

Guiding Principles

Purpose

The Clinical Ethics Consult Benchmarking Collaborative exists to develop a standard combination of metrics to measure the volume of clinical ethics consults and establish national benchmarks for understanding and assessing clinical ethics practices.

Roles

The Collaborative serves three main roles to fulfill its purpose:

1. Collect and provide access to data on clinical ethics consult volume as appropriate.
2. Moderate membership of the Collaborative.
3. Referee data sharing and potential violations of the data use agreement.

Membership Requirements

1. Accredited (State or TJC or similar accrediting body) Facility
2. Data capture has been or will be performed and shared with the Collaborative by the deadlines established by the Collaborative

Member Benefits

1. Provides a forum for discourse among Collaborative Members
2. Access to publications of Collaborative Members
3. Access to Annual Benchmarking Report
4. Access to data from their institution (old and current data) upon request
5. Access to comparative data from the CECBC besides what is in the Annual Benchmarking Report upon request, and if approved by the Data Access and Use subgroup, to use for discussion and analysis within their institution, for publication, or for research purposes

Guidelines for Collaborative Members

Upon joining the Collaborative, all Members agree to the following guidelines:

1. Access to data is only available to representatives of Member institutions who have contributed data, or participants of a subgroup.
2. Any proposals to publish data from the Collaborative must follow the publication rules below and be approved by the Collaborative.
3. Data will not be accepted after an established deadline unless an exception is approved.
4. A request to delete data from the database by a contributor must be honored and confirmed for the Member by the Collaborative Leadership Group except for data used for approved proposals or published products.
5. At least once a year, the Collaborative will:
 - a. Review collected metrics;
 - b. Assess the value of their continued inclusion;
 - c. Evaluate proposals for including new metrics; and

- d. Produce an Annual Benchmarking Report available to Collaborative Members.
6. Attend meetings of the entire Collaborative, which will occur at least quarterly.
7. To protect the confidentiality of Collaborative members, Members should only be able to access the data in aggregate and not hospital names or individual data points.
 - a. Participants of the Metric Clarification and Data Cleaning subgroup may access data at the level that identifies individual hospitals if necessary for the purpose of data analysis or quality control on field names, terms, definitions, data collection questions, or similar items.
8. Aggregate data will not be available to Members from the most recent year until the Annual Benchmarking Report is published. Participants in a subgroup may receive early access if needed for data analysis or to prepare the Annual Benchmarking Report.

Publishing Rules

In order to publish data from the Collaborative, the following rules must be followed:

1. The Collaborative must review and approve proposed publications before it is submitted to a journal or other publishing entity.
 - a. This only applies to the collective data from the Collaborative. This does not prevent a member health system from publishing their own data or publishing in conjunction with other Collaborative members, as long as the data does not come from the Collaborative.
2. The Collaborative must review and approve the abstract for a professional presentation at a professional conference that uses CECBC data before the abstract is submitted.
3. Data must be published in aggregate and in ranges so no hospital or system names can be tied to individual data points.
4. The publication must acknowledge the data came from the Clinical Ethics Consult Benchmarking Collaborative.
5. Data should be published in date ranges approved by the Collaborative.
6. Publications must include a disclaimer that consult volume is only one factor to consider when evaluating the success of a clinical ethics consultation service or when hiring an ethicist.
7. Open access or similar approaches (e.g., pre-pub access, open access PDFs, etc.) should be requested of the publishing entity.
8. Authors and presenters are requested to share the citations of the publications or information about the presentation (name, title, date, conference) to be posted on the CECBC website.

Leadership Group

A small leadership group will meet between quarterly calls with the entire Collaborative. The leadership group will have the following subgroups that also meet as needed:

1. Metric Clarification and Data Cleaning
2. Publication

3. Data Access and Use

Participation in these groups will be approved by the Leadership Group for a one year term and able to be reappointed by the Leadership Group. The Leadership Group may appoint individuals who are not employed by an institution that is a Member of the CECBC to serve on a group or subgroup if they have unique expertise that would benefit the Collaborative. While these participants are not automatically entitled to the member benefits as outlined above, they may receive a copy of the Annual Benchmarking Report upon request.