Data Management

- Data Management Guidance
- Data Management Tools and Resources
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- Sending Data to External Third Parties

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).

- UCLA Data Management Plan Tools and Guidance
- CDL Examples of Data Management Plans
- NSF Data Management and Sharing Plan
- UCLA OHRPP Guidance and Procedure: Data Security in Research

Researchers who are required to submit a data management plan as part of a funding proposal may wish to consult the DMPTool. The UCLA Library Data Management for the Sciences provides a guide to best practices for management of research data, including links to data services and selected repositories sorted by broad subject areas.

Please follow the links below for information about on-campus data-storage options.

- UCLA: Guidance on the proper handling of information technology, including personal information, can be found in the UCLA Institute for Digital Research and Education.
- LA Biomed/Harbor-UCLA Medical Center: Information Systems & Technology, Director, Mark Sleet (310) 222-6519 msleet@labiomed.org
- Charles R. Drew University of Medicine and Science: *not applicable at this time*.

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Data Collection Tools

- Citation Management
- Research Software Licensing (SAS, SPSS, JMP, SUDAAN, NVivo, ArcGIS)
- UCLA Library Data Management for the Social Sciences
- Case Report Form (CRF) resource from NINDS

Data Processing Tools

The UCLA Data Management & Curation Services provide subject-specific guidance tailored to individual researchers' data needs.

The Research Electronic Data Capture (REDCap) system offers a secure, HIPAA compliant web-based electronic data capture system that enables researchers to quickly and easily build surveys, data entry forms, and surveys with private data entry forms. The data entered into REDCap data entry forms and surveys is stored in a centralized system, which enables researchers to share data with their UCLA research teams and external collaborators in real-time. REDCap can be accessed from any computer or mobile device, including PCs, Macs, tablets, and mobile phones.

REDCap databases and surveys can be created on a self-service basis through an intuitive point-and-click REDCap form designer or on a consulting basis. To request the services of a CTSI consultant for the creation of your REDCap database and/or survey, please submit a consulting request through the CTSI. REDCap is available for use free of charge to the UCLA Research Community and its external collaborators.

For additional information, please contact the CTSI Consultation Services. To request the creation of REDCap user accounts for your research team members, please complete our request form or contact Martin Lai.

- Escalation with Overdose Control - interactive tool for designing and conducting dose-finding trials in cancer. Offered through Cedars-Sinai.

- REDCap - secure, web-based application for building and managing online surveys and data collection). UCLA CTSI offers complementary support during the process of defining and refining your database.
    - UCLA Contact: Martin Lai, MS, (310) 794-9396, mylai@mednet.ucla.edu
    - Harbor/LA Biomed Contact: Liz Chen, MBA, (310) 781-3601, lchen@labiomed.org

Data Management Resources

- The Institute for Digital Research and Education (IDRE) offers data storage, classes in statistics/data informatics, and consulting tailored to the individual needs of UCLA researchers.

- 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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Data Storage

Please follow the links below for information about on-campus data-storage options.

- UCLA: UCLA Institute for Digital Research and Education
- LA BioMed/Harbor-UCLA Medical Center: Information Systems & Technology, Director, Mark Sleet (310) 222-6519 msleet@labiomed.org
- Charles R. Drew University of Medicine and Science: Center for Biomedical Informatics

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Sending Data to External Third Parties

If you are sending data to external third parties, you will need to obtain special approval. View the process at Third-Party UCLA Health Data Agreements.

Health Data Oversight Committee (HDOC)

UCLA Health faculty members may establish Third-Party Health Data Agreements with any for-profit or not-for-profit entity outside UCLA Health. The agreements allow faculty members to partner with third parties and share UCLA health data for projects that have the potential to improve human health and benefit society. The Health Data Oversight Committee (HDOC) provides governance on health data sharing with external entities.

Committee Responsibilities:

1. Make recommendations to the Vice Chancellor, Health sciences on contracts involving health data with third parties by determining if a proposed relationship provides significant value to UCLA health and society
2. Attention to the University's unique responsibility and mission
3. Justice
4. Active Stewardship
5. Trustworthiness and Patient Engagement
6. Sharing Clinical Data outside the UC for Public Benefit
7. Promote Alignment and Collaboration
8. Ensure agreements meet the terms identified in the Third Party Health Data Agreements – Mandated Contract Terms
9. Exercise oversight over process for agreement negotiation and approval

Study teams should be able to explain the amount of data, type of data, and the sources of data that will be shared and how that data will be used. The following documents should be submitted with your HDOC request:

1. IRB approval or exemption notice
2. Protocol that describes the project's objectives
3. Informed Consent Form (if applicable)
4. Case Report Forms or protocol Data Dictionary
5. CIRC Letter (if applicable)

6. Budget or justification for cost recovery exemption

To submit a request or ask additional questions please open a ticket at Data Releases | Clinical and Translational Science Institute.

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Source URL:https://www.researchgo.ucla.edu/data-management-0?qt-view__vertical_tab_section__block_4=2

Drupal.jQueryUiFilter.globalOptions('accordion');