. They represent a major issue in healthcare: many of these diseases have an early or very early onset and/or lead to a significant decrease in life expectancy, and the journey to diagnosis takes about 4-6 years. Finally, most of them cause chronic illnesses with a large impact on the healthcare systems and people living with these conditions.

Research is needed to provide knowledge for prevention, diagnosis, better care and improvements in the quality of life for patients. Yet, research is hampered by lack of resources at several levels: (1) there are few scientists working on any given disease, (2) numbers of patients per disease are low and they are scattered over large geographic areas, causing difficulties in getting the number of participants needed for research, (3) existing databases and samples of human tissue collections are usually local, small, and not accessible or standardized, and (4) the complex clinical signs and symptoms of these diseases require interdisciplinary cooperation to improve research and treatment outcomes.

The specific characteristics of rare diseases make them a distinct field with exceptional potential for added value through European and international collaboration. RDs are a prime example of a research area that necessitates collaboration/coordination on a transnational scale.

In this context, the European Rare Diseases Research Alliance (ERDERA) has been established to further improve coordination of RD research efforts in European, Associated and non-European countries and contribute to the objectives of the International Rare Disease Research Consortium (IRDiRC). These actions are a continuation of the six Joint Transnational Calls for RD research projects launched previously by the European Joint Programme on Rare Diseases (EJP RD) since 2019 and by ERDERA since 2024.

## 2. Participating Organisations

Several national and regional funding organisations together with the European Commission (EC) under the PARTNERSHIP-COFUND mechanism have decided to fund multilateral research projects on rare diseases and will participate in the **ERDERA Joint Transnational Call (JTC) 2026**. The call opens simultaneously with the involvement of the following funding organisations in their respective countries/regions:

- Austrian Science Fund (FWF), Austria
- Research Foundation Flanders (FWO), Belgium, Flanders
- Fund for Scientific Research - FNRS (F.R.S.-FNRS), Belgium, French speaking community
- Public Service of Wallonia (SPW), Belgium, Wallonie
- Bulgarian National Science Fund (BNSF), Bulgaria
- Canadian Institutes of Health Research – Institute of Genetics (CIHR-IG), Canada
- Ministry of Health (MZCR), Czech Republic<sup>1</sup>
- The Research and Innovation Foundation (RIF), Cyprus
- Innovation Fund Denmark (IFD), Denmark

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<sup>1</sup> AZVCR (Agentura pro Zdravotnický Vyzkum Ceske Republiky), which is an entity affiliated to MZCR, will administer the work at the national level in relation to this Call



- Estonian Research Council (ETAG), Estonia
- French National Research Agency (ANR), France
- Foundation For Rare Diseases (FFRD), France
- Federal Ministry of Research, Technology and Space (BMFTR), Germany
- National Research, Development and Innovation Office (NKFIH), Hungary
- Health Research Board (HRB), Ireland
- Chief Scientist Office of the Ministry of Health (CSO-MOH), Israel
- Italian Ministry of Health (MoH-IT), Italy
- Fondazione Telethon (FTELE), Italy
- Tuscany Region (RT/TuscReg), Tuscany (Italy)
- Latvian Council of Science (LZP), Latvia
- Research Council of Lithuania (LMT), Lithuania
- National Research Fund (FNR), Luxembourg
- The Research Council of Norway (RCN), Norway
- National Centre for Research and Development (NCBR), Poland
- Foundation for Science and Technology (FCT), Portugal
- Executive Agency for Higher Education, Research, Development and Innovation Funding (UEFISCDI), Romania
- Slovak Academy of Sciences (SAS), Slovakia
- Slovak Centre of Scientific and Technical Information (SCSTI), Slovakia
- National Institute of Health Carlos III (ISCIII), Spain
- Swedish Research Council (SRC), Sweden
- Netherlands Organisation for Health Research and Development (ZonMw), The Netherlands
- The Scientific and Technological Research Council of Türkiye (TUBITAK), Türkiye

This year, the ERDERA Partnership is cooperating with the Funding Agency Xjenza Malta – as part of their A2P scheme, Malta-based researchers can join the ERDERA Call as cooperation partners and be eligible for up to €300,000 for their participation in a successfully funded project, provided that also the national application is successful. More information can be found [here](#).

### 3. Management and Evaluation Structures

The process includes the evaluation procedure of pre- and full proposals, the final selection and the award of research projects. Two boards, the Call Steering Committee (CSC) and the Scientific Evaluation Committee (SEC), will manage it with support of the Joint Call Secretariat (JCS) (ANR, France) for 2026 edition). **SEC and CSC members are not allowed to submit or participate in proposals within this call.**

The **Call Steering Committee** (CSC) comprises representatives from each funding organisation participating in the JTC 2026. 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 made by the CSC.

The **Scientific Evaluation Committee** (SEC) is a panel of internationally recognized, independent, experts (scientific and patients) 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 conflict of interest.

## 4. Aim of the Call

The aim of the call is to tackle RD patient-need led challenges and enable scientists to build, based on common interests and sharing of expertise, effective, multinational, interdisciplinary research collaborations. The expected impact lies in the future translation and use of the results to the benefit of patients.

The classification of RDs follows 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.

Accurately diagnosing RDs is a major challenge, with approximately 50% of individuals with a suspected of having a rare genetic condition remaining undiagnosed or misdiagnosed despite standard clinical genetics care. In addition, RDs of non-genetic origin - estimated to account for about 10% of all RD cases - remain an under-investigated area. On average, it takes around 5 years to establish an accurate diagnosis for people living with a RD (PLWRD)<sup>2</sup>. Given the complexity of these disorders, multiple and complementary diagnostic approaches are required. These unmet needs and challenges complexity underpin the objectives of this call.

### 4.1 Topic List

The goal of this call is to solve **Undiagnosed Rare Genetic diseases** and to address **complex, multifactorial Rare Non-Genetic diseases** by identifying causative variants in patients with no molecular diagnosis after prior genetic or genomic testing and providing diagnostic clarity for conditions of unknown or mixed pathogenesis.

Suggested focus areas are:

- Functional validation to classify variants of uncertain significance (VUS) and increase the diversity of functional genomics research, or validation of candidate VUS to improve outcomes for a broader range of patients using in silico, in vitro or animal model systems (e.g. CRISPR modified cells, iPSCs, organoids, etc.);
- Use of multi-omics or integrative methods (e.g. transcriptomics, epigenomics, etc.) to resolve ambiguous or complex variants;
- New tools/methodologies not yet validated in clinical setting, including biostatistics, advanced bioinformatics, and mathematics approaches (e.g. variant effect predictors, Artificial Intelligence (AI)-based annotation platforms, etc.);
- Systems biology and disease mechanism modelling;
- Integration of clinical, environmental, lifestyle, and sensor-derived data;
- Development of knowledge graphs or disease maps to link phenotypic and mechanistic insights;
- Use of advanced AI and modelling tools (graph ML, probabilistic causal models).

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<sup>2</sup> Faye, F., Crocione, C., Anido de Peña, R. et al. Time to diagnosis and determinants of diagnostic delays of people living with a rare disease: results of a Rare Barometer retrospective patient survey. Eur J Hum Genet 32, 1116–1126 (2024). <https://doi.org/10.1038/s41431-024-01604-z>

## 4.2 Excluded Diseases, Approaches and Topics

The following diseases, approaches and topics are excluded from the scope of the JTC 2026:

- Pre-clinical therapy development studies as covered in [ERDERA JTC2025 topic](#);
- Interventional clinical trials to prove efficacy of drugs/treatments/surgical procedures/medical procedures. This includes studies comparing efficacy, e.g., two surgical techniques or therapies, and projects whose main objective is the implementation of a clinical phase IV pharmacovigilance study;
- Projects focusing only on rare neurodegenerative diseases that are within the focus of Brain Health Partnership. These are: Alzheimer's disease and other dementias; Parkinson's disease (PD) and PD-related disorders; prion diseases; motor neuron diseases; Huntington's disease; spinal muscular atrophy and dominant forms of spinocerebellar ataxia. However, childhood dementias/neurodegenerative diseases are eligible;
- Rare infectious diseases, rare cancers and rare adverse drug events in treatments of common diseases. Rare diseases with a predisposition to cancer are eligible. Diseases with inborn errors of immunity/genetic predisposition to rare infectious disease are eligible.

## 4.3 General Considerations

The following **additional elements need to be considered in all proposals**:

- Proposals should integrate sex and gender considerations, underrepresented populations, or underrepresented patient sub-groups, as well as social components, e.g. different economic, educational backgrounds (see also Guidelines section 4.6);
- The project consortium should include at least one patient partner, i.e. a patient representative from patient advocacy organisation (PAO) or any other organized group if no patient organisation exists. Proposals must clearly describe the plan for patient partner(s) involvement and explicitly detail the approach to its funding within the proposed budget. The plan for involvement should clearly describe how patient partner(s) will bring their expertise throughout the life cycle of the research, from identifying and prioritising the research question, planning, design, conduct, analysis, oversight and governance, and dissemination. It should also, where appropriate, indicate how patient partner(s) involvement has impacted on the research proposal or will impact on the conduction of the research, and how such involvement will be reported. Annexes of the guidelines should be consulted for specific funding/reimbursement of PAOs.
- Leveraging existing infrastructures such as biobanks and model repositories (e.g., EuroBioBank, RD-Connect) and ensuring compliance with obligations to make generated resources publicly available, including depositing new mouse models or cellular lines in recognized repositories in accordance with FAIR principles;
- Appropriate bioinformatics and statistical methods, whenever included and justified, should constitute, an integral part of the proposal. Relevant personnel should be clearly specified and should either be an eligible partner of the consortium, part of the research group of an eligible partner or involved as direct contractors of an eligible partner. They cannot be external

collaborators that participate with their own funding. Their responsibilities must be clearly described and align with overall submission requirements, and a CV must be provided;

- Data generated or newly collected for the project must be made ready for reuse in accordance with the Findable, Accessible, Interoperable and Reusable (FAIR) Guiding Principles. Applying ERDERA's FAIR data stewardship services will contribute a new data resource to the ERDERA Data Hub (<https://erdera.org/data-hub/>). The Data Hub and the associated Virtual Platform (VP; <https://erdera.org/erdera-virtual-platform/>) are collective achievements of the ERDERA partnership that enable automated applications across multiple data and knowledge sources (see also Guidelines section 1.3). This should be achieved by contributing to the data resources already connected to the ERDERA Data Hub/VP or using other resources (local or external) that makes the data FAIR and connected.

To ensure this, projects are expected to:

- Include a data management plan (DMP) from the start of the project that outlines strategies for data sharing, long-term preservation, and sustainability, as may be required by national or ERDERA guidelines.
- Deposit all relevant datasets, metadata, and associated documentation in a resource connected to the ERDERA VP or apply ERDERA's FAIR implementation guidelines to a resource managed by the consortium.
- Adopt open, standardized data formats and ontologies to maximize interoperability with other rare disease resources and platforms.
- Ensure datasets have persistent identifiers (such as DOIs) and that metadata is sufficiently rich to support discovery and reuse.
- Define clear data access conditions and, where possible, enable open or controlled access in line with ethical, legal, and regulatory requirements.

Projects lacking in-house FAIR or data stewardship expertise are encouraged to engage and collaborate with the ERDERA Data Services Hub (DSH) early in the project to plan for data integration, stewardship, and compliance with FAIR principles.

- The genomic and other -omics data from participants and related family members generated by the funded projects should be shared with the ERDERA Diagnostic Research Workstream (<https://erdera.org/clinical-research/erdera-diagnostics/>) at most one year after being generated **if the index case remains genetically undiagnosed**.

Funded projects are encouraged to also share previously generated pertinent -omics data. In all cases, phenotypic data and minimal experimental metadata will also need to be shared.

To facilitate this approach, participating institutions (data controllers) are encouraged to adhere to the ERDERA Diagnostic Research Workstream (DRW) [Data Sharing Framework](#) to submit pseudonymised phenotypic and omics data for reanalysis using a distributed approach.

Information is collated in a structured and interoperable format using ontologies such as Human Phenotype Ontology (HPO, <https://hpo.jax.org/app/>), Orphanet Rare Diseases Ontology [(ORDO) <https://www.ebi.ac.uk/ols4/ontologies/ordo>], OMIM (<https://www.omim.org/>), and other international standards such as those promoted by the [Global Alliance for Genomics and Health](#) (GA4GH).

- The DRW ecosystem of resources is co-created with ERDERA's Data Services Hub (DSH), to ensure data FAIRness and interoperability with [ERDERA's Virtual Platform](#). Phenotypic data and short read genomic data are submitted through the [RD-Connect GPAP](#). Long-read genomic data, RNA-seq, and optical genome mapping data are



submitted through [RD3](#). Data access for re-analysis is facilitated by the European Genome Phenome Archive, which optionally enables long-term archival and controlled access services of the submitted datasets.

- Clinical and omics data are analysed by the Data Analysis Task Force using state-of-the-art analysis pipelines and methods. Results are interpreted within the framework of disease group specific Data Interpretation Task Forces organised by experts from corresponding European Reference Networks and Undiagnosed Disease Programmes.
  - For further information and clarification, the following resources are available: <https://erdera.org/wp-content/uploads/2025/12/ERDERA-Services.zip>.
- Generative AI (GenAI) approaches may be used only when their application is clearly justified, ethically sound, and demonstrably offers advantages over conventional methods. Projects proposing GenAI must ensure full compliance with relevant EU legislation and ethical frameworks, including the AI Act, the GDPR, and the JTC 2026 Guidelines (Section 4.6). Particular attention must be given to transparency, explainability, accountability, and mitigation of algorithmic bias, especially in clinical or diagnostic contexts. All AI-based methods must be robust, validated, and subject to appropriate oversight. Data protection and participant privacy must be safeguarded at all stages; whenever external AI tools (e.g., chatbots or online platforms) are used, data transfer must occur only through secure and compliant channels (e.g., API-based access without exposure of personal data).

## 5. Funding and Eligibility Criteria

### 5.1 Funding

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

Double funding of research projects is not permitted. The JCS and national/regional funding organisations may perform cross-checks of submissions against other funding initiatives managed by the same organisations (both national/regional calls and Joint Transnational Calls, e.g., European Partnerships such as ERA4Health, EP PerMed, THCS, Brain health etc. or Horizon Europe calls).

Consortia of projects funded in previous Joint Transnational Calls of the EJP RD or ERDERA can apply for funding to extend their cooperation in a new project, but only for new research activities not yet funded under the previous Call(s). These consortia must clearly demonstrate the success of the past/current project(s) and innovative scientific aims for their future collaboration. Their applications will compete with applications for new research projects.

### 5.2 Categories of Partners

Partners belonging to one of the following categories may request funding under a joint research proposal (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),



- Enterprises (all sizes of private companies). Participation of small and medium-sized enterprises (SMEs) is encouraged when allowed by national/regional regulations,
- Patient advocacy organisations (PAOs).

### 5.3 Countries and Region-specific Guidelines

Although applications will be submitted jointly by applicants from several countries, individual groups will be funded by their respective regional/national funding organisation. **Applicants, therefore, must contact their respective funding organisations and confirm their compliance with the national/regional rules in advance of applying** (see section 10). The adherence to the national/regional regulations in the “Guidelines for Applicants” document is mandatory. Including a non-eligible partner in a proposal will lead to the rejection of the entire proposal without further review. For additional information, please contact the JCS. Note that some regional/national funding organisations require a parallel proposal submission.

### 5.4 Consortium Makeup

#### 5.4.1 Limit number of partners

Only transnational projects will be funded. Each consortium submitting a proposal must involve four to six eligible principal investigator partners (referred to as partners below) from at least four different participating countries (see list in section 2). In specific cases, the number of consortium partners can be increased to eight partners (see table below). No more than two eligible partners from the same country can be present in each consortium; further national/regional limits may apply, see “Guidelines for Applicants”. Patient partners, requesting funding or not, do not count toward the total.

The number of partners can be increased to 8 in two cases:

1. The inclusion of partners from participating usually underrepresented countries (UCs) in projects (UCs: Estonia, Latvia, Lithuania, Slovakia, Türkiye), OR
2. The inclusion of an ECR as full partner (see section 5.6).

Number of research partners requesting national/regional funding	Inclusion of partner from UC	Inclusion of ECR partner
4	Not mandatory	Not mandatory
5		
6		
7	1 partner from the UC or ECR categories: 1 UC or 1 ECR	
8	One additional partner from the UCs or ECR categories e.g: 1 UC + 1 ECR or 2 ECR or 2 UCs	

#### 5.4.2 What is a partner? a collaborator? a sub-contractor?

To be considered as an eligible partner, a group must contribute substantially to at least one of the project's work packages. If the only role of a group is to provide patient access, data or samples for the study, they will not be considered as partners of the consortium, but can be included otherwise, via cooperation agreements (as collaborators) or subcontracting.

Consortia may include collaborators who secure their own funding. Collaborators cannot be work package leaders, and their contribution to the consortium must be described. As they do not receive funding as part of this call, they do not count toward the limit of 8 partners requesting research funding (nor is there a limit of collaborators per country, if their participation is justified). Collaborators must supply a letter of intent, CV (only at the full proposal stage), which must be entered into the online submission system.

If necessary, to implement the research activity, consortia may also include subcontractors if allowed by their country/regional regulations. Sub-contractors may cover only a limited part of the research activity, and their contribution to the consortium must be described. They do not count toward the limit of 8 partners requesting research funding (nor is there a limit of subcontractors per country, if their participation is justified and if subcontracting is possible according to national/regional funding rules).

#### 5.4.3 Consortium organisation

Each transnational proposal must nominate one project consortium coordinator among the project partner principal investigators. The coordinator must be an eligible project partner from an ERDERA JTC 2026 funding country/region. The project coordinator will represent the consortium externally to the JCS and to CSC, and will be responsible for its internal scientific coordination (such as management, reporting, and intellectual property rights issues). This workload should be considered in the requested budget estimate of the coordinator. A single principal investigator will represent each project partner. Within a joint proposal, the principal investigator of each project partner will be the contact person for the relevant country/regional funding organisation.

### **5.5 Patient Advocacy Organisations and Patient Involvement/Partnership**

From the start when preparing their proposals, consortia are expected to include and actively engage patient partners, i.e. patient representative (patients/caregivers/family members) from a patient advocacy organisation (PAO) or from any other organised group if no patient organisation exists. For information on where to find patient partners and PAOs willing to be involved in research, please see:

- Orphanet portal for rare diseases and drugs patient organisation directory,
- Rare Diseases Europe (EURORDIS),
- European Reference Networks (ERNs),
- [Foundation For Rare Diseases](#),
- European Patients' Forum <https://www.eu-patient.eu/>,
- Research Patient Partnership resources ([CIHR-IG](#))

For specific involvement of patients' partners dedicated to undiagnosed PLWRD, please consult the Guidelines (section 1.3.4).

The consortia should clearly describe the role and responsibilities of the patient partners, how they will operate, at what levels and stages of the research, and provide justifications for allocated resources in a patient involvement plan. It is expected that patient partners are involved in advisory/steering/governance group. It is expected that patient partners are involved throughout the research lifecycle where appropriate, and advise on issues such as:

- identifying and prioritising the research question,
- planning,
- design,
- conduct,
- analysis,
- oversight and governance, and
- dissemination.

For more information on patient-centred research projects and strategies to involve patient partners in your research project, please consult:

[EJP RD Short guide on patient partnerships in rare diseases research projects;](#)

[Health Research Charities Ireland Patient & Public Involvement;](#)

[Recommendations for Successful Patient Involvement in Scientific Research \(de Witt et al., 2016\);](#)

[Measuring what matters to rare disease patients \(Morel & Cano, 2017\);](#)

[CIHR's Institute of Genetics Patient Partnership resources.](#)

Funding for patient partners' organization (PAOs) is possible through the central funding mechanism. This funding mechanism is managed by ZonMw with budget from the European Commission on behalf of the ERDERA consortium. The budget per project is limited to a total of €25,000 over 3 years and regardless of the number of participating PAOs in a project. See the "Guidelines for Applicants" for further guidance and eligibility rules).

Alternatively, patient partners may also participate through national or regional funding schemes, or via subcontracting, depending on national or regional funding schemes, the proposed tasks and applicable funding rules". Any funding claim should be consistent with the tasks and roles of the patient partnering organisation.

## 5.6 Early Career Researchers

Research consortia are strongly encouraged to integrate Early Career Researchers (ECRs) as full research partners. ECRs must demonstrate independence and scientific excellence, and they should be clearly identified in the proposal and provide this information in their CV. **Please note that national/regional definitions for ECRs might differ.** A definition of ECRs and conditions for their eligibility are provided in "Guidelines for Applicants", section 3 or the national/regional annexes.

## 6. Registration and Submission

Research consortia that intend to submit a transnational project proposal should register via the electronic proposal system as soon as possible: <https://funding.erdera.org>.

There will be a **two-stage submission procedure** for joint applications: a pre-proposal and a full proposal stage. In both cases, one joint proposal document (in English) shall be prepared by the partners of a joint transnational proposal. The coordinator must submit it only to the JCS via the

electronic submission system. Proposals must be prepared using the templates provided in the electronic system. Proposals not conforming to the template instructions will be rejected.

#### Call Timeline

10th December 2025	Launch of the call
16th December 2025	Information webinar for potential applicants
12th February 2026	Pre-proposal submission deadline
4th March 2026	Pre-proposal eligibility check
Early May 2026	Invitation to full proposal
5th May 2026	Information webinar for applicants invited to submit a full proposal
8th July 2026	Full proposal submission deadline
23rd July 2026	Full proposal eligibility check
December 2026	Notification of funding decision

Only applicants explicitly invited by the JCS may submit full proposals.

In general, fundamental changes between the pre-proposal and the full proposal stages concerning the composition of the consortia, objectives of the project, or requested budget will be considered by the CSC only when a detailed rationale for the changes is provided to the JCS. Potential justifications may include advice gathered on the feasibility of the project indicating the need for additional expertise and/or resources, or the addition of partner(s) through the widening scheme. However, the national/regional regulations on eligible partners and budget caps will still apply and the budget change needs to be preapproved by relevant national/regional funding organisation(s).

Further information on submitting pre-proposals and full proposals electronically (including “Guidelines for Applicants” and submission templates) is available at the ERDERA website.

## 7. Evaluation Process

At the pre-proposal stage, applicants should focus on presenting the scientific idea/hypothesis and supporting preliminary results, studies or data. The applicants should describe the project, starting from an unmet need, and follow through to the expected endpoint of the study.

At the full proposal stage, in addition to the scientific content, a full description of the patient engagement plan, data management, statistical methods, and ethical and legal issues will be requested in compliance with EC requirements. Applicants should anticipate these requirements and ensure that they have consulted relevant experts to verify the feasibility of the project, and that the proposal can be completed within the defined timelines and budget (considering budget limits listed in the “Guidelines for Applicants”).

### 7.1 Evaluation Criteria

Evaluation scores will be awarded using a common evaluation form, according to specific criteria aligned with Horizon Europe rules (see below).

#### 7.1.1 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 concerning the criterion.
- 2: Fair: The proposal generally addresses the criterion, but significant weaknesses that need corrections.
- 3: Good: The proposal addresses the criterion well, but specific improvements are necessary.
- 4: Very good: The proposal addresses the criterion very well, but minor improvements are possible.
- 5: Excellent: The proposal successfully addresses all aspects of the criterion.

### 7.1.2 Criteria

#### **1. Excellence (0-5)**

- a. Clarity and pertinence of the objectives,
- b. Credibility of the proposed approach and methodology,
- c. Soundness of the concept,
- d. Innovative potential: development and application of new technologies or new uses/combination of existing technologies, groundbreaking new insights into diagnosing RD
- e. Competence of participating research partners in the field(s) of the proposal (e.g., previous work in the field, specific expertise), and
- f. \*\*Active and meaningful participation of PAOs and patient partners in the project (including identifying and prioritising the research question, planning, design, conduct, analysis, oversight and governance, and dissemination) as well as clarity of the patient partner involvement plan.

#### **2. Impact (0-5)**

- a. Potential of the expected results for exploitation and for future clinical, public health and/or other socio-economic health-relevant applications, including patients' needs,
- b. Benefit to patients, their families, and carers,
- c. Added value of transnational collaboration: gathering a critical mass of patients/material, sharing of expertise and resources, harmonisation of data, sharing of specific know-how and/or innovative solutions,
- d. Inclusion of Early Career Researchers as full partners (PI/research team leaders),
- e. Involvement of industry (for a socio-economic impact and/or an acceleration of research development, access to innovation and application for patients), and
- f. \*\*Effectiveness of the proposed measures to exploit and disseminate the project results (including management of intellectual property rights (IPR)), to communicate the project, and to manage research data.

#### **3. Quality and efficiency of the implementation (0-5)**

- a. Feasibility of the project (coherence and effectiveness of the work plan, including appropriateness of the allocation of tasks, resources and timeframe, access to data and material),
- b. Complementarity of the participants within the consortium, including the integration of patient partners,
- c. \*\*Appropriateness of the management structures and procedures, including risk management, contingency plans and innovation management,

- d. \*\*Plan for the sustainability of infrastructures or resources initiated by the project, and
- e. \*\*Use of relevant tools and standards complementary to published ERDERA diagnostic workstream documentation.

\*\*Sub-criteria 1f, 2f, 3c-e will only be assessed as part of the full proposal evaluation step.

## 7.2 Pre-proposal Review

### Eligibility check

The JCS will check all pre-proposals to ensure they meet the call's formal criteria (completeness of information in the submission platform, general eligibility criteria). The JCS will forward the proposals to the CSC members who will perform a check for compliance with country/regional eligibility rules. Please note that proposals not meeting the formal or national/regional eligibility criteria and requirements will be declined without further review.

### Peer review of pre-proposals

Each pre-proposal that passes the eligibility check will be reviewed by two SEC members with biomedical expertise, based on the above evaluation criteria and scores. The SEC will then meet online to establish a ranking of the pre-proposals. This ranking will be used by the CSC to decide which pre-proposals will be invited to submit a full proposal. The JCS will then inform the coordinators about the final decision and will send later on a consensus report to all applicants. Then corresponding SEC recommendations regarding their full proposal submission will be sent together with consensus reports to the successful applicants.

### Scoring rules

Each criterion will be scored out of five (5). Therefore, the maximum overall score for each proposal will be 15 points. To be approved for the full proposal stage, the application must receive a minimum threshold score of 12 points per expert vote.

### Widening

At the end of this stage research teams from underrepresented or undersubscribed countries may join successful pre-proposals after approval by the relevant funding organizations (see section 1.4 in "Guidelines for Applicants" for more details).

In case there are comments from the SEC that the patient involvement in a proposal is too low, additional PAO(s) may be added. They can still request funding from the Central Funding Mechanism for PAOs if they meet the eligibility criteria.

### ERDERA support services

Applicants that are invited to submit a full proposal are strongly encouraged to make use of the ERDERA support services for FAIR data, translational mentoring and regulatory advice (see section 1.3 in "Guidelines for Applicants" for more details).

### Diagnostic Research Workstream

Applicants invited to submit a full proposal are strongly encouraged to use the Diagnostic Workstream (DRW) support services for data submission, analysis, and interpretation in collaboration with ERDERA's Data Services Hub (see section 1.3 in "Guidelines for Applicants" for details).

### 7.3 Full Proposal Review

#### Formal criteria check

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

#### SEC meeting evaluation

The JCS will send full proposals to the SEC members. The SEC will then meet to discuss the proposals, assign their final scores and create a ranking list with proposals that are recommended for funding. The final consensus report for each consortium will be prepared by the SEC members and sent by the JCS to respective applicants.

#### Scoring rules

Each proposal will be evaluated by three biomedical reviewers (including methodological reviewers) and one patient reviewer. All reviewers will be present at the SEC meeting to discuss proposals and provide their feedback.

Biomedical SEC members will score each criterion out of five. The maximum score per biomedical SEC member is 15 points with a threshold of 12 points.

Patient SEC members, will assess the full-proposal according to the patient relevant evaluation criteria listed above (see 7.1.2). The maximum score per patient SEC member is 15 points with a threshold of 12 points.

#### Ethical evaluation

After the second SEC meeting, full proposals recommended for funding by the SEC will be remotely evaluated by independent experts in ethics. These experts will report on the feasibility of a given proposal to comply with the ethical requirements. If necessary, they will list those tasks to be done and documents to be submitted by the consortium to receive approval for funding from an ethics standpoint. **Only proposals approved by both the scientific and ethical evaluations (complying with Horizon Europe and regional/national ethical requirements) will be funded.**

### 7.4 Funding Decision

The CSC decides on the list of projects recommended for funding based on the ranking list established by the SEC, the ethical approval, and available funding.

Each CSC member organisation makes the final decision on its funding contribution according to its respective regulations, calendar and legal frameworks.

In cases where proposals receive identical scores/ranking, the CSC will determine a priority order for funding based on the below prioritization (in descending order):

- Availability of national/regional funding,
- Maximizing the use of national/regional funds,
- Patient centricity of the project,
- Proposals that address diseases not otherwise covered by a more highly ranked one,
- Proposals with participation of underrepresented or undersubscribed countries,
- Gender balance within consortia.





The JCS will notify all project coordinators of the final funding decision and disseminate the SEC consensus report. The list of funded projects will be published on the ERDERA [dashboard](#).

## 8. Redress Procedure

Applicants can appeal against the evaluation or eligibility outcome if they suspect a breach in the evaluation and selection procedures. This redress procedure applies solely to the procedural aspects of the call. It does not reopen or challenge the scientific or technical assessments made by duly qualified experts or evaluators.

Applicants may submit their appeal to the JCS up to seven (7) calendar days following the eligibility or evaluation outcome notification by the JCS at the end of each competition stage. The proposal outcome email containing the results of the evaluation will include information on the appeals procedure, which is described below.

### Admissibility of appeals

For an appeal to be admissible the following conditions must be met:

- The appeal must be submitted by the coordinator of the proposal to which the appeal relates
- Only one appeal per proposal will be considered
- The appeal must be submitted via email to the JCS within the seven (7) calendar days' deadline after receiving information on the eligibility or evaluation of the JCS. The appeal must contain the following minimum information:
  - The name of the call for proposals
  - The proposal acronym
  - The title of the proposal
  - A description of the alleged shortcomings of the evaluation procedure.

The appeal must demonstrate a procedural irregularity or a factual error. Appeals that do not meet the above conditions, or do not relate to the eligibility or evaluation of a specific proposal or express mere disagreement with the result or the reasoning of the evaluation will be judged as not suitable for redress.

### Procedure

Upon receipt of an appeal, an acknowledgement of receipt will be sent by the JCS within seven (7) calendar days. The acknowledgement shall report the redress process and the anticipated date by which a decision on the appeal will be communicated to the appellant. All appeals received by the seven (7) calendar days deadline will be processed together, and the decision of the CSC will be communicated to the appellant by the JCS within seven (7) calendar days after the decision has been made.

## 9. Contacts

Further information on ERDERA, the Call, and follow-up is available at the ERDERA website (<https://erdera.org/>).

### Call Contacts

Role	Organisation	Contact Details
Joint Call Secretariat	ANR	ERDERAcall@agencerecherche.fr
JTC Requests	INSERM	JTC-requests@erdera.org

### National and Regional Contacts

Applicants should refer to the guidelines document for country-specific information including national/regional rules that may apply. Applicants are strongly advised to contact the national/regional contact person to ensure eligibility before submitting their projects and to check for possible national/regional submission requirements.

Country/Region	Funding Organisation	Contact Details
Austria	Austrian Science Fund (FWF)	Dr. Doris Lucyshyn Doris.lucyshyn@fwf.ac.at  DI Anita Stürtz Anita.stuertz@fwf.ac.at
Belgium	Fund for Scientific Research – FNRS (F.R.S.-FNRS)	Dr. Maxime Bonsir +32 2 504 9236  Dr. Florence Quist +32 (0)2 504 9351  International@frs-fnrs.be
Belgium	Research Foundation Flanders (FWO)	Toon Monbaliu (FO) +32 (0)2 550 15 70  Kristien Peeters (SBO) +32 (0)2 550 15 95  europe@fwo.be
Belgium	Public Service of Wallonia (SPW)	Dr. Cédric Morana Cedric.morana@spw.wallonie.be Dr. Fleur Roland Fleur.roland@spw.wallonie.be
Bulgaria	Bulgarian National Science Fund (BNSF)	Milena Aleksandrova aleksandrova@mon.bg +359 884 171 363
Canada	Canadian Institutes of Health Research – Institute of Genetics (CIHR-IG) www.cihr-irsc.gc.ca	Pierre-Luc Coulombe pierre-luc.coulombe@cihr-irsc.gc.ca  +1 613 608-8943

Czech Republic	The Ministry of Health of the Czech Republic (MZCR), Czech Health Research Council (AZVCR)	Olga Laaksonen Phone: + 420 604 786 141 Email: olga.laaksonen@mzcr.cz  Monika Kocmanova Phone: +420 778 973 186 Email: monika.kocmanova@azvcr.cz
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France	Foundation For Rare Diseases (FFRD)	Dr. Pauline Nauroy jtc.erdera@fondation-maladiesrares.com
Germany	Federal Ministry of Research, Technology and Space (BMFTR) / DLR Projektträger (BMFTR/ DLR-PT)	Dr. Katarzyna Saedler Dr. Michaela Fersch Dr. Ralph Schuster  +49228-38212453 SelteneErkrankungen@dlr.de
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Ireland	Health Research Board (HRB)	Dr. Aisling Rehill Dr. Siobhán Hackett E-mail: HRB-JTCs@hrb.ie Phone: +353 1 234 5000
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Portugal	Foundation for Science and Technology (FCT)	Rita Cavaleiro (+351) 213 911 541 Pedro Ferreira (+351) 213 924 445 erdera@fct.pt
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