

AAA Foundation for Traffic Safety (AAAFTS) Longitudinal Research on Aging Drivers (LongROAD) Data Sharing Guidelines

The AAA Longitudinal Research on Aging Drivers (LongROAD) study provides a rich data source for those interested in examining older driver safety and mobility. Enabling access to these data will ensure the timely completion of important analyses and dissemination of results that could have valuable policy and scientific implications. However, data sharing with external parties is limited by the consent forms signed by study participants and the human subjects research protection policies of the individual study sites, and so these guidelines have been established to assure these limitations are observed while maximizing access to these data.

I. Eligibility to Request LongROAD Study Data

To submit a request, a request for LongROAD study data must meet the following requirements:

- Have established a collaborative relationship with one of the five LongROAD study sites (Bassett Research Institute, Johns Hopkins University, University of California San Diego, University of Colorado, University of Michigan) or the Administrative and Data Coordinating Center (Columbia University), for the purpose of conducting the proposed study. If you do not already have a collaborative relationship, please contact the AAAFTS's LongROAD Data Coordinator (longroad@aaafoundation.org) who can provide a referral. Please note that collaboration with any external requestor is at the discretion of each LongROAD site/investigator team member and not at the discretion of AAAFTS.
- Must be able to obtain Institutional Review Board (IRB) approval or a formal exempt determination from the applicant's home institution. Students and other researchers who do not meet their institution's requirements to serve as Principal Investigator must have a mentor or collaborator willing to serve in that role. (Exception: researchers who are directly added to a study site's IRB protocol are not required to obtain separate IRB approval.)
- Home institution must be a research organization or a designated research department or office within a larger organization. Research is defined as conducting studies and producing reports to contribute to generalizable knowledge around the issues central to the organization's mission. Research organizations can include institutions of higher education, government agencies, research foundations and non-profit research institutions.

II. Limitations on Sharing

- Data can only be shared by a LongROAD study site or Columbia University directly with an external collaborator. AAAFTS is not able to provide data to external researchers.
- Only the data tables/files and intervals necessary for the completion of a study may be shared with external collaborators.
- The following data tables/elements will not be shared with external collaborators: Medical Record Review - Diagnoses and Procedures, Medical Record Review - Healthcare Utilization.
- No data for Johns Hopkins University study participants may be shared with external collaborators unless those collaborators can be directly added to a study site's IRB protocol.
- All analyses should be performed at the study level unless adequate justification can be provided for limiting an analysis to a specific site or sites (to be included in the "Proposed Data Analysis" section of the Study Proposal form). It is not necessary to provide justification for excluding Johns Hopkins data if the exclusion is due to lack of access to these data.

III. Proposal Process

Prior to submitting a Study Proposal, external researchers interested in using LongROAD data should:

- Review the LongROAD Publication Inventory to ensure there is no duplication with previous research.
- Review the LongROAD Data User Guide to ensure that the data available can adequately address the proposed research question(s).

- Identify and confirm a collaborator on the LongROAD investigator team. Requestors may reach out to team members directly or to the AAAFTS's LongROAD Data Coordinator for assistance (longroad@aaafoundation.org). Eligible collaborators are:
 - a. Bassett Research Institute: David Strogatz (david.strogatz@bassett.org)
 - b. Columbia University: Guohua Li (gl2240@cumc.columbia.edu); Thelma Mielenz (tjm2141@cumc.columbia.edu)
 - c. Johns Hopkins University: Vanya Jones (vjones@jhu.edu)
 - d. University of California, San Diego: Linda Hill (llhill@health.ucsd.edu)
 - e. University of Colorado Anschutz Medical Campus: Carolyn DiGuseppi (carolyn.diguseppi@cuanschutz.edu); Emmy Betz (marian.betz@ucdenver.edu)
 - f. University of Michigan: David Eby (eby@umich.edu); Lisa Molnar (ljmolnar@umich.edu)

Submission of Study Proposal Documentation:

- Prepare a Study Proposal form in coordination with your identified LongROAD collaborator. The LongROAD collaborator should submit the completed form to the AAAFTS's LongROAD Data Coordinator (longroad@aaafoundation.org) and cc: the external requestor.
- You will receive email confirmation that your proposal has been received by AAAFTS within 5 business days after submission.

After AAAFTS Decision to Proceed with Data Sharing:

- Obtain and provide IRB approval/exempt determination to the LongROAD collaborating site and execute a Data Use Agreement (DUA). Alternatively, at some study sites, the requestor may be added directly to the sites' IRB protocol as a member of that site's LongROAD research team.
- Receive the data from the LongROAD collaborating site.

IV. Review Criteria

- Existence of a collaborative relationship with one of the five study sites or Columbia University.
- Non-duplicative of previous or ongoing research studies.
- Scientific and technical feasibility of the study.
- Qualifications of all people who will have access to the data.
- Consistency between requested data and study goals.
- Anticipated publications or other dissemination of results.
- Protections in place to maintain confidentiality of the data.
- Align with the mission of the AAAFTS and the goals of the LongROAD study.

V. Responsibilities of the Requestor

- Obtain IRB approval or exempt determination for the research. (Exception: researchers who are directly added to a study site's IRB protocol are not required to obtain separate IRB approval.)
- Use data only for studies for which AAAFTS has decided may Proceed with Data Sharing. Once completed, data stored outside of the study site should be destroyed within 1 year of publication.
- Make no attempt to identify individual subjects.
- Provide description and documentation (e.g., software code) for all newly created variables to the LongROAD Data Coordinator at the AAAFTS (longroad@aaafoundation.org).
- Protect data privacy and security. Do not share or distribute data.
- Acknowledge the AAA Foundation for Traffic Safety LongROAD study as the source of the data in all publications.
- Do not include any individual-level data as part of any publication, including as an addendum or deposited into a public repository. Provide the following statement whenever a data sharing statement is required by a journal or publisher: Restrictions apply to the availability of these data. Data may be available from the author [list collaborating investigator] with permission from the AAA Foundation for Traffic Safety and upon execution of a Data Use Agreement, with limitations on use.