

ADCS – Publication/Manuscript Citations Policy

Data Sharing

A primary objective of the ADCS NIA U19 grant is sharing its data with the general scientific community. The ADCS Data Sharing Committee and the Publications Committees (DPC) establishes policies and procedures to implement the data-sharing requirement. This document outlines the ADCS recommendations for sharing ADCS data as well as policies and citations for publications for the use of ADCS data. The intent of these policies is to facilitate data sharing with all qualified investigators, to encourage academic productivity, and to provide a mechanism for tracking and archiving data requests, intended analyses and publications related to, and resulting from, ADCS data.

Both NIA and the ADCS have agreed that de-identified data would be made available to the general scientific community. The ADCS Data Sharing Committee will review all data request applications and make a judgment based on their affiliation with a scientific or educational institution, and on the basis of the reason for the request. Legitimate requests will be approved once an application is completed and a data use agreement is fully executed.

De-identified ADCS imaging and clinical data will be granted as determined by the ADCS Data Sharing Committee to individuals who register, complete an application, and adhere to the ADCS Data Use Agreement and ADCS Data Access/Sharing policies. These data fall under the definition of a “Limited Data Set” as defined in 45 CFR Part 164.514.

Applicants will:

1. Initiate a request by accessing the ADCS website at:
<http://www.adcs.org/Industry/Datasharing.aspx>
2. Email their completed ADCS Data Access/Sharing Request form to:
adcsdataaccess@ucsd.edu
3. Complete an ADCS Data Use Agreement

When the application is received and approved by the Data Sharing Committee, and a fully executed agreement is completed, the requested ADCS data will be sent to the Applicant via Blu Ray Disk(s). Applicants will be required to provide the following information:

- Name and contact information
- Organization/Academic Affiliation/Company Name
- Position/Role

8/04/2017 4:15 PM

- Proposed hypothesis(es)
- Methods
- Analysis plan
- Signed Data Use Agreement

Applicant information will be available to other registered data users so that they can determine whether to collaborate in research already in progress, compete with current projects, or embark on a new research topic. Applicants will receive annual requests to update the application information. These requests will also solicit responses to the following queries about manuscripts:

- Title of each manuscript in development
- Lead (or senior) author of each manuscript in development and contact information for that author
- Status of each manuscript in development (In development, In submission, In press/published)
- Citation of each published manuscript
- Each published manuscript to be listed and uploaded in an electronic file

Non-compliance with the required updates will jeopardize further access to ADCS data. The purpose of listing each proposed analysis with a lead investigator is to allow and encourage investigators considering similar projects to collaborate and to identify the individual who is taking responsibility for the use and reporting of the requested data.

Publications

The ADCS DPC will be charged with the administrative review of manuscripts only, and is not tasked with evaluating the scientific merits of analyses or abstracts.

Regardless of what total or subset of data is used in analyses or publications, as part of the Data Use Agreement, authors/investigators using ADCS data in publications will be required to agree to the ADCS Publication/Manuscript Citation Policy as follows:

- Attribution of authorship should generally follow the ICMJE guidelines for authorship and should be considered in all instances where ADCS data is primary to the manuscript.
- To allow that the ADCS can track manuscripts which have utilized its data, it is preferable that the Alzheimer's Disease Cooperative Study be appropriately named either as an author or by acknowledgement or by key word.
- As appropriate wording can be considered such as: "Data used in the preparation of this manuscript/publication/article were obtained from the Alzheimer's Disease Cooperative Study legacy database".

8/04/2017 4:15 PM

- All manuscripts will acknowledge the support of NIA using the NIH grant number: U19 5U19AG010483 for the ADCS (see Data Use Agreement) and funding by the ADCS in the support acknowledgement section of the manuscript using language similar to the following: “Data collection and sharing for this project was funded by the Alzheimer's Disease Cooperative Study (ADCS) (National Institutes of Health Grant U19 5U19AG010483)”
- Manuscripts will be submitted to the ADCS DPC for administrative review 30 days prior to submission and the author will apprise the ADCS of acceptance or rejection. If accepted, the author will provide the full manuscript citation.
- A copy of the manuscript will be provided to the ADCS upon publication of the manuscript. If permitted by the journal, a version of the article or link to the article will be uploaded onto the ADCS website.
- Open Access policies for all ADCS publications with NIA funding must be followed.

Exceptions

The ADCS DPC does not intend to review manuscripts for scientific quality and acknowledges that ADCS data may be used to support publications with conflicting results. The ADCS DPC has the right and authority to address and act accordingly on the following:

1. Failure to Follow Data Use Agreement. If users inadvertently violate the ADCS Data Use Agreement, it is likely that they will self-correct as infractions are discovered. If users willfully violate the Data Use Agreement, the sole sanction available to the ADCS will be to revoke access to ADCS data.
2. Fraudulent Use of Data. As soon as the DPC becomes aware of any breach of the Data Use Agreement, immediate steps will be taken to address the breach and sanction those in violation. This may include discontinuing the user's data access and/or reporting the violation. Should the ADCS DPC discover an attempt to publish data obtained fraudulently, the data user will be sanctioned through NIH communication with them or their academic supervisors.
3. Manuscripts of Insufficient Quality. If a review of a proposed manuscript reveals that it is egregiously poor in terms of language, writing, or sensible substance, the ADCS DPC can recommend that the authors withdraw their submission if significant revisions are not made. If the authors choose to submit the manuscript regardless, the ADCS DPC will have three options: 1) request that the acknowledgement credit be withheld; 2) request that the authors publish a statement to the effect that while ADCS data were used, the ADCS did not find this manuscript of sufficient merit to warrant submission for publication, or; 3) revocation of privileges to use ADCS data in the future.

8/04/2017 4:15 PM

4. Journal Objections. It is possible that journal editors may object to the acknowledgement format with the caveat that those ADCS names credited have gathered data but not participated in the analysis and writing of the paper. The ADCS DPC can authorize exceptions to the acknowledgement policy or can negotiate with journal editors as needed on a case-by-case basis.

Data and publications issues will be adjudicated by the ADCS DPC, however, if investigators disagree with the decisions of the ADCS DPC, they can appeal to the ADCS Steering Committee for final arbitration.

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8/04/2017 4:15 PM