# Annex 1 – Research Proposal Form

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| **Contact Information of the Person Responsible for the Proposal** |
| **Legal name of the organization** |
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| **Name and surname of the contact person** |
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| **E-mail address of the contact person** |
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| **Postal address of the organization** |
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| **Disease of interest on which the research will focus** |
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| **Project or Study Information** |
| **Project title** |
|  |
| **Project typology** |
| Study of the natural history of the disease  Quality of life study (of patients and/or caregivers)  Patient registry or observatory  Validation of scale/s  Correlation of data with clinical imaging  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:  Patients  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?**  **Yes** (Please fill in the sections you can answer for now and [request a meeting](mailto:info@share4rare.org))  **No** (Please continue to fill out the form) |
| **Study sample size (and, if applicable, control group size):** |
|  |
| **Study hypothesis** |
|  |
| **Specific study objectives** |
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| **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?**  Yes  No |
| **Participants Recruitment** |
| The patient entity or organisation will be in charge of the recruitment  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?**  Yes  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](mailto:info@share4rare.org).