



CALL FOR RESEARCH PROJECTS

[Rules for Submission](#)

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Executive Summary

This document describes the Call for Research Projects in the Share4Rare (S4R) platform. S4R uses collective intelligence for the generation of awareness and advanced knowledge to perform research in the field of rare diseases.

The Call will be open from **July 5th 2023 to September 30th at 17:00h CEST.**

Share4Rare. The platform

The mission of Share4Rare (S4R) is to enhance research in rare diseases by generating knowledge collaboratively. Conceived as a platform for interaction between patients and caregivers, S4R promotes communication between users who share needs, doubts and daily challenges.

On the other hand, S4R offers researchers a secure infrastructure to carry out their research, with the accompaniment of a team of professionals trained to provide personalized support and facilitate the research process.

Objective

The objective of this Call is to select 2 research projects to be co-implemented and developed on the Share4Rare platform.

Research topics

Whether qualitative or quantitative research, the projects that Share4Rare encourages are those that facilitate the understanding of aspects of the rare disease such as its impact on the quality of life of people who suffer from it or who live with it, the description of the natural history of the disease, the side effects of specific treatments, the prognosis of the disease, etc.

Calendar

This Call will be open from **July 5th 2023 to September 30th at 17:00h CEST.**

The end date of the collaboration will be defined according to the selected project

The evaluation process will consist of 2 stages: Admission and Assessment.

Fundació San Joan de Déu (FSJD) holds the right to modify the scheduling of the Call due to internal requirements.

Application Process and documentation

Applicants must fill in the **contact form** with the data from the organization and the person responsible of the project. They must also fill in the **application form** providing all the required information about the project.

Finally they must sign the **financial commitment** letter, stating that applying organization has the necessary initial contribution to carry out the project.

These three documents must be completed and emailed to the attention of the Share4Rare Coordinator: info@share4rare.org within the specified period. The forms and the letter of financial commitment can be found in Appendices 1, 2 and 3.

Before sending the documents, and in case that applicants deems it appropriate, they can request an online advisory meeting from the Share4Rare Coordinator to clarify any doubts about the project proposal and the budget.

Language of the application

Proposals must be written either in Spanish or in English.

Who can apply?

Patients' organisations or academic institutions and other related stakeholders interested in promoting research in which patients are key for the gathering of relevant information about the rare disease.

What will the applicants have access to if their application is selected?

- Participate and promote research with a patient-centred approach.
- Use **Share4Rare** to collect clinical data and information delivered by patients and caregivers.
- Access to services for data study and analyses.
- Access to support of a team specialized in collaborative scientific initiatives in the field of rare diseases.
- Access to basic tools such as forms, models, validated scales, guidelines and support material for enhancing citizen science projects.

Evaluation Process

The evaluation process is composed of two stages: admission and assessment. In the first stage, eligibility checks will be conducted by the coordinator of Share4Rare (FSJD). All pre-selected applications will be reviewed to ensure the fulfilment of the criteria published in this Rules for Participation. Any application which does not fulfil the criteria published in this Rules for Participation or that does not have the mandatory documents will be rejected and a notification will be sent to the applicant.

Stage one: Admission. Criteria

Applications submitted within the established period and written entirely in Spanish or English will be accepted.

Only one proposal per researcher, responsible or research group will be accepted.

Proposals accompanied by the contact form and the letter of financial commitment will be accepted.

Stage two: Assessment. Process

Once the admission criteria have been checked, the evaluation process will be carried out.

The Share4Rare Coordinator (FSJD) will request the evaluation of the applications from a Data Access Committee (S4RDAC) composed ad hoc of experts from the Share4Rare team and members of external institutions: the S4R coordinator, a member of an ethics committee, two patient representatives, a data scientist, two clinical experts and a legal advisor. S4RDAC will evaluate each application based on the information available on the application form.

If deemed necessary for adequate evaluation, the applicant can be invited to an online/phone interview to present the research project in more detail.

The evaluation of the proposals will be individual, that is, each member of the S4RDAC will make its individual evaluation of each proposal. During the assessment, S4RDAC experts will be asked to rate each application assigned to them according to three criteria:

Research impact (Score 1-10): score in terms of expected impact of the research project:

- a. Commitment from the applicant to recruit patients to be involved in the research project.
- b. Quality and innovation of the proposal/Research question.
- c. Uniqueness of the study.

Alignment with the interests of the community of patients, proposals covering unmet medical needs will be prioritized.

Network impact (Score 1-10): score in terms of expected impact of the investigator and the research project in the Share4Rare community:

- a. Willingness to participate in the dissemination and communication activities of the research project.
- b. Availability to produce reliable information on the disease.
- c. Willingness to share the Share4Rare platform within their Social Media and institution communication tools.

The evaluation will include comments to clarify and/or justify each of the scores. These comments must be consistent with any scores awarded and serve as input to any consensus discussion and related consensus report. The minimum threshold to retain an application for each individual criterion is 7. The overall threshold, applying to the sum of the two individual scores, is 15. Applications not reaching these minimum thresholds will not be considered for use of S4R platform.

Feedback on the evaluation process

The Share4Rare Coordinator will send a decision letter and an evaluation report to all eligible applicants.

S4RDAC will formally reject all applications not eligible or failing to reach any of the threshold scores for evaluation criteria. Rejection does not prevent an applicant to apply again to subsequent calls.

Appeal Procedure

Applicants have 20 calendar days from the date of sending of the formal decision letter to request clarification of the evaluation process. This can be done by submitting a request to Share4Rare coordinator at the email address: info@share4rare.org. Share4Rare coordinator will confirm receipt and respond to the request within a maximum period of 15 calendar days.

Financial contribution

The estimated cost of a research project is 30,000 EUR per year, although it may vary upon the particular conditions of the project. Whatever the cost is, FSJD will co-finance 50% of the expenses related to the management of the research project, up to a maximum of 15,000EUR.

The amount of financial contribution will be dedicated to cover:

- Dedicated staff to guide patients through the research project and to monitor patient enrolment.
- Ethics committee application.
- IT support to develop the research project on the S4R platform.
- Engagement and communication activities and other services to promote the research project.
- Data analysis services including data curation.
- Report of the results.
- Scientific publication advisory support.
- Crowdfunding tool.

All applications must be accompanied by the **letter of financial commitment**.

The research project will begin with the approval of the S4RDAC and 30 natural days upon the payment of 50% of the applicant contribution. The remaining 50% will be paid at the end of the project.

General obligations

The use of Share4Rare should be cited on the same basis all software that was used to generate and analyse data in scientific publications. Share4Rare team members won't appear as author in the publications (unless this is requested).

Confidentiality

The confidentiality of the applications presented is guaranteed throughout the entire process. In any case the general characteristics of the applications may be disseminated and, in course, the name of accepted projects (included logo) a brief description, the name of the project and his/her photo may be published through, without limitation, press releases, e-mails, and website to communicate information about the Call.

The information content and the results of the projects, as well as any other information and documentation exchanged within the framework (including information regarding other project participants) of the Call shall be considered confidential information (hereinafter the “**Confidential Information**”).

The Share4Rare Coordinator, the S4RDAC Committee and all the applicants, as well as any other person attending the activities, shall undertake, unless prior authorization in writing is received from the other parties, to:

- Keep the Confidential Information strictly confidential and not to disclose it to any Third Parties.
- Not use the Confidential Information for any purpose other than the development of the project.
- Restrict access to the Confidential Information exclusively to those employees, collaborators, and/or professional advisers that, under the obligation of confidentiality, need to access the Confidential Information strictly for the development of the Project; and
- Return the Confidential Information without keeping any copies or summaries when the Call is terminated.

Confidential Information does not include information that: (a) is or becomes publicly known or available before or at the moment at which it is received or obtained; (b) the information is obtained without being subject to any confidentiality obligation; or (c) the disclosure of the information is required by law or judicial order in which case said disclosure request must be previously notified, in advance, to the other party, so that the latter can implement the actions it considers necessary to prevent or limit the disclosure.

Data Protection

The applicants authorize Share4Rare Coordinator to access, use, and share information from the projects submitted to the Call, including all documents referred to therein, whether submitted at the time of the application or at a later stage, for the purposes of this Call and to the extent necessary, including but not limited to, the evaluation, selection and following up the projects.

Data subjects can ask for more information and/or exercise their rights of access, rectification, removal, restriction, portability, and objection before the Data Protection Officer of FSJD at C/Santa Rosa, 39-57, 08950 Esplugues de Llobregat, Barcelona, or at the e-mail address hospitalbarcelona.dpd@sjd.es.

Other obligations

1. Applicants shall collaborate with Share4Rare representatives on the implementation of the activities indicated in the proposal in line with the highest quality standards and state-of-the-art scientific development, and in compliance with the provisions of all legal obligations under applicable EU, international and national law.

2. Applicants are sole responsible for the recruitment of users for their research study, which will be supported by Share4Rare dedicated staff on the registration, validation and enrolment to the study.
3. Applicants must provide any information requested by Share4Rare in writing at any time to verify the proper implementation of the activities in compliance with the general obligations.
4. Applicants must immediately inform Share4Rare of any situation affecting the implementation of the activities foreseen in the proposal. In particular the applicant must promptly provide any relevant information on:
 - a. any obstacles and/or limitations that may prevent or are likely to affect or delay implementation of the activities foreseen in the proposal;
 - b. any relevant changes in the applicant legal, financial, technical, organisational or ownership status that may affect implementation of such activities;
 - c. any circumstances that may affect the applicant's due diligence in the management of the Financial Contribution or the compliance with the obligations of this Call for Research Projects.

Appendix 1 - Contact Form

Contact details of the person in charge of the proposal
Name and Surname
Email
Legal name of the organisation
Address of the organisation
Disease of interest
Title of the project
Objective/s of the project (max. 1000 characters)
Summary of what you intend to do / study (max. 1 page)

Please, complete the contact form provided above and send it via email to info@share4rare.org:



Appendix 2 – Application Form

Research opportunity details
Title of project
Name and affiliation of the person in charge of the proposal
Is a patient organisation involved in the research study? (If yes)
Does this patient organisation have a scientific advisory board?
Research experience of the person in charge of the proposal (or the group) during the past 5 months, if any
Stage of the project
Funded/Pre-funding
If pre-funding, please give details of the planned source of funding and the key dates for submission, resolution and the beginning of the funding
Do you plan to use the Share4Rare Crowdfunding tool to fund your research project?
Yes/No
Has the project been approved by an ethics committee? If yes, please attach the correspondent approval
Yes/No
Please give a summary of the proposed activity in the format provided below
Study title: Justification of the need: Hypothesis: Objectives: What next/who to contact:
Target population - Disease: - Who can participate? - How many patients are you planning to enrol?
Methodology - Stage of the project where are you planning to incorporate the Share4Rare research tool - How many questionnaires will be used? - Are them validated scales? - How many questions per questionnaire?



<ul style="list-style-type: none">- Which information do you plan to collect?- Which statistics will you use?
How will the study benefit people affected by the disease?
Is there any patient organization that will support recruitment?
How do you expect to recruit the users for your research project? Please notice Share4Rare will not be responsible of the users' recruitment.
Has the project sponsorship of a pharma company? Which is the purpose of this support?
Yes/No
How will you feedback to Share4Rare and the people who get involved regarding how their involvement has made a difference and of the outcome of the research?

Please, complete the application form provided above and send it via email to info@share4rare.org



Appendix 3 – Letter of Financial Commitment

From:

(Name and surname of the proposal's responsible)

(Name of the Organization or Institution)

(Mailing Address)

(E-mail)

To:

Begonya Nafria Escalera

Share4Rare Coordinator

Fundació San Joan de Déu (FSJD)

C/ Santa Rosa, 39-57, 08950 Esplugues de Llobregat, Barcelona

info@share4rare.org

Dear,

I declare that I am aware of the economic conditions required for the development of the research project on the Share4Rare platform and that I will comply with the following co-financing agreements:

The annual estimated cost of a research project is €30,000, although it may vary upon the particular conditions of the project. Whatever the cost is, Fundació Sant Joan de Déu (FSJD) will contribute with 50% of the cost, up to a maximum of €15,000 and the applicant will undertake the rest of it.

In all cases, the applicant undertakes to make a first payment of 50% of the budgeted cost at the beginning of the project. The remaining 50% will be paid at the end of the project.

The research project will begin with the approval of the S4RDAC and 30 calendar days after the payment of 50% of the contribution by the applicant entity.

Likewise, I undertake to comply with the financial obligations described in the Rules for Submission and to inform of any change or financial situation that may affect the development of the project.

Sincerely,

(Applicant's signature)

(Applicant's name and surname)

(Place and date of the signature)

Please, fill in the letter of financial commitment provided above and send it via email to

info@share4rare.org

