

SCMR Registry Data Access Policy

Highlights:

1. The Registry is accessible to all SCMR Members for all types of health-related research that is in the public interest, without preferential or exclusive access for any person or organization.
2. SCMR Members who are active contributors of data to the Registry are permitted to lead Registry research projects as Principle Investigator (PI), and to view and search the Registry database at any time through the Registry portal.
3. SCMR Members who are not active contributors of data to the Registry are not permitted to serve as sole PI on Registry research projects, but may partner with a contributing site as a co-PI or Co-investigator. Non-contributors are unable to directly view or search the Registry database. However, any SCMR member may submit a search request to the SCMR Registry Committee. The Registry Committee will review the request and work with the submitting member(s) to run the search, or a modified search, as appropriate.
4. An effective search will result in a tally of the number of cases meeting the specific search criteria, a list of which sites contributed these data, and the number of cases contributed by each site. This information (number of cases and contributing sites) will be incorporated into an application for access to these data and submitted to the Registry Committee for approval.
5. If approved, the SCMR Registry Committee will contact the Contributors of data required for the project, present the research proposal, and request data access.
6. Each individual Contributor reserves the right to decide whether their data may be used in the proposed study.
7. Once a research project is approved, and contributing sites have agreed to participate, the relevant data from the participating sites will be aggregated into an SCMR Registry folder. Only the SCMR Registry Committee has the ability to create an aggregate data folder comprised of data from multiple contributors.
8. Access by researchers to the aggregate data is granted only for the purposes of the specific research project detailed in the approved proposal, and under the terms and conditions specified in the SCMR Registry Data Access Policy.
9. All results arising from use of the data, including but not limited to trained AI models and associated source code, must be published as open source for use by any person, company, or other entity without cost or limitation.