

ADCS Data Access/Sharing Policy

Accessing Data

Qualified scientists may obtain access to imaging, clinical, genomic, and biomarker data for the purpose of scientific investigation, teaching, or planning clinical research studies. Please navigate to the ADCS website <http://www.adcs.org/Industry/Datasharing.aspx> for more information. Using ADCS data in your research requires adherence to the information outlined in the documents listed below. *Note: documents are subject to updates by the ADCS.*

- ADCS Data Access/Sharing Request Form
- ADCS Data Access/Sharing Policy
- ADCS Data Use Agreement
- ADCS Publications/Manuscript Citations Policy

Applying for Access to Data

The application process includes acceptance of the ADCS Data Use Agreement and the submission of an online application form. The application must include the investigator's institutional affiliation and the proposed research to be conducted using ADCS data.

Application Review

Applications for ADCS data are reviewed by the Data Sharing Committee which includes the ADCS Director. Each application is carefully reviewed to ensure investigator affiliation with a scientific or educational institution and on the basis of the proposed research. Incomplete applications or those without a clear research focus will not be approved. The results of the review will be sent via email, and approved applicants will receive the requested data via Blu Ray Disk(s).



Data Accessibility for ADCS Members:

Datasets from ADCS clinical trials in which the primary paper reaches the “in press” status, will be made available to ADCS Steering Committee members via a request process modeled on the one developed by NACC and ADNI. (See below for details).

Data Accessibility for the Public:

Datasets from ADCS clinical trials will be made available to any qualified person 1 year after the primary paper is published. Qualified persons may make a request via the same process used by Steering Committee members (see below for details).

Requesting ADCS Datasets - The Process:

1. The Investigator/Requestor, whether a Steering Committee member or non-Steering Committee member, initiates their request via the ADCS website (see link above) and sends their completed request form to: adcsdataaccess@ucsd.edu.
 - a. Investigator/Requestor completes a 2-page request in which:
 - i. a specific hypothesis(es) is/are proposed for testing
 - ii. a specific rationale and methods are given for why the requested ADCS dataset is suitable for addressing that hypothesis
 - iii. a specific analysis plan is described for addressing the hypothesis, and
 - iv. specific instruments are listed that would be used in the analysis.
2. The proposal is reviewed by the ADCS Data Sharing Committee. A listing of all requests is reviewed in order to determine if a substantially similar request has already been proposed by another investigator. If that is the case, the latter requestor would be informed of the other investigator's previous request. However, that would not preclude the latter requestor's eligibility to receive the dataset.
3. Access to the appropriate data set will be granted after approval is obtained by the ADCS Data Sharing Committee, which will be provided for any legitimate request.
4. The Investigator/Requestor must submit completed manuscripts to the ADCS Publications Committee for review prior to journal submission. The manuscript is vetted by the ADCS Publications Committee for issues relating to human subjects, disclosure, and proper acknowledgment of the ADCS.
5. Requests that are not geared towards completing a manuscript will also be entertained on a case-by-case basis.

– End of Document – Updated 10.31.16