



## Research Request for Non-Identifiable Dataset

(Send to [williams@sninsonline.org](mailto:williams@sninsonline.org))

Request Date: 1/25/2024

Project Name:			
Primary Investigator:		Email Address:	
*Other Contact:		Email Address:	

\*Contact must be authorized to receive dataset on behalf of primary investigator.

**Context and Research Question** (4-5 sentence summary that will be distributed to each center for approval):

**Non-identifiable dataset(s) being requested (includes follow up data):**

Acute Ischemic Stroke (AIS)    Cerebral Aneurysm (CA)    Cerebral Arteriovenous Malformation (AVM)

**Year(s) for which data are requested:**

All available or specify date range:  to

**Required Documentation:** The following information must be provided with the Research Request Form in order to be considered for approval.

- 1) NIH Biosketch/CV,
- 2) Abstract with Research/Statistical Plan (1-2 pages), including but not limited to:
  - a. Key variables for study
  - b. Inclusion/exclusion criteria
  - c. Relevant references to existing studies that inform to this study
- 3) IRB Approval or Exemption for Proposal at your institution, and
- 4) Statement of Relevant Conflicts for all listed investigators

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*Only active participating NVQI-QOD sites are eligible to submit proposals. (Active = entering consecutive data > 1 year.) Only 2 research project approvals in progress per institution.*

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This Data Use Agreement (the “Agreement”) is entered into and made effective as of the last date of signature below by and between Society of NeuroInterventional Surgery (“SNIS”) on behalf of the SNIS Patient Safety Organization (“SNIS PSO”) and Dr. \_\_\_\_\_ (“Recipient”).

SNIS PSO will provide a non-identifiable data set for project, “\_\_\_\_\_” (The Project), to Recipient on the condition that Recipient agrees to the following by signing this form:

1. The Recipient shall not use or further disclose the data set other than as required to complete The Project. The Recipient acknowledges and agrees that SNIS owns all right, title and interest in the data set provided under this Agreement; the data set is provided “as is” without any warranty or guaranty as to its accuracy or completeness; and SNIS is not responsible for any acts or omissions of Recipient in conducting the Project.
2. The Recipient shall allow access to the data only to individuals directly accountable to the Recipient.
3. The Recipient shall use appropriate safeguards to prevent use or disclosure of the data set other than as permitted by this Agreement.
4. The Recipient agrees that this study must be approved by the IRB of the institution that takes responsibility for performing the research prior to publication. Since only fully de-identified data are used for this research, such projects are normally deemed as not requiring human subjects review by an IRB.
5. Publication is subject to review by the NVQI-QOD Governing Council to verify publication is in accordance with NVQI-QOD data and accurately represents the registry.
6. Upon completion of the project, or should this Agreement be terminated for any reason, including, but not limited to Recipient’s decision to cease use of the data, Recipient agrees to destroy or return all data provided pursuant to this Agreement in a manner as directed in writing by SNIS PSO. Recipient will provide written certification of destruction of data sets.
7. The Recipient agrees to present or publish approved project within 24 months with one refresh allowed within that period. The SNIS PSO reserves the right to ask Recipient to return or destroy the dataset if no progress is demonstrated according to these guidelines. Any research publications emanating from the dataset should be submitted to the *Journal of NeuroInterventional Surgery* or the *Journal of Neurosurgery* for right of first refusal, prior to submission to other peer reviewed journals.
8. Authorship Credit: Primary authorship by Recipient investigators performing project. SNIS PSO encourages invitation of 1 author or at least 1 collaborator from all sites that have authorized their data use for this project. Published research must include byline “on behalf of the NVQI-QOD Registry Investigators”. The title of the published research should also include: “<Title>: A study from the NVQI-QOD Registry” or “From the NVQI-QOD Registry: <Title>”.
9. Either party may terminate this Agreement upon thirty (30) days prior written notice to the other party.



This Agreement constitutes the entire understanding and agreement of the Parties regarding the subject matter hereof and shall cancel and supersede any and all prior communications, representations, agreements or undertakings, whether oral, written or otherwise, between the Parties relating to such subject matter. This Agreement may only be modified, amended, supplemented or assigned in a writing and signed by duly authorized representatives of each Party.

**SNIS PSO**

Name (print): Marie Williams Denslow, CAE  
Title: Executive Director, SNIS PSO  
12587 Fair Lakes Circle  
Suite 353  
Fairfax, VA 22033  
williams@snisonline.org

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

**Recipient**

Name (print): \_\_\_\_\_  
Medical Center: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone: \_\_\_\_\_  
Email: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

