# Annex 1 – Research Proposal Form

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| **Contact Information of the Person Responsible for the Proposal** |
| **Legal name of the organization** |
|  |
| **Name and surname of the contact person** |
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| **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** |
| [ ]  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[ ]  CaregiversAge 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) [ ]  **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?** [ ] 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.