

Bulletin #08

Request for Proposal Questions and Answers

File #C-2401280 Rare Disease Registry Funding

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Questions may have been edited for clarity or to maintain confidentiality. Answers will be provided in the language of the original submission.

Question 1, Received May 14, 2024

Reference Request for Proposal (RFP) Section 3.2 (Proposal Preparation Instructions)

Question: I need clarification regarding the project's end date. Initially, we were informed that the contract was to end after 10 months, yet the recent update mentions a completion requirement by March 31, 2025, effectively a 9-month period. Can you please clarify the expected end date for the project?

Answer: To clarify, the end date for the project is March 31, 2025. This time frame is set to ensure that all work is completed within the fiscal year, which aligns with our funding and administrative procedures. Given this fixed end date, we advise all applicants to tailor their project proposals to ensure that all work can be realistically completed within this time frame. Please note that the actual start date of the project will depend on when the contract is fully executed. To facilitate a smooth and timely start, we encourage all applicants to expedite the contract signing process.

Question 2, Received May 14, 2024

Reference RFP Appendix 2 (Expenses)

Question: Is it permissible to use rare disease registry funding to cover salaries for project leads, co-leads, and principal investigators? If so, what specific guidelines should be followed for these budget allocations?

Answer: Part of the budget can be allocated toward the salaries of project leads, co-leads, and principal investigators, as long as these expenses are directly justified in the context of the project's goals and the overall budget. It is important that such allocations are clearly detailed in your proposal under the financial proposal requirements. This should include specifying the amount of time these key personnel will dedicate to the project and how their involvement contributes to achieving the project's objectives.

Question 3, Received May 14, 2024

Reference RFP Section 3.2 (Proposal Preparation Instructions)

Question: We have received inquiries about the level of detail required for describing team members in the application. Specifically, can you clarify what information is needed for "affiliations" and what level of detail is necessary for each lead, co-applicant, and other collaborators, considering space limitations and the need for comprehensive conflict of interest information?

Answer: In the context of your application, "affiliations" should detail the specific relationship of team members, primary leads, and co-applicants with their primary professional settings, such as their departments and institutions. To clarify, we require comprehensive details, as stated in the RFP, for leads and co-applicants who will be directly involved in the project. This detailed

information helps us evaluate the team's capacity and suitability for successfully managing and implementing the project. However, for collaborators at various clinical sites involved in data collection or other supportive roles that do not directly influence the specific projects proposed for this RFP, it is sufficient to list their names and a brief summary of their involvement.

Question 4, Received May 14, 2024

Question: Can the allocated funds be used to purchase computers and other essential hardware and/or software for operations? In which budget category should we include items such as the purchase of equipment or software, since these are not covered under an hourly rate?

Answer: Yes, funds can be used to purchase computers and other essential hardware and/or software necessary for project operations. All equipment and software purchases should be listed under the Tangible Items section in your budget. A new financial proposal form will be available on the RFP website that includes a designated section for these items. When detailing these items, please add them to the form, specifying the number of units and the unit cost for each item.

Question 5, Received May 14, 2024

Question: Following the update in Bulletin 7 that the submission will be in the form of a contract, not a grant, we have concerns regarding the legal implications, as our registry operates under a larger hospital corporation. We are concerned that there will be a very large overhead and also that the institution will have concerns regarding entering a contract with a third party that is not part of our original agreement, and/or that this will create a substantial delay for approval. Could you please send us a copy of the contract for our legal team to review? If the contractual terms are too onerous, we will likely not be able to submit our full proposal.

Answer: We recognize concerns regarding potential overhead costs. Overhead costs will be detailed in the contract, and we are open to discussing these terms with you to ensure that they are both reasonable and mutually agreeable. Regarding your institution's concerns about entering into a contract with a third party, we are prepared to engage in discussions with your legal and administrative teams to clarify any issues and expedite the approval process. Our goal is to ensure that the contractual terms do not create barriers to participation. Given the structured timeline of the project, which must be completed by March 31, 2025, we emphasize the importance of expediently reviewing and signing the contract. Delays in this process could impact the project's timelines and deliverables. After applicants are notified of the outcome of their proposal submissions, contract terms will be shared with those applicants who are successful.

Question 6, Received May 15, 2024

Question: Bulletin 7 clarifies that funding is provided through a contract rather than a grant. Are project leads completely bound by their deliverables for payment? Would you recommend setting specific dates for each deliverable, or would a time frame suffice? What are the implications if deliverables are delayed (e.g., due to extended Research Ethics Board approvals)?

Answer: Yes, payment under the contract is contingent upon the completion of the deliverables specified in the contract. We recommend setting specific dates for each deliverable to provide clear, measurable targets for project execution.

To manage financial risk and ensure project completion, the contract will specify that 50% of the funding will be disbursed at the project's launch. The remaining 50% will be released upon the project's successful completion and fulfillment of all contractual deliverables.

We understand that project timelines might be affected by unforeseen circumstances, such as delays in obtaining Research Ethics Board (REB) approvals. While we aim to be flexible by considering extensions on a case-by-case basis, it is crucial for applicants to understand the distinction between a contract and a grant, and that the successful completion of deliverables is necessary for final payment. If there is uncertainty about obtaining timely REB approval, applicants might consider deferring their submission until the next RFP when such approvals are secured.

Question 7, Received May 15, 2024

Question: Who is considered the executor of the contract? Is it the organization managing the registry, the principal investigator affiliated with this organization, or the institution hosting the registry servers?

Answer: The executor of the contract should be the entity or individual who can ensure oversight and accountability for the project's execution and the appropriate use of funds. Typically, this would be the organization managing the registry. However, if the registry is managed by a steering committee without a single leading organization, the executor could be the custodian organization that oversees data-sharing agreements and operations. If the principal investigator is directly affiliated with the managing organization and plays a significant role in the oversight and execution of the project, they could also serve as the executor. Ultimately, the designated executor should be capable of fulfilling the contractual obligations and ensuring the project's objectives are met efficiently.

Question 8, Received May 15, 2024

Question: Are applicants permitted to submit letters of support from organizations where data linkage is proposed?

Answer: Yes, letters of support from organizations involved in proposed data linkages can be included as supplementary materials with your application. As stated in Bulletin 6, letters of support do not count toward the 8-page limit for your proposal.

Question 9, Received May 15, 2024

Question: Is it acceptable to modify the subheadings in different sections of the proposal while adhering to the overall 8-page limit? Currently, the structure includes separate aims, each detailed with objectives, work plans, alignment with RFP objectives, risk and mitigation, and deliverables.

Answer: Yes, it is permitted to modify the subheadings in different sections of the proposal, provided the total document does not exceed the 8-page limit. It is important that the modified structure still clearly addresses all of the required elements, such as objectives, work plans, alignment with RFP objectives, risk and mitigation strategies, and deliverables and information about performance measures.

Question 10, Received May 15, 2024

Question: How can I remove the example entries in red from the locked Excel file titled *Financial Proposal Form*? These examples are obstructing the entry of actual costs. I need the password or guidance on how to unlock the file for editing.

Answer: An updated version of the financial proposal form is now, which allows you to input your actual costs directly. Please contact contracts@cadth.ca if you haven't already received it.

Question 11, Received May 15, 2024

Question: Appendix 3 of the RFP states, "To facilitate a standardized reporting process, we will provide a form for the submission of these metrics and data.". We do not have this form. Is it needed for submission, or can we provide this information as part of the write-up? Alternatively, would you like us to provide our own table for this section?

Answer: The specific form mentioned in Appendix 3 will be provided only to successful applicants once the competition concludes and contracts are signed. This form is designed to standardize the reporting of performance measures included in the contract. At the proposal stage, you are not required to use this form. Instead, we ask you to include proposed performance measures related to your project within your proposal.