JTC2022
Information Webinar
Question & Answers

Question list :

TOPICS

Which is the reference for the definition of rare disease?

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

Where can we find a detailed list of included diseases?

There is no such a list. It has to follow the definition of what is considered as a rare disease (as defined in the call text, Section 4. *Aim of the call*) and not be part of the excluded area (as defined in the call text, Section 4.2 *Excluded approaches and topics*). You can find prevalence of rare diseases on the Orphanet website.

Can the project be about only one rare disease or will be prioritized projects about several rare diseases with signs in common?

There will be no such prioritisation, it depends on the question that you are trying to address. If you want to lump several rare diseases into one and try to improve the diagnosis for them or find new pathways, then lump them together, that can make a greater impact. But if there is just one rare disease where you have something very specific in mind that could also be a possibility. It really depends on what are /is the disease(s) and what's the status of the research in that disease area.

Are the projects dealing with human patients prioritized or will projects in basic research (cells and animal models) considered for funding?

The call is more about improving diagnosis for patients. Cellular and animal models can be used to validate the results, but these are not the primary aspects of the call.

What is your definition of 'functional genomics', is it going into functional genomics down to cell biology?

The definition is broad, it can go down to cell biology.

What is the definition of a 'pathway model'?

Pathways can either be molecular pathways where you might be able to find similar point of access for diagnosis, or also similar phenotypes that allow common diagnosis.

Does research on digital diagnosis biomarkers is encouraged in this call?

It can be part of a project in this call.

Would the development of an App dedicate to Rare disease diagnosis be eligible for the project?

It depends a bit on what the App is doing at the end and how it accelerate diagnosis (as well as if it is feasible in the timeframe). The validation of the App could also be part of the project.

Is the development of new statistical methods for a rare disease encouraged by this call?

The call is about getting new methods to better diagnose RD. Statistical analysis can be part of that to develop new methods on how to do it better

Can registries on genetic background of rare disease be funded by this call?
There is no encouragement to setting up new registries but you can use data from registries to better facilitate the diagnosis research.

Does all types of research targets are possible: Transition, Accelerator, Innovation...?
The call is not specifically focusing on one part of the development process.

Can rare disease include variable age of onset - paediatric, juvenile and ADULT?
Yes

Does the current call concern only methods for improvement of the DIAGNOSIS of a rare disease? And not for the methods that can improve our UNDERSTANDING what happens to patients after the diagnosis?
Understand what happens to the patients after diagnosis and also where they are referred to, how the overall experience can be improved can also be part of the research.

Is a call including new therapies foreseen after this 2022 call?
This information is not available.

Is ALS included in the grant?
No, ALS cannot be funded.

Are all types of Motor Neurone Diseases, including ALS, excluded?
ALS is excluded. The terms for excluded neurodegenerative diseases are (call text): Projects focusing only on rare neurodegenerative diseases which are within the main focus of the Joint Programming Initiative on Neurodegenerative Disease Research (JPND). 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. Interested researchers should refer to the relevant JPND calls. However, childhood dementias/neurodegenerative diseases are not excluded.

Are rare cancer is excluded?
Yes

Is Ataxia-Telangiectasia eligible in the call?
Yes

Are fungal infections considered as rare diseases?
Infectious diseases (including fungal) are excluded.

I am considering applying for the muscle form of neutral lipid storage disorder (NLSD). While NLSD has some 50 cases worldwide, for NLSDM only 5 cases have been reported worldwide. Clearly there is no patient organization for this and also 4 partners in 4 countries is not easy to find. How to deal with this? Is NLSDM eligible as a disorder anyways?
The disorder should be eligible. Concerning the patient engagement, you need to specify why a certain amount on engagement cannot be reached and how you plan to get patient/patient support input for your research

Is Lafora disease included in the grant?
Lafora disease is eligible for the call.

Is the biliary colangitis included in this call?
Biliary cholangitis is eligible for the call.

Are all neurodegenerative diseases excluded? What about retinal degeneration in ophthalmology? These are rare diseases, too.
No, only those mentioned in the call text, so retinal diseases are eligible

Is schistosomiasis is considered a rare disease?
Schistosomiasis is an infectious disease, so not eligible.

Is myastenia gravis considered rear disease within this call?
Myasthenia gravis is eligible for the call.

Are Pituitary endocrine adenomas eligible (Cushing, Acromegaly, etc.)?
Pituitary endocrine adenomas are eligible for the call.

Is hereditary spastic paraplegia included in the grant?
Hereditary spastic paraplegia is eligible for the call.

Gaucher disease fulfils the criterium as rare disease: carriers of GD are at increased risk for Parkinson: this not causing a problem for a GD project application?
Gaucher disease is eligible for the call.

CONSORTIUM MAKE UP

Can a national partner be a (informal) consortium of 2 labs from 2 different institutes?
Two partners from two different institutes from the same country can participate as different partners. You may check national eligibility rules in the Guidelines for applicants – *Annex 1 Country and Region Specific Guidelines*. In any case the consortium must include at least 4 different countries.

What is the definition of a sub-contractor?
If necessary, to implement the action, consortia may also include sub-contractors, according to country/regional regulations. Sub-contractors may cover only a limited part of the action, 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 limitation of subcontractors per country, as long as their participation is justified and if subcontracting is possible according to national/regional funding rules).

Is it correct that 4 teams need to be involved, not necessarily from 4 eligible countries, but from at least 2?
No, a consortium needs at least 4 partners from 4 eligible countries.

Is it correct that a consortium could be composed, for example, by 2 partners from Spain, 2 from Italy, 1 Germany and 1 France?
Yes, if all are eligible following the national eligibility rules.

Can you please clarify the conditions where the consortium can be increased to 8? If by inclusion of early career researcher, does all partners have to be early career researchers or only one is enough?
The number of partners can be increased to 8 in two cases:
1. The inclusion of partners from participating countries usually underrepresented in projects (Slovakia, Hungary, Lithuania, Poland, and Turkey).
2. The inclusion of Early Career Researchers as full partners

If the funding agencies are from different countries, do the PIs from 4 different countries have their separate projects or do they combine to make it one proposal?
Applications will be submitted jointly by applicants from several countries but individual groups will be funded by their respective regional/national funding organization.

Can one partner be in an applicant in two different consortia?
Mostly yes, but please check national eligibility rules in the Guidelines for applicants – *Annex 1 Country and Region Specific Guidelines*.

Can the project include only researchers and MDs?
Not only. Partners can belong to one of the following categories: Academia, Clinical/public health sector, Enterprises or Patient advocacy organisations. Please check the Call text, section 5.1 *Funding* for complete information

Is it needed/possible to include companies / industry partners?
Yes, partners for Enterprises (all sizes of private companies) can participate. Participation of small and medium-sized enterprises (SMEs) is encouraged when allowed by national/regional regulations.

ELIGIBILITY

Can one submit the same year an ERC and be PI or partner in this call?
There can be no double funding for activities already funded by EC H2020 and Horizon Europe calls. In case you are applying for different projects and asking for funding for different tasks, you can submit the same year.

Can a PI who is the coordinator of a running project that will end on December 2022, apply for this call? If yes, can he apply as a coordinator?
Please check the national eligibility rules in the Guidelines for applicants – *Annex 1 Country and Region Specific Guidelines*.

Please elaborate on the eligibility criteria for medical doctors from Europe. Is this based on specialist training date and the 2-7 years?
There is no general limitation but please check national eligibility rules in the Guidelines for applicants – *Annex 1 Country and Region Specific Guidelines*.

What is the definition for Early Career Researchers for this Call?
Please check section 4.1 of Guidelines for applicants to consult its official definition.

Is this call only for early career researchers?
No. But their participation is encouraged.

Do patient organisations count for the number of countries participating? Can they represent the mandatory fourth country or are four research partners non-PAO required?
That depends on the national regulations. If the PAO can be an independent funded partner in the specific country, than they can be e.g. a fourth partner.

Can subcontractors also be in other countries, e.g. fund a patient organisation in Portugal from Belgian money, while Portugal does not participate?
This depends on the national regulations.

How can you propose funding PAO if the national agencies do not follow your initiative?
The funding of PAO depends on national regulations, PAOs could also be funded as subcontractors.

Can international patient organisations (ePAGs) also be included? Are these eligible for funding?
The patients' organisations have to be legal organisations to be funded, thus ePAGs per se might not be eligible for funding but a patient organisation from the ePAG eligible for funding by one of the participating funding organisations could be eligible.

Can you please share the link for the short guide on patient partnerships in rare diseases research projects?
https://www.ejprarediseases.org/our-actions-and-services/patients-in-research/

Does the participation of early career partners increase the possibility of success of the proposal?
The participation of early career researchers is encouraged but will not increase the success rate and their participation in the project has to be scientifically justified, as all other partners of the consortia.

Are eligible as partner groups from Portugal?
No, Portugal does not participate in the call.

Are USA, UK, NZ, labs eligible as partners?
Partners from countries not participating in the call cannot apply in a consortium as funded partners. They can only participate as collaborators with their own funding.

Would you please elucidate "Please note that the inclusion of a non-eligible research partner (principle investigator) in a proposal leads to the rejection of the entire proposal without further review."?
This note means that in case one of the partners in a consortium is not eligible, then the whole consortium will be considered as non-eligible and will follow the evaluation process. Applicants therefore must contact their respective funding organizations and confirm eligibility in advance of submitting an application. The adherence to the national/regional regulations in the Guidelines for applicants is mandatory.

Do we need formal proof of eligibility or is sufficient if partner inquires and receives confirmation?

No formal proof of eligibility are requested in the proposal but the inclusion of a non-eligible partner in a proposal will lead to the rejection of the entire proposal without further review. Applicants therefore must contact their respective funding organizations and confirm eligibility in advance of submitting an application. The adherence to the national/regional regulations in the Guidelines for applicants is mandatory.

BUDGET

What's the budget per project?

This depends on the national regulations and composition of the consortium, please check the guidelines.

What is the maximum budget that can be applied?

The maximum budget is defined in the Guidelines for applicants for each participating funding agency.

Is a specific budget offered for coordination/coordinators? Would be very helpful, this is the glue that sticks consortia together.

This depends on your national regulations, usually coordination can be part of the funding request.

Is there a list with the expected amount of partners funded per country?

The committed budget and expected number of partner to be funded for each participating funding organisation is described in the Guidelines for applicants.

For one proposal from 4 different countries will there be a single budget or 4 different budget?

4 different budgets.

CONTENT OF THE PRE-PROPOSAL

Do we need to provide a data management plan at the submission stage?

The data management plan has to be described in the full proposal stage.

Where can we find on the website the forms to complete with the guidance for length, etc.?

Link to the pre-proposal form:
https://www.ejprarediseases.org/wp-content/uploads/2021/12/JTC2022-Form-Pre-Proposal_fv.docx

GENERAL QUESTIONS

Could you give us the link to register and find research partners?

Link to the JTC2022 matchmaking tool:
https://live.eventtia.com/en/jtc2022matchmaking

Could you give us the link to all information on the call?
Link to the EJP RD JTC2022 webpage: https://www.ejprarediseases.org/jtc2022/

Could you give us the link to register and create consortium for the application?
Link to the electronic submission system:
https://ptoutline.eu/app/ejprd22

Is there any contact point we can contact if we have further questions when building the project?
For general questions regarding the joint call please contact the Joint Call Secretariat at the ISCIII, Spain: Ignacio Baanante Balastegui (Ibaanante@isciii.es ; +34 91 822 25 76) and Maria Druet (mdruet@isciii.es ; +34 91 822 2530)
For questions regarding national eligibility criteria and requirements please contact the national contact person:
https://www.ejprarediseases.org/joint-transnational-call-2022-announcement/

Where we can find national information about this call?
Link to the Guidelines for applicants (starting in page 13) :
https://www.ejprarediseases.org/documents-jtc2022/

What is the advantage of calling a project a 'new' project or an 'extension'?
There is no advantage. In the case of an extension, a dedicated part to describe results of the previous project is available.

Where can we find information on already funded projects?
Link to previous funded projects in EJP RD: https://www.ejprarediseases.org/our-actions-and-services/funding-opportunities/funded-projects/

FAIR /DATA

Can the main PI be located in a different site than the site hosting the data? This is about the EU regulations not allowing Canada to host the data.
The coordinator does not necessarily have to hold the data, it can be hold by a partner is located within EU.
There is some work ongoing in the EJP RD to work out the specification to enable data to be federated to be able to do analysis on federated data. It could mean that even if based in Canada, the data that is in Europe could be used, and the other way around as the data stays in its legal environment.

Does this upcoming grant proposal need to comply with FAIR standards?
We advise to link to FAIR groups/service providers, possibly via the EJP RD, to address the FAIR requirements in the call. FAIR should not get in the way of the science you apply for, but FAIR collaborators can help your project be FAIR & VP compliant once it starts.

How is it possible to share data between partners with the GDPR and other rules? Is FAIR for this kind of purpose?
Having data FAIR at source: you enable the possibility that your data stays at source and can be visited, being a form of sharing as well. It can avoid some legal issues to move data from one place to another.

Is linking to RD Connect and uploading genomic data to their database, sufficient to be 'FAIR'? Idem for ELIXIR?
It's generally advisable to upload it when you can. When there are platforms like the RD Connect, Genome Phenome analysis platform, EGA or some of this repositories, it is generally advisable to upload your data there if possible. Some aspects of FAIR would be covered by those repositories.

In the case of the development of an App, the FAIRification process will need some specific expertise in terms of partners involved in the whole app development and ensuring data availability...is there some specific mentoring area dedicated to that?
In some cases the FAIRification is not something only for data management, it's also a part of the project. It is not a problem, FAIRIfication experts can be part of the consortium. The mentoring service could also be used as it will be how to get to an implementation of an App within the project. This part will have to be detailed more specifically in the full proposal.