Policy title: *ELHS Standard Data Request Form*
Approval status: Reviewed by Holland & Knight; Final
Version date: 08/24/2026

***Epilepsy Learning Healthcare System (ELHS) Standard Data Request Form***

*Information that is obtained or used for research is confidential and must be used only for statistical reporting or research purposes. Therefore, it is necessary to ensure, to the extent possible, that any use of such data be limited to research by legitimate researchers, and in accordance with applicable laws and this Standard Data Transfer Request.*

*This Request to transfer data is made from the following Recipient/Requestor to the Epilepsy Foundation on behalf of the Epilepsy Learning Healthcare System.*

**Part I: Requestor information**

1. Requestor full name:
2. Requestor email:
3. Requestor institution:

**Part II: Requestor certifications**

*The following are required Yes/No questions. If answer to any question(s) is "No," request will be unable to proceed and Requestor should contact elhs@efa.org*

1. ☐ The investigator is affiliated with an ELHS center, an academic institution and/or non-profit organization.
   *(Requests from external researchers, for-profit and industry entities are reviewed and managed using a separate process; contact elhs@efa.org for more information).*
2. ☐ Investigator has documentation of human subject protection training.
3. ☐ The research question aligns with ELHS's research agenda and is not currently being addressed by another investigator. In case of overlap, the ELHS Operations Team may suggest the investigator connect with the research team already working on a similar research question.
4. ☐ The research questions proposed can be answered with the de-identified ELHS dataset. The investigator will need to list the variables needed for completion of the study.
5. ☐ The Investigator is affiliated with or has access to an IRB that will provide review and documentation of its determination. Additionally, the investigator is subject to institutional policies to address protocol violations or other non-compliance, for example, if the requestor fails to meet the expectations (e.g., re-identifies data). A data sharing expectations document needs to be submitted to the requestor's IRB

along with the protocol and should be retained by the investigator with the IRB's determination letter.

6. ☐ The investigator, if a trainee, has identified a senior mentor. If no mentor has been identified, the investigator may ask for assistance in identifying a mentor among the ELHS centers.

**Part III: Request details**

1. If applicable, Senior Mentor:

2. In fewer than 300 words, please provide a brief description of what the proposed project entails, including the background/rationale and if/how it will be published, e.g., Publication in a peer-reviewed journal, conference presentation, etc.:

3. Using the ELHS Data Dictionary for reference, please list all variables you are requesting:

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**Terms and Conditions:**
Terms and conditions for any approved data transfer are specified in the ELHS Registry Data Use Agreement. The Requestor should be familiar with all terms and conditions prior to submission of this Data Request Form. The ELHS Registry Data Use Agreement is available for review at epilepsy.com/elhs

**Attachments:** Please attach documentation of Human Subjects Protection Training along with completed Standard Data Request Form to elhs@efa.org

**E-Signature:**
The Requestor certifies that the statements made in the applicable Data Use Agreement and as above regarding the planned use of the Data are complete and accurate. The e-signature below indicates that the Requestor requests receipt of the Data under the above stated provisions and pursuant to the ELHS Registry Data Use Agreement, including submission of the IRB determination if request is approved, before any data will be transferred.

Signed _____

Name _____

Date _____

**Email completed form to elhs@efa.org**