# **REDCap Overview & Use**





## What is REDCap?

REDCap is short for Research Electronic Data Capture.

Electronic Data Capture (EDC) is an umbrella term for any software program designed to collect and house research data prior to statistical analysis. There are a wide range of EDC programs used by pharmaceuticals, government organizations, and contract research organizations (CROs).

REDCap is an EDC designed primarily for use by research universities and their associated health system partners.

### Approved Human Subject Research

REDCap is a great tool; however, it can only be used for certain kinds of projects. Its main purpose is to be utilized for Human Subject Research projects, which must be fully approved by the respective institutional IRB (Northwestern or Lurie Children's).

Some departments require additional approval of Human Subjects Research. For example, any research for the Lurie Cancer Center must also be approved by the Scientific Review Committee. Please consult with your department leadership for any additional requirements for Human Subjects Research approval.

Note: Operational/healthcare quality improvement projects are separate from Human Subjects Research.

### Additional Projects within Feinberg School of Medicine

Feinberg School of Medicine (FSM) employees can also use REDCap for several other kinds of projects. This use, however, is not available to those affiliated with Lurie Children's, Shirley Ryan Lab, etc.

**Workflow Data Capture or Asset Tracking:** This can include documenting shipping numbers for a project that involves sending items to participants.

**Academic or Research Program Intake Forms:** This does **not** include intake forms for general clinical operations. Non-research related PHI cannot be entered into REDCap.

**Work-Related Opinion or Feedback Surveys for Evaluation Purposes:** This can include a seminar feedback form, registration for a conference, or tracking participant involvement.



#### **REDCap Use & Misuse**



- Investigator-initiated research
- Surveys & longitudinal studies
- Sensitive data requiring security

- Statistical analysis of data
- ◆ Storing non-research related personal health information (PHI)
- Surveys for non-work purposes

It is a HIPAA violation to store Protected Health Information not for research use on NU FSM systems including NU REDCap. This includes PHI from Northwestern Medicine affiliates, Shirley Ryan Ability Lab, Lurie Children's Hospital, or any other entity covered under HIPAA.