

EXTRACORPOREAL LIFE SUPPORT ORGANIZATION



Phone: 1-734-293-2101

ELSO Scientific Oversight Committee Policy

Release of Anonymous Hospital Identifiers

Background

The ELSO Steering Committee has agreed that anonymous hospital identifiers can be considered for release with selected Data Requests. It is essential to provide safeguards for this data in order to protect privacy of individuals and individual institutions. This emphasis on protection ensures that the ELSO Registry's Data Use Agreement with individual centers is not compromised, and centers continue to contribute patient data with the same expectations of privacy as previously.

Principles

1. Investigators are prohibited from releasing, disclosing, publishing or presenting any individually identifying, or individual center identifying information obtained from the anonymous hospital identified data. It is the Principle Investigator's responsibility to prevent data use violation by anyone who has access to the data.
2. Data violations involving center-level data are of paramount concern to the ELSO Community. If a violation were to occur, it could impact the credibility of institutions and investigators. This misuse could result in a loss of privacy for individual patients or release of individual center data which is in direct contradiction with ELSO Registry's Data Use Agreement.
3. Investigators must not attempt to learn the identity of individuals or individual centers through any deliberate technical analysis.

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Protocol

1. Investigators will be required to submit a Data Request form for review by the Registry Data Requests Committee. If the proposed analysis is accepted by the committee, investigators will be required to comply with requirements for Large Dataset Request, initial the principles of conduct (as above) and submit the form to ELSO. Note: requirements for Large Dataset Request include:
 - Research proposal must include investigators from at least 3 centers contributing data to ELSO
 - Each proposal must include the statistician (MS or PhD) who is involved in the project proposal and analysis
 - Each proposal must include a plan of the contributions of the names investigators in the same way as this is included with some manuscripts for publication
 - Manuscript will be reviewed prior to submission for consideration for publication
2. The risk of individual patient or individual center identification is increased under certain circumstances. Institutions must be clustered in groups of 5 or more for publication, and no sub-groups of ≤ 10 patients will be reported.
3. No attempt should be made to learn the identity of individual centers through any deliberate or technical analysis. No communication should be made with individual centers to attempt to clarify or check data provided.
4. Investigators must not publish any report through any media, data that could identify individual establishments directly or by inference.
5. The ELSO Registry must be prominently referenced and acknowledged as the source of the data. The actual process of this is currently under development – we will update this form as it becomes clear.

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