

THE INSTITUTE FOR SYSTEMS MEDICINE APPROPRIATE/INAPPROPRIATE USE OF THE CLINICAL DATA REPOSITORY

The Clinical Data Repository (CDR) is a collaboration of academic and healthcare partners striving to improve health outcomes by supporting translational health research. This CDR developed by the Institute for Systems Medicine (ISM) extracts datasets from healthcare organizations following a trusted broker model. Investigators request de-identified datasets queried from the CDR data warehouse.

There are many reasons to share patient outcome data and it is the intent of the ISM to provide healthcare data through the CDR. Sharing data reinforces open scientific inquiry, encourages diversity of analysis and opinion, promotes new research, makes possible the testing of new or alternative hypotheses and methods of analysis, supports studies on data collection methods and measurement, facilitates the education of new researchers, enables the exploration of topics not envisioned by the initial investigators, and permits the creation of new datasets when data from multiple sources are combined.

It is therefore imperative that all investigators utilizing data from the CDR understand and agree to the following pertaining to appropriate and inappropriate use of the CDR.

- The use of the requested data set (or any part), for purposes other than research, analysis, and aggregate statistical reporting is strictly prohibited. Data from the CDR can be used only as permitted by the agreement with ISM.
- The use of the requested data set (or any part), for purposes of identifying individuals is strictly prohibited.
- The release or disclosure, or the aiding in the release or disclosure, of the data set (or any part) to any person who is not a member, agent, or contractor of the contracted organization or investigatory team is strictly prohibited.
- Linking or attempting to link, the discharge records of persons in the data set with individually identifiable records from any other source is strictly prohibited.
- Use of the data set to learn the identity of any person included in the data set or to contact any such person for any purpose is strictly prohibited.
- Using or participating in the usage of the data set, for commercial or competitive purposes is strictly prohibited.
- Using or participating in the usage of the data set for purposes of identifying and/or contacting participating establishments and organizations is strictly prohibited.

No data shall be released from the CDR without following established procedures for review and approval to gain access to such data. The CDR is governed by the ISM Data Privacy and Monitoring Board and the ISM Scientific Advisory Board. All requests for data must be reviewed and approved by facilities contributing data to the CDR and by the governing Institutional Review Board.