

Appendix 2 – Application Form

Research opportunity details
Title of project
Name and affiliation of the person in charge of the proposal
<p>Is a patient organisation involved in the research study? Yes/No.</p> <p>If yes, does this patient organisation have a scientific advisory board? Yes/No.</p>
<p>Research experience of the person in charge of the proposal (or the group) during the past 5 months, if any</p>
<p>Stage of the project: Funded/Pre-funding (Please, take into account the mandatory financial contribution and the payment terms)</p>
<p>Has the project been approved by an ethics committee? Yes/No If yes, please attach the correspondent approval.</p>
<p>Please give a summary of the proposed activity in the format provided below (3 pages max.):</p> <p>Study title:</p> <p>Justification of the need:</p> <p>Hypothesis:</p> <p>Objectives:</p>

Regarding the study:

Target population:

- **Who can participate? (patients, caregivers, specific disease, age rank)**

- **In what countries is the study going to be held?**

- **In what languages is the study going to be held?**

- **What is the expected sample size?**

Methodology:

Write down the name and features of each one of the questionnaires that will be used:

- **Questionnaire 1:** (Name/Title). Validated/Not validated. Number of questions. Type of information collected

- **Questionnaire 2:** (Name/Title). Validated/Not validated. Number of questions. Type of information collected

- **Questionnaire 3:** (Name/Title). Validated/Not validated. Number of questions. Type of information collected

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- **Questionnaire 4:** (Name/Title). Validated/Not validated. Number of questions. Type of information collected

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- **Questionnaire X:** (Name/Title). Validated/Not validated. Number of questions. Type of information collected

Describe the data analyses needed to be done by Share4Rare: what variables and what statistical tests

<p>How will this Project benefit to people affected by <u>(name of disease)</u> _____?</p>
<p>Patients recruitment: Will you need support in recruiting patients? (Yes/No) In case the applicant will recruit the patients, please describe how it is going to be done. Please, take into account that Share4Rare will give technical support and guidance to patients enrollment through the online registration process.</p>
<p>Has the project sponsorship of a pharma company? Yes/No</p>
<p>If yes, which is the purpose of this support?</p>
<p>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? (Examples: sending a <i>thank you</i> letter with the final report, through a webinar, a video, an infographic document, etc.)</p>
<p>Do you have any dissemination actions planned that will bring visibility to the study and help recruit participants? Please describe them briefly.</p>
<p>Is the applicant (Patient Organization) a member of the Share4Rare Community or is planning to be?</p>

Please, complete this application form and send it to info@share4rare.org.