

Policy title: *Publications Policy*

Approval status: Final

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Epilepsy Learning Healthcare System (ELHS) Publications Policy

Purpose

The Epilepsy Learning Health System (ELHS) network and its individual ELHS members are involved in projects that may intersect and overlap, may be complementary, or could generate conflict. A publication policy should enable open and free discussion of ideas/data which should simultaneously facilitate work at member institutions, investigations within ELHS, and large-scale collaboration with industry, other consortia, and patient organizations. The publication policy aims to balance the sensitivity and novelty of the ideas/data developed at member institutions and within ELHS with the need for rapid and feasible dissemination of ideas/data among members and non-members to rapidly and broadly improve outcomes for patients with epilepsy.

The policy's over-arching guiding principle is that ELHS aims to maximize the dissemination of ideas, data, and analyses from members, member institutions, and ELHS for the benefit of patients with epilepsy.

The policy will be evaluated annually by the ELHS network members and any revisions will be adopted after a majority vote of the network. The policy and any revisions will be provided to each ELHS site and will be available to access in the ELHS Commons site.

Project Types

ELHS recognizes that its activities will lead to publishable findings from ELHS itself and member institutions.

1. Projects including network ELHS ideas/data/analyses/workgroups: Projects must be reviewed and approved by ELHS Publications Committee and all relevant co-authors prior to submission for publication or presentation. Contributions by relevant ELHS members and general support of ELHS should be appropriately acknowledged. The policy statements discussed below are particularly relevant.
2. Projects including only site level data but developed as a result of ELHS projects, data elements, or data collection: ELHS members are strongly encouraged to involve the ELHS Data Coordinating Center and/or Operations Team members may have helpful input, can help disseminate the project within ELHS, and ensure links to ELHS are acknowledged. ELHS members are encouraged to follow the policy statements discussed below.

Guiding Policy Statements

- ELHS encourages dissemination of ideas/analyses from member sites and ELHS to help share knowledge and improve outcomes for patients with epilepsy.

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- ELHS members are encouraged to present analyses from ELHS-related projects at relevant professional/scientific meetings in the form of abstracts, oral presentations, and invited sessions.
 - ELHS members are encouraged to publish ELHS-related projects in scientific journals.
 - ELHS members are encouraged to present to patient support organizations and publish projects in newsletters or publications from patient support organizations.
 - ELHS members are encouraged to seek funding for work related to epilepsy quality improvement for ELHS itself or related projects at member institutions.
- ELHS members should act with the recognition that long-term ELHS success requires that members recognize their responsibility extends beyond their own group, institution, or funding framework. To this end:
 - ELHS members should communicate transparently, share data and ideas in good faith, and bring up potential conflicts early in the process.
 - ELHS members are encouraged to clearly outline the boundary of their ELHS-related work versus non-ELHS related work to avoid conflicts.
 - ELHS members should be transparent about their intended projects and give other ELHS members sufficient opportunity to contribute through use of ELHS email or meetings.
- ELHS members should not publish or communicate on behalf of ELHS to outside collaborators, media, industry, or potential funding organizations without input from the ELHS Operations Team, and following the publications process described here. This will help present ELHS as a cohesive entity and ensure coordination across ELHS.
- ELHS Publications Committee should respond within two weeks to requests from members related to submission to professional/scientific meetings, publications, or other items.

Central ELHS Data

Data generated within the context of ELHS should be shared freely among members but should not be shared/discussed outside ELHS without permission of ELHS Operations Team and the primary researcher/project leader who generated the data/analysis.

ELHS members should not share data or results generated within ELHS with for-profit companies, outside research consortia, or individual external researchers without prior approval of ELHS Operations Team.

General concepts to avoid conflict:

- “Relevant ELHS members” have or might make a substantive contribution to a manuscript. They should be provided sufficient opportunities for involvement with an appropriate timeframe.
- Project leaders should not pressure relevant ELHS members to accept/reject authorship due to unreasonable time constraints (“This manuscript will be submitted in two days.”).

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- Project leaders should not involve relevant ELHS members too late in the process of manuscript development to be able to provide meaningful input (“The manuscript has already been written.”)
- Project leaders should not give undue credit to co-authors/authors above relevant ELHS members based on political consideration (“My Chair needs to be the senior author.”)
- It is the responsibility of the ELHS Data Coordinating Center in conjunction with individual project leaders to enable and implement the necessary infrastructure for data sharing.

Authorship and Acknowledgement

Authorship requires a substantive intellectual contribution to the scientific work and may vary by journal. Contributions may include study conception or design, methodology, data acquisition, analysis, or interpretation. Criteria for authorship are defined according to the following guidelines established by the International Committee of Medical Journal Editors (ICMJE):

1. Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work.
2. Drafting the work or revising it critically for important intellectual content.
3. Final approval of the version to be published.
4. Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated or resolved.

If all the above criteria are not met, then the individual may be acknowledged as a non-author contributor.

First and/or senior author preference will be given to the investigator(s) who conceptualize the study and generate the primary data to be used in the manuscript.

Authorship order and preference on resulting publications should not be unduly influenced by academic rank or unequal access to data or analysis results.

Publications must credit the ELHS registry with: “The author(s) acknowledge the Epilepsy Learning Healthcare System as the source of the data used in this paper. The analysis, interpretations and conclusions expressed do not necessarily reflect the views or policies of the Epilepsy Learning Healthcare System.”

Funding Applications

The use of ideas or data generated within the context of ELHS for applications for external funding is strongly encouraged. However, members must be mindful of potential consequences of such commitments to ELHS as well as potential areas of overlap with other investigations which could be complementary or conflicting. If specific ELHS components are required, then members should obtain input from ELHS Operations Team prior to funding submission. ELHS Operations Team will provide input promptly (within two weeks) and should aim to facilitate funding applications. Proposals which utilize the ELHS infrastructure or resources are expected

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to provide some funding for ELHS which should be determined in advance with ELHS Operations Team.

“On Behalf of the ELHS Network”

Most publications will include specific named authors (criteria above) and the statement “on behalf of the ELHS Network.” The list of members of ELHS will be broad and include all people who are members of ELHS centrally and each member site, generally within the last two years. A detailed list will be maintained by ELHS at the Epilepsy Foundation and posted on the ELHS Commons site.

Disclosures

Each sponsor for ELHS (generally within the last two years) will be listed under disclosures. If the project was funded by a specific sponsor, then the sponsor will also be listed as a sponsor of the study.