Illinois REDCap Service Model

Research Electronic Data Capture (REDCap) is a secure web application for building and managing surveys and databases for research studies. The Interdisciplinary Health Sciences Institute (IHSI) is administering the use of REDCap for the University of Illinois at Urbana-Champaign campus. This system is intended for the construction, data collection, and data management of active research projects conducted by Illinois investigators.

HIPAA Capability

Illinois REDCap is among the systems and services that meet requirements established by the Health Insurance Portability and Accountability Act of 1996 (HIPAA). This makes REDCap an ideal system for collecting Protected Health Information (PHI) and other high risk or sensitive data. However, data for any research project meeting the criteria outlined below can be collected in REDCap; the data do not need to contain PHI or be high risk. More information about the University’s data classification system can be found here.

Illinois REDCap, like many other electronic data collection and management systems, is HIPAA-capable. Part of being HIPAA-compliant requires that users conduct certain practices, such as limiting access to and restricting export of high risk data. As such, part of what makes Illinois REDCap HIPAA-compliant is the appropriate data collection and management practices of Illinois REDCap users. The Protecting High Risk Data document contains information about managing high risk data; this document is required reading before using Illinois REDCap.

REDCap Support

The IHSI REDCap team and Research IT currently provide infrastructure and administrative support at no cost to the Illinois research community.

Administrative support includes creating and managing REDCap accounts and basic training through workshops, office hours, and consultations. Workshops and office hours are conducted with support from the University Library. Additionally, the IHSI REDCap team will publish a monthly newsletter and maintain educational materials through a website. The IHSI REDCap team will also assist with some steps in the lifecycle of a research project, as detailed in the “Project Lifecycle” section below.

Infrastructure support includes REDCap system maintenance, such as system upgrades, security patches, and technical documentation.

User Eligibility

Accounts will be available to anyone affiliated with research projects at the University of Illinois at Urbana-Champaign. Each project must have an Illinois Principal Investigator (PI) who is responsible for the project, data, and the HIPAA-compliance and project access of study personnel.

It is the responsibility of the PI to ensure that all collaborative personnel:

1. Complete the appropriate study-specific, related training;
2. Review and adhere to the University of Illinois at Urbana-Champaign policies and procedures outlined in the User Account Agreement and Protecting High Risk Data document; and
3. Complete an annual user access review for each project that is in production.

If the PI is not a current Illinois REDCap user at the time of a research team member’s Illinois REDCap access request, the request will not be processed until confirmation is received from the PI that they agree to the terms of the Illinois REDCap Account User Agreement via email or through completion of the User Request Form.

Users are responsible for project creation, providing individual project access to research team members, and ensuring their project is compliant with any approved Institutional Review Board (IRB) and/or Institutional Animal Care and Use Committee (IACUC) protocols.

User accounts will be suspended if:
1. The Illinois REDCap User Agreement is violated. Users will receive a notice from the IHSI REDCap Team if their account is suspended due to a violation of the Illinois REDCap User Agreement.
   a. To reinstate the account, the violation must be resolved and the user must indicate their understanding of how to prevent the violation in the future.
2. An account is inactive. An account is deemed inactive if the user has not logged into Illinois REDCap for a period of six months. Users will not receive a notice if their account is suspended due to inactivity since this is an automatic action by the REDCap software.
   a. To reinstate the user account, the user should email redcap-admin@illinois.edu and request their account be restored.

Project Eligibility

For a project to be eligible for Illinois REDCap, it must be a research project that is actively collecting data. We abide by the Department of Health and Human Services definition of research as “a systematic investigation that is designed to contribute to generalizable knowledge.” Some projects that are currently ineligible for Illinois REDCap are:

- Projects that are strictly quality improvement or quality assurance;
- Operational support, such as tracking trainings or office supplies; and
- Office polls and/or surveys, such as asking where to host an office lunch.

Active collection means that data is currently being collected and entered into the system. Illinois REDCap is not intended to be a long-term repository or warehouse for project data. If a project is no longer active, the IHSI REDCap Team will notify the research team that the project needs to be migrated to a long-term storage option, such as a Box Health Data Folder. We consider a project to no longer be active if new data has not been entered into a project in one year.

Project Lifecycle

Projects in REDCap will have the following lifecycle.

1. The project is created by a REDCap user.
2. The project is built and tested by the REDCap user(s).
a. The IHSI REDCap team will not make any changes to project builds or do any testing of the project prior to moving projects to production.

b. For more information about testing a project, review the Move to Production Checklist.

3. The research team will request the project be moved to production.
   a. It is important to move projects to production to protect the integrity and validity of the data. It is more difficult to accidentally delete or corrupt data when a project is in production.
   b. The IHSI REDCap team will request or confirm information about the PI, compliance documentation, and agreements, such as data use agreements.
   c. The IHSI REDCap team will run the data dictionary through an algorithm to identify specific actions that could be taken in REDCap to improve data protection and validity. Suggestions may include marking identifiers, adding field validations, adding minimum/maximum values, or making multiple choice answers uniform.

4. The move to production request is approved by the IHSI REDCap team.

5. Data are collected.

6. When the project is no longer active, data need to be migrated to a long-term storage option, such as a Box Health Data Folder. The project should be deleted from REDCap.
   a. A project is considered no longer active if new data has not been entered into a project in one year.
   b. A project can be deleted by going to the “Other Functionality” tab and selecting the button that says, “Delete the project.”
      i. Archival and deletion are not the same thing. Projects must be deleted, not archived.
   c. The research team will be notified by the IHSI REDCap team if it’s identified that a project is no longer active.
      i. The research team will have one month to remove the inactive project from REDCap.
      ii. If the project is not removed from REDCap in one month, the project will be archived.
          1. The users listed on the project will be notified that the project was archived.
          2. Archived projects are still accessible, and data can be still be exported.
          3. To view archived projects, go to your “My Projects” tab and select the link below the table that says “Show archived projects.”
      iii. After three months in archival, the project will be deleted from Illinois REDCap, at which point the data will be un-recoverable.
          1. The users listed on the project will receive monthly notifications during this three-month period to remind them of the project’s status and deletion date.
          2. The users listed on the project will be notified that the project was deleted.
   d. The IHSI REDCap team appreciates the cooperation of researchers in deleting projects and maintaining records. Server space is a large cost of REDCap, and deleting projects helps keep server costs low and REDCap free for the Illinois research community.