

Frequently Asked Questions (FAQs)

Notice of Special Interest regarding the Availability of Administrative Supplements and Urgent Competitive Revisions for the Establishment and Maintenance of a Research Database for Neurological Manifestations of the SARS-CoV-2

Notice Number: [NOT-NS-20-046](#)

Scope of the Administrative Supplement

1. Will there be more than one awardee for this NOSI?

NIH anticipates a single awardee. However, we will accept and encourage applications proposing collaboration between eligible data coordinating centers (DCCs) holding active U01 or U24 awards per the NOSI and other research groups that are not otherwise affiliated with a DCC.

2. Is there an award ceiling in terms of direct or total dollars available per year? How many years of supplemental support may be requested?

NINDS has not set an award ceiling. The estimated award is in the range of \$250-500K/year for direct costs. The budget period should not exceed the duration of the parent award.

3. What is the anticipated time window from award to system deployment?

Given the evolving pandemic, rapid development and deployment is needed. There is, however, no specific time window. Please provide your anticipated timeline for database and web portal development and implementation in your application. A phased approach may be considered.

4. What parent announcement number should be used when applying under this NOSI?

Per instructions in the NOSI, the supplement application can be submitted using PA-18-935 (Urgent Competitive Revision to Existing NIH Grants and Cooperative Agreements (Urgent Supplement - Clinical Trial Optional) or PA-18-591 (Administrative Supplements to Existing NIH Grants and Cooperative Agreements (Parent Admin Supp Clinical Trial Optional)), whichever is most applicable. The NOSI number (NOT-NS-20-046) must be included.

Data collection

5. Who will provide/enter data into the web portal? Is data entry to come from institutions or health care providers?

The web portal is intended to collect near real-time data directly from health care providers and institutions. Data can also be incorporated from electronic health records.

6. Will data be collected from practitioners and institutions across the U.S. or would there be more targeted recruitment, such as a regional sample? Will NIH focus on collecting data from existing NINDS network or grant sites?

The NeuroCOVID database is intended to collect data broadly from throughout the USA and will not be targeted to a region, network, or grant sites. NINDS will publicize the NeuroCOVID database widely and aims to collect data spanning both inpatient and outpatient settings

- 7. Do you expect data to be collected in “real time” during the COVID-19 outbreak or can data be collected retrospectively in addition to longitudinally (needed to collect neurological sequelae of infection)?**

The intent is to collect near-real time data , as the COVID-19 outbreak continues to evolve. Due to the emergent nature of the pandemic, we need a system that can be set up and deployed in a timely manner. The NeuroCOVID database system should have the capability to accept follow-up information on patients. The system should include the capacity to be extended to allow collection of retrospective data, including that from electronic health records. As stated above, a phased approach may be considered.

- 8. Does the data collection platform need to be open source?**

We encourage, but do not require, the use of open source resources. Our goal is to have a system that is freely available to all users and can be accessed using any web or mobile browser.

- 9. What specific information will be collected? Who will decide the contents of the data collection form?**

NINDS will provide guidance on relevant data to be collected on SARS-CoV-2 patients with neurological manifestations. The core dataset is not anticipated to be extensive and will include, but not be limited to, Common Data Elements (CDEs) for neurologic signs, symptoms, and testing. The core dataset will be as user-friendly as possible for those entering data manually into the web portal. NINDS expects the applicant to use the NINDS CDEs and other existing international data standards where available.

- 10. Should the application include plans to clean, harmonize, and/or distribute the data for research purposes? Should it include plans for a public use dataset, data dictionary, and distribution procedures?**

Cleaning, harmonizing, and/or distributing data are beyond the scope of this NOSI, but it is expected that the database will be built with the capacity to incorporate such functions in the future. The application should address setting up the NeuroCOVID Database and web entry portal. The system should also include field limits and automated queries to minimize inconsistent or missing data.

Global Unique Identifiers (GUIDs)

- 11. Are the use of GUIDs mandatory? Is the use of GUIDs practical? Does NINDS want the applicant to use the same GUID used by Federal Agencies?**

The purpose of GUID use is to be able to link data from an individual subject across time and across different health care providers. The GUID system used by Federal Agencies is not required. Any approach that can accomplish the goal of tracking and linking individual subjects can be considered.

Please direct all inquiries to:

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