

## **KU Alzheimer's Disease Center Resource Sharing Policies and Guidelines**

The KU Alzheimer's Disease Center (KU ADC) encourages and facilitates research and publications by current and new investigators. The KU ADC Administration is eager to help generate successful proposals, secure funding, and complete and publish study results.

Should you have questions and need assistance, please contact Executive Director of the KU ADC.

### **Resource Request Process**

Applications are submitted online at <https://redcap.kumc.edu/surveys/?s=wQMXHa> .

Requests for consultation or expertise are handled in an expedited manner by the appropriate Core Directors and do not require Executive Committee review. Requests for consultation will need to be submitted at <https://redcap.kumc.edu/surveys/?s=wQMXHa> .

Applications for data, human subjects, images and biospecimens are reviewed and approved by the KU ADC Executive Committee.

Your application for ADC resources must include the following information:

- Type of resources (participants, data, biospecimens, images) requested
- Brief research summary (purpose, background and preliminary findings, methods, analytical plan).
- Funding information
- HSC or IACUC approval status as appropriate

Applicants should consider consulting the appropriate Core Director for feedback and assistance.

### Core Leaders or Contacts:

- Clinical Core: Jeff Burns, MD – [jburns2@kumc.edu](mailto:jburns2@kumc.edu)
- Data Management and Statistics Core: Jonathan Mahnken, PhD – [jmahnken@kumc.edu](mailto:jmahnken@kumc.edu). Note: For DMS Core assistance, also register your project through the Department of Biostatistics by clicking "Register Now" at <http://biostatistics.kumc.edu> (be sure to check the KU ADC box in the Center Affiliation section of the form to direct your request to the DMS Core).
- Neuropathology Core: Kathy Newell, MD – [knewell@kumc.edu](mailto:knewell@kumc.edu)
- Education Core: Eric Vidoni, PT, PhD – [evidoni@kumc.edu](mailto:evidoni@kumc.edu)
- Neuroimaging Core: Bill Brooks, PhD – [wbrooks@kumc.edu](mailto:wbrooks@kumc.edu)
- Mitochondrial Genomics and Metabolism Core - Eli Michaelis, PhD- [emichaelis@ku.edu](mailto:emichaelis@ku.edu) or Russell Swerdlow, MD - [rswerdlow@kumc.edu](mailto:rswerdlow@kumc.edu)

Once your application has been entered online, you will receive an email acknowledging the request. The request will be referred to the appropriate core leader(s) for review and, if indicated, presentation at the next executive committee meeting.

### **Requests for Study Participants:**

Studies using human subject participants from the KU ADC must be approved by the investigator's overseeing Human Subject Committee (HSC) prior to initiating the research proposal. Resources, information and application forms for the KU HSC can be found at <http://www2.kumc.edu/researchcompliance/hscadditionalresources.htm> and <http://www2.kumc.edu/researchcompliance/human.htm>. Investigators must provide a copy of their HSC initial approval and annual re-approvals to the KU ADC office.

Investigators requesting data related to human subjects should:

- discuss with the appropriate Core Leader(s) related to the data requested
  - ❖ [jburns2@kumc.edu](mailto:jburns2@kumc.edu) Clinical Core
  - ❖ [jmahnken@kumc.edu](mailto:jmahnken@kumc.edu) DMS Core (data, study design, and statistical analysis plan)
- apply on-line for the resources at <https://redcap.kumc.edu/surveys/?s=wQMXHa>
- apply for the appropriate approval, exemption or determination at <http://www2.kumc.edu/researchcompliance/hscforms.htm> if required by the KUMC HSC.
- complete the KU ADC Data Use Agreement provided at the end of this document.

After receiving the KU ADC approval of the request, the investigator will need to provide copies of HSC approval or an HSC exemption if using de-identified biospecimens.

### Participant Identification

All subject-based data must be stored using a designated "KU ADC PARTICIPANT ADC (RED) NUMBER". Data may not be stored using names or initials.

Any deviation from using the KU ADC participant ID numbers creates an inability to pair individual project's data with the KU ADC DSM Core data. Questions related to this can be addressed to Jonathan Mahnken, PhD at [jmahnken@kumc.edu](mailto:jmahnken@kumc.edu).

NOTE: Investigators requesting KU ADC participants may only utilize those participants for the one specific, approved study. If the investigator wants to use the participants for any other study, the investigator must follow the KU ADC Guidelines for requesting resources.

### Investigator Orientation to KU ADC Participants

Before accessing KU ADC human subjects, the investigator and any research assistants who may be in contact with the participants must receive an orientation to procedures for contacting, scheduling, and utilizing the participants. After the study has been approved, the Recruitment Division Coordinator will contact the principal investigator to set-up an orientation. Reporting guidelines regarding the participants will also be reviewed.

### **Requests for Bio-specimen Samples:**

Disclaimer: No screening for infectious agents has been performed on tissues or bodily fluids provided by the KU ADC. The investigator must take appropriate precautions.

ALL biospecimens materials (fluid, blood, tissue) remain under the authority of the KU ADC Executive Committee. Approval of their usage is based upon the committee's recommendations. No third party sharing is allowed without the written permission of the KU ADC.

The investigator requesting bio-specimens will need to

- discuss with Anne Arthur at [aarthur@kumc.edu](mailto:aarthur@kumc.edu) or 913-588--5535
- discuss with the appropriate Core Leader(s)
  - ❖ [jburns2@kumc.edu](mailto:jburns2@kumc.edu) (blood)
  - ❖ [knewell@kumc.edu](mailto:knewell@kumc.edu) ( brain tissue)
  - ❖ [emichaelis@ku.edu](mailto:emichaelis@ku.edu) or [rswerdlow@kumc.edu](mailto:rswerdlow@kumc.edu) (RNA, DNA, platelets, and cybrid cell lines)

After receiving the KU ADC approval of the request, the investigator will need to provide copies of HSC approval or an HSC exemption if using de-identified biospecimens.

Investigators requesting bio-specimens are asked to return any unused or remaining bio-specimens to the KU ADC.

### **Neuroimaging Core:**

The KU ADC maintains a database of previously obtained scans that are potentially available to investigators.

Requests for research protocols involving neuroimaging should be discussed with William Brooks, PhD, [wbrooks@kumc.edu](mailto:wbrooks@kumc.edu), Core Leader, and are reviewed by the Executive Director and the Core Leader.

### **Data Management and Statistics Core (DMS):**

Requests for DMS Core services should be directed to <http://biostatistics.kumc.edu>. Be sure to check the box for KU Alzheimer's Disease Center in the Center Affiliations section, as this will route your project directly to the DMS Core. The form is very brief, and should only take about 2-3 minutes to complete and submit.

Approved data requests will be fulfilled with the assistance of Amber Watts, PhD, who will be a liaison between the investigator and the DMS Core.

### **Reporting and Publishing Results:**

The contribution of a Core should be acknowledged in resulting publications and co-authorship from the Core should be considered when appropriate by reason of intellectual contribution. Please discuss concerns and ambiguous situations with the KU ADC Executive Director.

Acknowledgement of the KU ADC contribution and listing of our grant number (P30 AG035982) in publications and grant proposals is expected. Such acknowledgments assist in documenting our success in enhancing and supporting research, a major criterion for evaluation in future KU ADC grant renewals.

Accepted publications and abstracts: For work using KU ADC resources, one copy of EVERY MANUSCRIPT (journal or book) OR ABSTRACT ACCEPTED FOR PUBLICATION should be submitted to the Education Core director when requested.

Final publications and abstracts: For work using KU ADC resources, one copy of EVERY MANUSCRIPT (journal or book) OR ABSTRACT ACCEPTED FOR PUBLICATION. Publications must follow NIH Public Access policies and obtain a PubMed Central ID number. An electronic version (PDF) of the reprint of every abstract, journal article, or book chapter is to be submitted to the Education Core director. You must comply with applicable NIH Public Access Policy as it relates to use of ADC resources in a timely manner and as requested.

Case Studies and Case Series Reports: When submitting your approved publication (abstract, journal article, chapter) of case studies or case reports to the KU ADC, include a cross reference (KU ADC Registry number "RED number") list of participants reported on in the publication. Do not identify participants in the actual publication by this number.

Posters and Presentations: When presenting your research at a local, national or international conference, please use the approved KU ADC template for posters and presentations.

You may be asked by the KU ADC to present your data at a KU ADC-sponsored event.

You also may be asked by the KU ADC to share your data in the KU ADC's secured database after it has been published.

## **University of Kansas Alzheimer's Disease Center (KUADC) DATA USE AGREEMENT**

I request access to data or the research participant pool managed by the KU ADC for the purpose of scientific investigation, teaching, or the planning of clinical research studies and agree to the following terms.

1. I will receive access to de-identified data and will not attempt to establish the identity of, or attempt to contact any of the KU ADC subjects.
2. I will not further disclose these data beyond the uses outlined in this agreement and my data use application and understand that redistribution of data in any manner is prohibited.
3. I will require anyone on my team who utilizes these data, or anyone with whom I share these data to comply with this data use agreement.
4. I will accurately provide the requested information for persons who will use these data and the analyses that are planned using these data.
5. I will respond promptly and accurately to requests to update this information.
6. I will comply with any rules and regulations imposed by my institution and its institutional review board in requesting these data.
7. I will ensure that Investigators who utilize KU ADC data use appropriate administrative, physical and technical safeguards to prevent use or disclosure of the data other than as provided for by this Agreement.
8. I will report any use or disclosure of the data not provided for by this Agreement of which I become aware within 15 days of becoming aware of such use or disclosure.
9. I will use the KU ADC poster and/or presentation template when presenting the data at a local, national or international conference or meeting.

If recruiting human subjects from the prospective participant pool, I agree to the following:

10. I will receive access to a select set of individuals by the Outreach and Recruitment or Clinical Cores and not attempt to contact other individuals in the pool who have not been designated for my study.
11. I will work with the Outreach and Recruitment Core to harmonize and use approved materials (telephone scripts, recruitment letters, etc...) for promoting the study, and to provide all requested information for tracking participation.
12. I will ensure that my study staff represent the KU ADC in an appropriate and professional manner and will work with the Outreach and Recruitment Core to train study staff on standard procedures for accurate tracking and interaction with participants.

If I publish abstracts using data from KU ADC, I agree to the following:

13. I will cite KU ADC as the source of data and the KU ADC funding sources in the abstract as space allows and will report abstracts to the KU ADC when requested.

If I publish manuscripts using data from KU ADC, I agree to the following:

14. I will acknowledge funding by the KU ADC 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 University of Kansas Alzheimer’s Disease Center (KU ADC) (National Institutes of Health Grant P30 AG035982).  
KU ADC is funded by the National Institute on Aging.*

*IMPORTANT NOTE: It is the policy of the KU ADC to make analyzed data available to investigators as quickly as possible. However, data analysis for this project is expected to take years as methods for analysis of these datasets evolve. Therefore, I understand that any processed data that I download might be preliminary and that results may change as new methods of analysis are implemented. I will familiarize myself with the analysis methods so that I am aware of the limitations of these data prior to using them for scientific purposes.*

I understand that failure to abide by these guidelines will result in termination of my privileges to access KU ADC data.