Data Management

- Data Management Guidance
- Accrual to Clinical Trials (ACT)
- Data Management Tools and Resources

Data Management Guidance

Data management plans (DMPs) encourage researchers to think about how they will responsibly handle the data they collect, and are required by many funders. The National Science Foundation (NSF) requires that all grant proposals be accompanied by a data management plan. Other federal funding agencies have similar requirements or will have soon. This guidance will serve as a starting point to guide researchers through the data life cycle process with available tools either on campus or through the California Digital Library (CDL).

- Data Management General Guidance
- UCSD Library Data Management Best Practices
- CDL Examples of Data Management Plans
- NSF Data Management Plan Policy

Researchers who are required to submit a data management plan as part of a funding proposal may wish to consult the DMPTool. The UCSD Research Data Curation Program can provide additional guidance on managing and sharing research data.

You may also find useful information from the UCLA Library Data Management for the Sciences, which also provides a guide to best practices for management of research data, including links to data services and selected repositories sorted by broad subject areas.

Data Storage Information

- UCSD Library Data Storage, Backup, Repositories and Sharing

UCSD Guidance on the proper handling of sensitive data can be found in the UCSD Guidelines for Handling Sensitive Data.

Guidance from UCSD HRPP:

- UCSD Guidance on HIPAA Privacy Rule Information
- SOPP Privacy and Confidentiality of Research Records
- SOPP Confidentiality of Collected Specimens or Data

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ACT

The ACT Network is a real-time, open access platform allowing researchers to explore and validate feasibility for clinical studies

UC San Diego Altman Clinical and Translational Research Institute (ACTRI) is pleased to announce that it has partnered with the Accrual to Clinical Trials (ACT) Network to bring real-time cohort exploration and discovery to its researchers. Initially developed as UCReX, ACT has evolved into a network that incorporates >120 million lives, spearheaded by UCSD, University of Pittsburgh, Harvard and UT Southwestern.

ACT was developed by members of the Clinical and Translational Science Awards (CTSA) Program consortium to enable cohort discovery using a web interface in a HIPAA-compliant manner, without requiring study-specific IRB approval. It offers open-access to a national network of leading academic medical research centers and generates aggregate patient count data from an investigator's real-time, iterative searches. Using ACT, UC San Diego Health researchers can explore patient populations, confirm and demonstrate study feasibility, and identify potential partners for multi-site studies. ACTRI is one of the first 21 CTSA hubs across the country to launch the ACT Network. Now linking 48 hubs and a Trial Innovation Network (TIN) resource, the ACT hubs share ontologies, governance and data use agreements. UCSD has performed cohort discovery searches for the TIN. Led by UCSD with University of Pittsburgh, UT Southwestern and Harvard, the NCATS ACT network is an important tool for research design to assure studies are performed at the appropriate hubs.

ACT is available to all UC San Diego Health researchers at *no charge*, but registration is required.

[Register for ACT](#)

[More information about ACT](#)

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Data Collection Tools

- [Citation Management](#)
- [Research Software Licensing](#)
- [Case Report Form (CRF) resource from NINDS](#)

Data Processing Tools

Clinical Trials and Sample Repositories

[Velos eResearch](#) is an integrated software system for managing clinical trials. The software links to the UCSD Health's Epic Electronic Medical Record System to provide improved information and integration for clinical research projects. One module within this platform, called eSample, will track biological samples and link them to the Electronic Health Record. A robust support team assists investigators in implementing their protocols, study budgets, and calendars. Velos eResearch is a web-based system that supports

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- Creation of budgets

- Creation of protocols with calendars

- Scheduling of subjects

- Electronic case report forms

- Tracking visits and events

- Creation of invoices

- Reporting

Request Velos Access under the Biomedical Informatics tab on the CTRI Service Request Form.

Simple Studies and Surveys

- REDCap (Research Electronic Data Capture) is a secure, web-based application for building and managing online surveys and databases.
- With REDCap's streamlined process for rapidly developing projects, an investigator may create and design projects using 1) the online method from his or her web browser and the Online Designer; and/or 2) the offline method by constructing a 'data dictionary' template file in Microsoft Excel, which can be later uploaded into REDCap. Both surveys and databases (or a mixture of the two) can be built using these methods.
- REDCap provides automated export procedures for seamless data downloads to Excel and common statistical packages (SPSS, SAS, Stata, R), as well as a built-in project calendar, a scheduling module, ad hoc reporting tools, and advanced features, such as branching logic, file uploading, and calculated fields.

Request REDCap Access under the Biomedical Informatics tab on the CTRI Service Request Form.

Electronic Health Record Queries

The **Clinical Data Warehouse for Research (CDWR)** pulls a subset of the data from the Electronic Health Record system and allows investigators to query patient information in a HIPAA-compliant manner. The data are primarily drawn from UC San Diego Medical Center's Clinical Data Warehouse, which contains data from more than 2.4 million patients collected during the last two decades, and represents 5.8 million outpatient visits, over 130,000 Emergency Department visits, and over 1.8 million inpatient admissions.

Patient Information Extract Service (PIES) in electronic health records is a service that identifies specific patients, and extracts identified, de-identified, or limited patient-level datasets from electronic medical for clinical research projects. An approval by the Institutional Review Board (IRB) is required for extracting identified and limited datasets. Our support team will execute queries on CDWR and return results to users, as approved by their IRB protocols. **Click on the "Request ACTRI Services" button above for more information.**

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If only counts of patients matching certain criteria are required, please use the Accrual to Clinical Trials tool. To request an account, please fill out a Service Request Form.

NOTICE: If you plan on collecting data for the purpose of human subjects research, your project must be reviewed and approved by your Institutional Review Board.

Other Data Management Resources

- Data Management for Clinical Research Online Course. Coursera offers FREE online courses in a variety of subjects and specialties from 62 leading Universities and Colleges worldwide. UCLA is one of the teaching institutions, and new Universities are signing up every month. You do not receive a grade for the class, but if you participate and successfully complete all assignments and tests then you receive a certificate upon completion. All you have to do is go to the site, create a login, browse offered courses and sign up. When the course is about to begin you will receive an email with all the details. This course is called Data Management for Clinical Research, and it is being offered by Vanderbilt University (the creators of REDCap). Here is the link to the class details: https://www.coursera.org/course/datamanagement.

- Merritt is a new cost-effective repository service from the University of California Curation Center (UC3) that lets the UC community manage, archive, and share its valuable digital content. For more information, see merritt.cdlib.org or contact UC3.

- The University of California Curation Center (UC3) is a creative partnership bringing together the expertise and resources of the California Digital Library (CDL), the ten UC campuses, and the broader international curation community to foster collaborative analysis, projects, and solutions to ensure the long-term viability and usability of curated digital content.

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