

## **Sight Outcomes Research Collaborative (SOURCE) Bylaws**

### **I. Name.**

- a. The name of the group is the Sight Outcomes Research Collaborative (SOURCE)

### **II. Purpose.**

- a. The purpose of SOURCE is to allow multi-institutional collaboration for the purpose of accelerating outcomes research and quality improvement in ophthalmology.

### **III. Code of Conduct**

- a. The success of SOURCE depends upon a cooperative model of information exchange.

Member institutions and representatives are expected to:

- i. Respect the intellectual property presented and the comments made by presenters and discussants.
- ii. Disclose competing interest or obligations that may conflict with new or existing projects.
- iii. Refrain from using or sharing confidential information without the consent of the SOURCE Executive Board
- iv. All provider-identifying and institution-identifying elements must be removed prior to public disclosure of any data
- v. No data gained from analysis of SOURCE data for research or quality improvement purposes will be used for competitive or marketing purposes
- vi. Failure to adhere to the code of conduct or these bylaws is grounds for dismissal from SOURCE and removal of any funding support

### **IV. Goals/Objectives.**

- a. Develop a structure for multi-institutional collaboration and data sharing.
- b. Develop the information technology infrastructure to pool a wide variety of data on patients with ocular diseases.
- c. Develop/Enlist the statistical infrastructure to analyze the data.
- d. Provide an academic collaborative where faculty from multiple institutions will be able to collaborate in outcomes research.

### **V. Members.**

- a. Any ophthalmology department or practice can apply for membership in SOURCE.
- b. Membership only requires that the institution uses EPIC as its electronic health record system and that the ophthalmology department chair or head of practice and faculty support the project through their willingness to submit their data into the central SOURCE repository.
- c. Active/Contributing members are member institutions that have submitted their historical data for all prior eye care recipients from the time the site when live on EPIC to the present into the central SOURCE repository and continue to submit data on a monthly or quarterly basis going forward. Proper

submission of data to SOURCE requires use of Datavant de-identification software to remove patient health identifiers. The SOURCE Data Team will validate sample data a site submits to ensure accuracy and completeness of data. These members can submit research proposals and manuscripts to be evaluated by the SOURCE Research Committee (SOURCE-RC). These members may be represented on the Executive Board and may vote during the Executive Board election.

#### VI. Executive Board.

a. The Executive Board serves without pay and is comprised of ophthalmology department chairs or head of practice of active/contributing member institutions, as well as the Executive Director, Research Director, and Quality Improvement Director of SOURCE.

i. When SOURCE is comprised of over nine active/contributing institutions, up to nine ophthalmology department chair/head of practice Executive Board members are elected to serve on the Executive Board for a three-year term.

ii. If an elected Board Member leaves their position for any reason, a re-vote will be held to replace the vacated position.

iii. The Executive Director, Research Director, and Quality Improvement Director of SOURCE have seats on the Executive Board regardless of the number of member institutions.

#### b. Executive Board Elections

i. Executive Board members are elected via a runoff process

ii. Nominees for Executive Board elections are solicited each year for the three open positions. Nominees will have a minimum of two weeks to submit their nominations. Nominees must include a short biographical sketch and photo. Self nomination is encouraged.

iii. Each active/contributing member institution may place one vote for each open position on the Executive Board.

iv. Voting by proxy is permitted. Proxy voting allows transfer of voting rights from one institution to another with voting rights to vote for that institution in its absence.

c. The Executive Board is responsible for approving the participation of each provisional and active/contributing institution and voting on ad hoc issues (e.g. data requests outside of the SOURCE-RC purview, partnerships and relationships, etc.). Passage of any issues requires a simple majority (i.e. one more than half) of the Executive Board members or their designated appointee present at the meeting. Presence is defined as either via physical or electronic means.

d. Other officers will be determined by the Executive Board as they are deemed necessary.

e. The usual (Robert's) parliamentary rules governing deliberative bodies will govern the Executive Board meetings

#### f. Executive Board Voting.

i. Matters requiring Executive Board review and approval will be performed at an Executive Board Meeting

- ii. A simple majority (i.e. one more than half) of Executive Board members or their designated constitutes a quorum. Presence is defined as via either physical or electronic means.
- iii. In absence of a quorum, no formal action will be taken except to postpone the Executive Board vote to a subsequent date.
- iv. The Executive Board is also responsible for reviewing and voting on all proposed revisions to the SOURCE bylaws. Bylaw changes require a two-third majority of Executive Board members or their designated appointee present at the meeting.

#### VII. Scientific Advisory Board.

- a. The Scientific Advisory Board (SAB) serves without pay and consists of prominent health care luminaries.
- b. Members of the SAB are elected by the Executive Board by simple majority.
- c. The SAB will meet at a frequency determined by the Executive Board to discuss current ophthalmology research needs and the ability of SOURCE to address those needs, and to provide recommendations to the Executive Board.

#### VIII. Committees.

##### a. SOURCE Research Committee (SOURCE-RC)

- i. The SOURCE-RC is comprised of individuals identified from their institutions as the Research Champion/Principal Investigator (PI)
- ii. The SOURCE-RC serves as the publication committee of SOURCE and is responsible for reviewing, refining, and modifying any research proposals and manuscripts created by researchers at active/contributing institutions. All proposed research studies using data from the central SOURCE repository must pass a peer review process by the SOURCE-RC prior to submission for publication.
- iii. The SOURCE-RC is to meet via teleconference on a monthly basis and once in person at the SOURCE Annual Meeting during the ARVO conference to discuss and evaluate submitted research proposals and manuscripts.
- iv. The SOURCE-RC approves research proposals and manuscripts using a simple majority (i.e. one more than half) of the members present at the meeting. The senior statistical consultant is to serve as the tie-breaking vote, in the event of a tie.
- v. The SOURCE-RC will make all reasonable effort to review all research proposals and manuscripts within 30 days of the research proposals' or manuscripts' submission dates.

#### IX. Meetings.

- a. Special meetings may be called by the Executive Board provided that at least thirty (30) days' notice of such meeting is sent to all members.
- b. The usual (Robert's) parliamentary rules governing deliberative bodies will govern the SOURCE meetings.

#### X. Funding

a. SOURCE coordinating center activities will be funded through coordinating center self funding, foundation, grant, and industry-sponsored research. All funding received will be documented and submitted annually to the Executive Committee for review. All funded projects will be reviewed by the existing SOURCE review process.

i. All research efforts will involve three costs (forms of value):

1. Principal investigator (PI) center cost varies for hypothesis development, data cleaning, analysis, and manuscript preparation.

2. SOURCE coordinating center (University of Alabama at Birmingham) cost varies for hypothesis refinement, data extraction and cleaning.

3. SOURCE data 'intellectual property' (shared across SOURCE contributors) for the high quality data itself

ii. Types of funding

1. Foundation and government sponsored research: SOURCE data and collaborative infrastructure can and will be used for competitive proposal submissions for foundation / government grants. In this context, there are clear mechanisms in place (budget request) for compensation. In accordance with the external sponsor mechanisms in place, a SOURCE site would request effort allocation for each of the local individuals involved in the project. Prior to proposal submission, the PI would contact SOURCE to receive a letter of support indicating data availability and develop a budget estimate for central SOURCE costs. The University of Alabama at Birmingham will serve as a subcontractor on the proposal.

2. Industry sponsored research: Vendors may identify the value of SOURCE data and its value to drive market creation, product refinement and effectiveness analyses. A single SOURCE site would serve as the primary contractor. The budget will include their negotiated costs as well all research effort costs. Any active SOURCE member may develop an industry-funded research proposal.

iii. Any data access fees collected by the coordinating center will be distributed as follows

1. Until the annual coordinating center operating cost of SOURCE is held in reserve, 100% of the data access fees will be held by the coordinating center

2. Once the annual operating costs are held in reserve, 50% of the data access fees will be distributed to the coordinating center and 50% of the fees will be distributed to the centers contributing data to the study in a manner proportional to the number of patients included in the study

3. Any center not contributing data to the study will not receive any portion of the data access fees

4. The coordinating center reserve fund will be reviewed by the Executive Board annually and the ledger statement of the funds will be distributed to the Executive Board on an annual basis

XI. Data Ownership.

a. Each institution continues to retain sole rights to the data they contribute to the central SOURCE repository. Institutions may choose to withdraw their data from the central SOURCE repository at any time. Upon receipt of written request, either physical or electronic, from a member institution, their data is to be removed from the central database within 30 business days. In the event that this data has

already been extracted for research and/or publication purposes, all reasonable effort will be made to ensure that it is excluded from use for any study that is not yet in data analysis phase

b. SOURCE does not own the data stored in the central SOURCE database, does not have responsibility for ensuring the validity of the data, cannot forward or transfer data without written expressed consent by each contributing institution, or use data without following the data sharing rules described below unless approved explicitly for that purpose by the SOURCE-RC.

c. Participants in SOURCE-DC do not acquire intellectual property rights in SOURCE-DC Data or in future inventions or discoveries made by SOURCE-DC Participants using SOURCE-DC Data.

## XII. Data Sharing.

a. All data from the contributing sites are stored at a central repository. The hosting institution is responsible for warehousing the data and ensuring appropriate safeguards are in place for ensuring its safety and accessibility.

b. After achieving active/contributing member status, the amount of data contributed does not determine priority in authorship. All active/contributing member institutions have equal access to data stored in the central SOURCE repository.

c. All active/contributing member institutions may submit research proposals and manuscripts to be reviewed and evaluated by the SOURCE-RC.

i. Research proposals must indicate the specific data elements from the SOURCE master data element list that are being requested. Proposals must also include a proposed list of authors in the order in which they will appear in the final manuscript, a detailed introduction, methods, and proposed statistical analysis.

d. The principal investigator (PI) of a research proposal must be from an institution that contributes the data elements requested. Alternatively, the PI may partner with a PI from another institution that does submit that data element.

e. Once a research proposal is approved by the SOURCE-RC, the SOURCE programming team will extract the approved data elements for the specific research study. The PI of the proposal and members of his or her team (biostatisticians) is provided access to these data which will be housed on a server at the University of Alabama at Birmingham. If the PI determines they need additional data from the SOURCE database, s/he must resubmit their proposal to obtain the new data.

The PI can only use this deidentified dataset to answer the specific research question posed in the proposal and may not use this data for other research purposes. The PI has 24 months to submit a completed manuscript to the SOURCE-RC for review. The SOURCE-RC will confirm that the PI has followed the proposed research methods and followed the intent outlined in their original proposal. If they fail to submit a completed manuscript within the 24-month timeframe or fail to follow their original methods or research intent, they are prohibited from using the specific dataset for purposes of publication of the manuscript.

f. Once a manuscript is approved by the SOURCE-RC, the PI may submit the manuscript to the peer-reviewed journal of his or her choice.

g. The SOURCE-RC will strive to review all research proposals and manuscripts within 30 days of the research proposals' or manuscripts' submission dates.

h. All conflicts in authorship are to be resolved by the involved parties.

XIII. Exclusivity.

a. Participation or contribution of data into the central SOURCE-RC repository does not confer exclusivity. Each institution may continue to use their own data for their individual research studies and/or contribute that data to other research studies.

XIV. Conflict of Interest.

a. Personal interests, whether or not considered a conflict of interest, should be disclosed annually. These interests include consulting relationships, equity relationships, financial relationships, familial relationships, and speaker’s fees.

b. Any member of SOURCE who has a financial, personal, or official interest in, or conflict (or appearance of a conflict) with any matter pending before the group of such nature that it prevents or may prevent that member from acting on the matter in an impartial manner, will offer to voluntarily excuse him or herself and refrain from discussion and voting on said item.

c. SOURCE members and all principal investigators must disclose any conflicts of interest during the submission of each research proposal and annually.

XV. Amendment.

a. The Executive Board is responsible for reviewing and voting on all proposed revisions to the SOURCE bylaws. Bylaw changes require a two-third majority of Executive Board members or their designated appointee present at the meeting.

XVI. Dissolution

a. Participation in the SOURCE is entirely voluntary. If the Executive Board decides, via a two-thirds majority, that the SOURCE should dissolve, all data should be removed from the central repository within 30 days. Existing research and publications already under consideration for submission may continue. Signees to this agreement affirm that they will not use shared data to initiate new research in the event that the SOURCE is dissolved.

Terms of Membership Participation Agreement

Institution Name: \_\_\_\_\_

We have thoroughly read the SOURCE bylaws and agree to all the terms of membership participation.

\_\_\_\_\_

Print Name: Department Chair and/or Print Name: Ophthalmology Champion/PI

Head of Practice/Sponsor

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

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