

How to use REDCap for GDPR-Regulated Research

The [General Data Protection Regulation](#) (GDPR) is a regulation regarding data protection and privacy in the [European Union](#) (EU), the [European Economic Area](#) (EEA), and the United Kingdom (UK). You can learn more about the GDPR on the [System's GDPR website](#). REDCap, as a data collection tool, can be used to collect data subject to the GDPR.

Does the GDPR apply to your research?

The GDPR may affect your research if:

- Your research involves the personal data of persons physically present in the EEA or the UK;
- You want to re-use personal data you previously collected from persons in the EEA or the UK (e.g., for a previous research project) or you want to obtain existing personal data about persons in the EEA or the UK from other persons or units at the U of I (e.g., admissions data) to use in your research;
- A person or entity physically present in the EEA or the UK is providing you with the personal data of research subjects located anywhere in the world;
- You intend to conduct data scraping involving the accounts or websites of persons or entities physically present in the EEA or the UK; or,
- You are collaborating with researchers or entities physically present in the EEA or the UK.

The University of Illinois has an online GDPR Self-Assessment Tool to help you determine if your activities are subject to GDPR. The tool can be accessed [here](#).

Web Privacy Notice

To ensure persons visiting University of Illinois websites understand applicable privacy policies and the impact of the GDPR, every publicly available University of Illinois webpage, including survey pages, must have a link to the System's Web Privacy Notice in the footer. If you are collecting data that is subject to GDPR, you must indicate this on your Move to Production survey so that the REDCap team can add this language to survey footers for you.

Special Categories of Personal Data

The GDPR limits processing of *special categories* of personal data, which includes personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, genetic data, biometric data for the purpose of uniquely identifying a natural person, health data, and data concerning a person's sex life or sexual orientation. Research participants must give explicit consent before this personal data can be collected and processed as part of the research. The Office for the Protection of Research Subjects (OPRS) has [consent templates](#) developed that ask for explicit consent to collect these special categories of personal data. If the consent process is conducted in REDCap, branching logic (also called "skip logic") can stem from the consent form to display or hide questions that collect special categories of personal data based on a participant's answers.

Right of Erasure

The *right of erasure* allows a data subject to request the erasure of their personal data. In REDCap, the default is for logging information to be retained even if a record is deleted. If you are collecting data that is subject to the GDPR, you must indicate this on your Move to Production survey so that the REDCap team can adjust this setting for you. Procedures for handling GDPR-related requests are found on the [System's GDPR website](#).

Pseudonymization

Consistent with the GDPR, stored data should be *pseudonymized* so that data cannot be attributed to a specific subject without additional information. Upon data export, use one of the many data export options that will remove identifiers, or export a limited amount of data without identifiers by using the "Reports" function. Pseudonymized personal data is still subject to the GDPR.