

Data Access Policies and Procedures for Collaborative Research

ACS Discovery – Population Science

The American Cancer Society (ACS) [Population Science](#) (PopSci) investigators work with scientists across the world to share data and resources from our cohort studies to collaborate on impactful research studies.

Here's an overview about how to prepare for and submit a request for data access for research collaboration, as well as a preview of the review and acceptance process.

Note: All approved projects will require a standard ACS Research Collaboration Agreement and may be subject to fees for use of data and biospecimens to offset staff time and specimen storage, processing, and shipping costs (not including assays).

Review cohort information. We encourage potential collaborators to review the ACS cohort resources before submitting the Data Access and Collaboration Request form below. Review the following study descriptions and questionnaires to be sure we have the information available to answer your research question.

- [The American Cancer Society's Cancer Prevention Study 3 \(CPS-3\): Recruitment, Study Design, and Baseline Characteristics](#)
- [Follow-up of a Large Prospective Cohort in the United States Using Linkage With Multiple State Cancer Registries \(CPS-3\)](#)
- [The CPS-3 FFQ Is a Reliable and Valid Measure of Nutrient Intakes among Racial/Ethnic Subgroups, Compared with 24-Hour Recalls and Biomarkers \(CPS-3 Diet Assessment Substudy\)](#)
- [Cryopreservation of Whole Blood Samples Collected in the Field for a Large Epidemiologic Study \(CPS-3\)](#)
- [The American Cancer Society Cancer Prevention Study II \(CPS-II\) Nutrition Cohort](#)
- [Establishment of the CPS-II Nutrition Cohort Colorectal Tissue Repository](#)
- [CPS-II Questionnaires](#)
- [ACS Population Science Investigators](#)

Complete the External Data Access and Collaboration Request form (use the link at the end of this paragraph). This form collects preliminary information to help PopSci researchers assess your project. To fill out the form, you will need the following information (* indicates required information):

- Lead investigator's name and title*
- Institutional affiliation*

- Email address*
- Short bio of training and experience (no more than 300 words/1500 characters)*
- Additional investigators*
- Project title*
- Single paragraph description of proposed project (no more than 300 words/1500 characters)*
- Study population(s)*
- Names of ACS PopSci investigator(s) you are collaborating with (if applicable)
- Grant submission timeline (if applicable)
- Summary of the type(s) of biospecimens sample(s) needed for this project (if applicable)

<https://forms.office.com/r/iVvjSXY8nw>

Familiarize yourself with the evaluation criteria PopSci uses to determine whether to request a full proposal. We consider your project's:

- Overlap with existing research.
- Feasibility to address the research question using PopSci cohort resources.
- Appropriateness of cohort data/resources to answer the research question.
- Consistency with ACS mission priorities.
- Burden to participants and/or department capacity.
- Potential costs to ACS.
- Potential conflict of interest.

The PopSci team's initial review of Data Access and Collaboration Request forms may take up to 8 weeks. During this time, please contact cohort.data@cancer.org with any questions related to your request. Successful applicants will be invited to submit a full proposal.

Submit a full proposal if you received a request for one. A PopSci investigator will support the applicant through the proposal submission using a standardized template that requires the following information:

- Background/Introduction
- Specific aim(s)
- Methods (maximum length: 3 paragraphs)

- Proposed Timeline
- References
- Biospecimens details (if applicable)

The collaborating PopSci investigator may provide simple frequencies and cross tabs for proposal development, and evaluation of statistical power. However, during development of the proposal, the team will not share data.

Submit the completed proposal by email to the collaborating PopSci investigator and cohort.data@cancer.org for review.

Understand how PopSci reviews full proposals. PopSci investigators review proposals on a rolling basis. Proposal review may take up to 8 weeks. When needed, we may seek input from one or more external advisors.

PopSci reviewers evaluate projects according to these criteria:

- The proposed research question is focused and of high public health, clinical, and/or scientific significance.
- For proposals involving the Cancer Prevention Studies, the proposed research question requires prospectively collected data/samples or is best addressed using prospectively collected data/samples, and/or enhances the value of the ACS database and/or our sample repository.
- The amount of material requested for a biospecimen-based research proposal is appropriate, and not excessive. (Our biospecimens are a finite resource.)
 - The study design is appropriate to address the research question:
 - The study sample (i.e., inclusion/exclusion criteria, subgroups) is well described and appropriate.
 - The study design demonstrates acceptable laboratory standards and quality control procedures (if appropriate)
 - The sample size will provide adequate power for answering the question, or the number of available ACS samples will make a sufficient impact on the proposed analysis (i.e., in a consortium analysis) to justify our sample handling and collaboration efforts.
 - The statistical analytic approach is appropriate.
- The collective research team has appropriate knowledge, qualifications, and experience to conduct the study.

During our review, we may ask you to provide additional details or to revise your proposal based on PopSci feedback.

Enter into a Research Collaboration Agreement for an approved project. After ACS PopSci approves a proposal, we will initiate a Research Collaboration Agreement using a standard template, and we will share this for review by the collaborating institution. The Agreement will include the agreed upon Research Plan (taken from the approved proposal). The terms of the Agreement include (but are not limited to):

- Expectations for ACS co-authorship of collaborative works
- Standards for appropriate use of research materials (data and/or specimens)
- Cost recovery fees for data and/or specimens
- Ownership of project results
- Confidentiality terms related to ACS research materials.

These situations may have additional requirements:

- **For projects that require subgrant information or letters of support**, the ACS Sponsored Projects Office will be engaged to prepare any necessary documentation. It may take up to 4 weeks to prepare these documents.
- **For projects utilizing a new laboratory for sample processing/analysis**, pilot QC testing will be required to test correlation/variation before all samples are sent for processing/analysis.
- **For projects that overlap highly with the standard programming practices and expertise of PopSci**, a program review of analytic code may be required.

Note: An IRB approval letter or appropriate documentation indicating the project is non-human subjects research may be required.