



New S4R services portfolio

SELECTION OF RESEARCH PROJECTS FOR 2025

February 2025

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1. INTRODUCTION

What is Share4Rare?

Share4Rare (S4R) is an online platform focused on rare diseases research. The S4R community consists of patients, caregivers, and patient associations from over 50 countries who actively contribute their data and experiences to the studies or research projects conducted on the platform. In this way, S4R allows knowledge to be generated collaboratively.

S4R aims to support new projects based on patient-reported data by 2025 to promote rare diseases research.

Benefits of Share4Rare for Researchers:

S4R provides a secure and private infrastructure for collecting self-reported data from patients or their caregivers and professional support throughout the project's implementation and development.

The services S4R offers to the research teams during the project's implementation in the platform are:

- Guidance from a specialized team in rare diseases research initiatives and data-based projects.
- Advice on study design: sample size; hypotheses and objectives; questionnaire design; identification of the statistical variables to be studied; consultation with researchers from the Sant Joan de Déu Research Institute.
- Support on obtaining project approval from the Ethics Committee of the Sant Joan de Déu Research Foundation.
- Implementation of the questionnaires and scales in different languages.
- Support on recruiting participants by condition (and symptoms), country, or other demographic characteristics.
- A private and secure environment for collecting patient data and clinical image data through forms, validated scales, clinical image files, etc.
- Access to statistical analysis services for the collected data and support in interpreting the result reports.
- Advice and support in disseminating the results to participants (design of dissemination materials).

This document describes the guidelines to be followed by patient associations, academic institutions, or other entities in order to request services for the development of research project on the S4R platform.

2. PROJECT SELECTION PROCESS

Objective

The ultimate goal of the Project Selection Process is to promote the generation of scientific knowledge about rare diseases. To achieve this, we will provide support to research projects that require the services offered on the S4R platform.

Type of projects

Projects submitted must require data that are self-reported by patients or their caregivers, whether they are studies on a specific rare disease or cross-sectional studies for a group of diseases. The projects can be addressed to collect quantitative or qualitative data and target different goals such as the description of the natural history of the disease, patient registries, analysis of the disease burden, quality of life of patients and/or their caregivers, creation and/or validation of scales, correlation between patient-reported data and clinical imaging data, etc.

Who can request a service from S4R?

Patient organizations, academic institutions, or any interested parties aiming to promote research in rare diseases, in which the patient is the key element for collecting relevant information about the disease.

Deadline for submission, evaluation, and selection

This process will open on 24 February 2025 and close on 31 August 2025.

This process is non-competitive, all projects that meet the requirements described in this document and that submit the documentation within the established deadline will be evaluated.

The final definition of the services required by each project will be jointly agreed upon between the S4R team and the applicant entity. After the initial evaluation of the project and the necessary meetings to discuss the terms of the collaboration, a proposal of services and its quotation will be provided for the approval.

Confidentiality

Within the framework of this selection process, all information provided by applicants will be considered confidential. Therefore, the Sant Joan de Déu Research Foundation commits to maintaining the utmost secrecy about it until both parties agree otherwise.

3. SUBMISSION AND APPLICATION PROCESS

To submit a request of service, entities must send the **Research Proposal Form** (Annex 1) to the email address info@share4rare.org, written entirely in Spanish, Catalan, or English. Any questions regarding the information required in the form can be included in the same email. Any clarifications or notifications from S4R will also be sent via this email.

The deadline for submitting the **Research Proposal Form** is 31st August 2025 to the above-mentioned email address.

This document will be evaluated by the S4R FSJD Coordination team, who will provide an initial quotation of the project based on the information provided by the applicant. This assessment will be sent to the applicant via email.

An online meeting will then be scheduled with the contact person of the organization/company that requested the services. The purpose of this meeting is to assess the project's needs and agree on the terms of the services to be provided by the S4R team.

Based on the agreement between both parties, the S4R FSJD Coordinator will provide the applicant with the final quotation for the services. This will cover the project's costs according to the specific requirements of each study:

- Advice on the design of the research project.
- Submission of the project for evaluation by the FSJD Ethics Committee, necessary for the start of a research project.
- Design and implementation of data collection questionnaires.
- Translation of the questionnaires or scales into different languages, if necessary.
- Design of dissemination activities and materials for the study.
- Creation of an informative landing page to facilitate participant registration in the study.
- Project management (including regular meetings with the applicant entity and/or Principal Investigator).
- Data analysis and result reporting.
- Advice on scientific publications.

If the applicant accepts the final quotation, they must communicate this via email and attach the **Financial Commitment Letter** (Annex 2). This will initiate the project execution on the agreed calendar. The applicant must pay 50% of the service cost within 30 calendar days of accepting the proposal of services. The remaining 50% will be paid in two installments: 25% halfway through the project and 25% upon completion.

Annex 1 – Research Proposal Form

Contact Information of the Person Responsible for the Proposal
Legal name of the organization
Name and surname of the contact person
E-mail address of the contact person
Postal address of the organization
Disease of interest on which the research will focus
Project or Study Information
Project title
Project typology
<input type="checkbox"/> Study of the natural history of the disease <input type="checkbox"/> Quality of life study (of patients and/or caregivers) <input type="checkbox"/> Patient registry or observatory <input type="checkbox"/> Validation of scale/s <input type="checkbox"/> Correlation of data with clinical imaging <input type="checkbox"/> Other. Specify:
Summary of the main objective of the study. How will the study benefit people affected by the disease? (maximum 1 page)
Study Population
Who is the study aimed at:
<input type="checkbox"/> Patients <input type="checkbox"/> Caregivers
Age range of the study population, only if the population is patients:
In which language(s) the study will be implemented:
In which country(ies) the study will be implemented:

Methodology
Do you need help with the project design? <input type="checkbox"/> Yes (Please fill in the sections you can answer for now and request a meeting) <input type="checkbox"/> No (Please continue to fill out the form)
Study sample size (and, if applicable, control group size):
Study hypothesis
Specific study objectives
Timeline: How long will the study last? Indicate the estimated start date and the estimated end date:
Do you have or will you have the questionnaires and/or scales that are part of the study and will be implemented in Share4Rare? <input type="checkbox"/> Yes <input type="checkbox"/> No
Participants Recruitment
<input type="checkbox"/> The patient entity or organisation will be in charge of the recruitment <input type="checkbox"/> We need Share4Rare to recruit participants
In case the applicant organization is recruiting participants, please describe how it will be done. Please note that Share4Rare can provide technical support and follow-up in the registration of participants.
Pre-funding or sponsorship
Is the project sponsored by any pharmaceutical company? <input type="checkbox"/> Yes <input type="checkbox"/> No
If yes, please indicate the purpose of such sponsorship:
Dissemination
How will you inform Share4Rare and the participants about the research results? (e.g., thank you letter and final report, informative webinar, video of the researcher)
Are there any dissemination actions planned to help give visibility to the study and recruit participants? Please describe them briefly.

Please send the completed application form to info@share4rare.org.

Annex 2– Financial Commitment Letter

(Name and surname of the person responsible for the proposal)

(Name of the organization or entity to which they belong)

(Full address)

(E-mail address)

.....(Date)

A/A: Begonya Nafria Escalera
Share4Rare Coordinator
San Joan de Déu Foundation (FSJD)
C/ Santa Rosa, 39-57
08950 Esplugues de Llobregat, Barcelona
info@share4rare.org

Dear:

(Name and surname) in my capacity as
(position)..... of the (organization)..... I declare that I am aware of the
financial conditions required for the development of the research project on the Share4Rare
platform and that we will comply with the following agreements:

- The annual cost of the project will be fully funded by the applicant organization.
- We undertake to make a first payment of 50% of the service cost within 30 days of the budget acceptance, 25% of the budget cost halfway through the project, and the remaining 25% at the end of the project.

We also undertake to report any financial changes or situations that may affect the development of the project.

Yours faithfully,

(Signature of applicant)

(Full name of applicant)

Please complete and sign the financial commitment letter and send it to info@share4rare.org.