

Wisconsin Longitudinal Study

Guidelines for Requesting Non-public Data

The Wisconsin Longitudinal Study is committed to the privacy of its study participants and WLS staff takes great care to maintain their confidentiality. We offer three levels of access to WLS data.

Public data or Level one data should be sufficient for most research questions. This access requires a brief registration on our web site before downloading the data. This level of data has the unique key identifier "idpub."

Level two data includes measures labeled "not available for public release." These measures slightly increase the risk of re-identification. To use these measures you must provide a written explanation justifying why the publicly available data are not sufficient to answer your question. You also need to provide a CV and proof of human subjects training for yourself and if applicable each researcher with whom you will work. Please note that certain combinations of level two variables may require a level three review. Level two data are distributed to users via an encrypted file transfer and have the unique key identifier "idpriv."

Level three data include geographic identifiers, dates, and measures that group study participants into schools. Access requires the same items as level two, documentation of IRB approval from the researcher's home institution, and a fully-executed data access agreement. Level three data are only accessible via the WLS secure server. The server allows you remote access to the WLS data but prohibits you from placing the data on any other machine or network. The server provides commonly used statistical packages for your research.

Researchers should note that all levels of WLS data are considered Human Subjects Data and any research involving Human Subjects Data requires IRB approval. WLS researchers are also reminded that they should not publish any tables with cell sizes less than or equal to five.

Decisions about whether to grant access to Level 2 or Level 3 data are made by the Principal Investigator of the WLS project.

To request Level 2 data please submit the following to roan@ssc.wisc.edu

1. A written explanation of why the publically available level one data are not sufficient to answer your research question(s).
2. A copy of a Curriculum Vitae (CV) for every researcher who needs access to the data file. If student or post-doc please also submit the name and CV of a faculty sponsor.
3. Proof of human subjects training for every researcher who needs access to the data file. If student please also submit proof of human subjects training for your faculty sponsor.
4. A specific list of Level two variable names (including the variable description) to which you are requesting access. Also indicate whether you want the wide or long version of the WLS data. When you receive your data, the file will include the level 2 versions of all requested variables AND the public or level one version of all the remaining variables. Information on all variables is available in our online codebooks.
5. The preferred format of the data file; Stata, SPSS, or SAS.

To request Level 3 data please submit the following to roan@ssc.wisc.edu

1. Short proposal (5 pages maximum) describing the research question and study design.
2. A copy of a Curriculum Vitae (CV) for every researcher who needs access to the data file. If student please also submit the name and CV of a faculty sponsor.
3. Documentation of IRB approval from home institution.¹

Upon receipt of the above then:

1. Your application will be reviewed by the WLS PI.
2. Upon acceptance of your proposal the PI and any staff needing access to the data will be required to complete the DATA ACCESS AGREEMENT RESTRICTING DISCLOSURE AND USE OF RESTRICTED DATA FROM THE WISCONSIN LONGITUDINAL STUDY. This agreement must be signed by an official representative of the requesting PI's Institution. A sample of this agreement is attached.

¹ Researchers from UW –Madison should contact Joe Savard (joe.savard@wisc.edu) before submitting to IRB.

DATA ACCESS AGREEMENT RESTRICTING DISCLOSURE AND USE OF RESTRICTED DATA FROM THE WISCONSIN LONGITUDINAL STUDY

This Data Use Agreement (DUA) is entered into the _____ day of _____, 20__ between the Board of Regents of the University of Wisconsin System on behalf of the University of Wisconsin-Madison, Wisconsin Longitudinal Study (WLS) and the

_____ (Receiving Agency) wherein

_____ (Investigator) is the researcher responsible for the projects using the WLS Restricted Data files.

Whereas, WLS has a data bank containing confidential information (the WLS Restricted Data including the WLS Genetic Data), and

Whereas, Investigator has an IRB or equivalent Ethics Committee-reviewed study requiring access to one or more files of the said data bank, and has submitted that plan to WLS (the Research Plan), and

Whereas, the Investigator and all other employees or agents of Receiving Agency having access to WLS Restricted Data under this Agreement (Supplemental Users) (collectively Researchers) acknowledge that this Restricted Data was obtained by WLS under representations that the identity of the individuals participating in the WLS would be kept absolutely confidential, acknowledge that the WLS Restricted Data is being provided to the Investigator and Supplemental Users under a strict pledge of confidentiality and non-disclosure as further described in this Agreement, and agree to take all necessary steps to ensure the continuing security and confidentiality of the WLS Restricted Data, as further described in this Agreement.

In consideration of the WLS providing access to the WLS Restricted Data, the Receiving Agency, its Investigator(s), and Supplemental Users, agree:

1. The WLS Restricted Data under this Agreement includes both the original WLS Restricted Data files provided by WLS, and any variables and fields derived from them.
2. No attempt shall be made to identify the individual person, family or household, employer, or benefit provider (except sole source providers of public benefits), either directly or inferentially in this or other WLS datasets.
3. If the identity of any person, family or household, employer, or benefit provider, or establishment in this file is inadvertently discovered, then (a) no use will be made of this knowledge, (b) the Director of WLS will be advised of this incident immediately, (c) the information that would identify any individual or establishment will be safeguarded or destroyed, as requested by WLS, and (d) no one else will be informed of the discovered identity.
4. The following guidelines will be employed when producing tabulations for distribution:
 - Magnitude Data: Ensure that no cells/strata with $n < 5$ are produced

- Frequency Data: Apply a marginal threshold of $n \geq 5$ and cell threshold of $n \geq 5$ to all tabulations
 - Protection against complementary disclosure: additional cells may be suppressed, i.e., complementary disclosure, to make sure the primary suppressions cannot be derived by subtraction from published marginal totals.
5. Only aggregate statistical summaries of the data and analyses (frequency tabulations, magnitude tabulations, means, variances, regression coefficients, and correlation coefficients), shall be published, subject to the provisions above.
 6. WLS shall be cited as the data source in any publications or research based upon these data, and a copy of any publications shall be provided to the WLS. The following citation should be included in any research reports, papers, or publications based on these data:

In text: "The Wisconsin Longitudinal Study is sponsored by the National Institute on Aging (grant numbers R01AG009775, R01AG033285, and R01AG041868) and was conducted by the University of Wisconsin."

In references: "Wisconsin Longitudinal Study. Produced and distributed by the University of Wisconsin with funding from the National Institute on Aging (grant numbers R01AG009775, R01AG033285, and R01AG041868), Madison, WI."

7. Investigators will do this research on a secure remote server. WLS will grant access to a server that houses the WLS Restricted Data as well as commonly used software programs. Researchers will be able to transfer software output files, statistical tables, and graphs off the server once they have been vetted by WLS staff. The Restricted Data and any data sets derived from it shall not be removed from the WLS secure server.
8. To the extent permitted by law, Receiving Agency shall hold harmless and indemnify the University of Wisconsin, its agents and employees, for any claims of breaches of confidentiality arising out of the Receiving Entity's, its Investigators and Supplemental Users use of the data provided under this Agreement including failure to abide by any section of this Agreement or any accidental or intentional violation of privacy of any contributor to any WLS data resource.
9. Access to Restricted Data will be limited solely to the Investigator(s) who are signatories to this Agreement, and to Supplemental Users (research assistant/associate, postdoctoral scholar, graduate student, undergraduate student, or other individual working on the research project and who are employees or agents of Receiving Agency). All Investigators and Supplemental Users agree not to share or provide copies of any files received by this Agreement to any other person or organization.
10. Receiving Agency and its Investigator shall ensure that any Supplemental Users granted access to the Restricted Data shall first agree to the same terms of confidentiality and non-disclosure as set forth in this Agreement through a written acknowledgement such as that included in Exhibit A. Such acknowledgements shall be made available to WLS upon request.

11. WLS Restricted Data will be used solely for scientific and public policy statistical research, and not for any administrative or law enforcement purpose.
12. Qualitative analysis of audio files that require printed transcriptions are not considered to be WLS Restricted Data. Such information may be freely published by the Investigator and may be used for ongoing research programs approved under this Agreement. When producing transcriptions for distribution, the following guidelines are to be employed:
 - a) All first and last names, employers or company names must be removed from the transcription
 - b) All mentions of locations must be removed from the transcription.
13. Researchers are prohibited from publishing results that identify geographic areas below the level of Census Division. Under certain circumstances, Researchers using WLS Restricted Data who have access to state-level geographic information may wish to report state-level summary information. In such cases, analysis results must be submitted to the WLS for review and approval prior to presentation or publication.
14. All public representations of WLS Restricted Data involving geographic identifiers below Census Division must be submitted to WLS for review and approval. WLS will confirm receipt of materials via email to the Investigator, and will make every effort to review the materials within 10 business days of confirmed receipt. Investigator(s) agree to modify representations as suggested by WLS before public presentation.
15. No attempt will be made to link WLS Restricted Data with any other dataset, except as specified in the approved Research Plan; specifically, there may be no linkages of:
 - a) the WLS Restricted Data with any other WLS research datasets; or
 - b) any WLS Restricted Dataset containing information derived from Social Security Administration records, with any dataset containing geographic information at a level of aggregation more detailed than Census Division, except with explicit written permission from the Social Security Administration; or
 - c) any of the WLS Restricted Data with any other dataset without written approval from WLS.
16. The WLS Restricted Data are and remain the sole property of the University of Wisconsin, and the Receiving Agency, Investigator(s) and Supplemental Users will not disclose them to any third party. The Receiving Agency agrees that in response to any request for WLS Restricted Data under the federal Freedom of Information Act, 5 U.S.C. 552 or similar state sunshine law, it will refuse to disclose the WLS Restricted Data on grounds that it is not a Receiving Agency record subject to disclosure under that Act or is alternatively exempt from disclosure under that Act. Receiving Agency will immediately notify WLS of any such requests and will provide WLS with sufficient opportunity to seek a protective order.
17. Use of WLS Restricted Data provided by WLS to the Investigator will be confined to the research described in the Research Plan submitted to and approved by WLS; the approved Research Plan is incorporated by reference into this Agreement.

18. The Investigator(s) will provide annually within 30 calendar days of the anniversary of this Agreement the following:
 - a) Project title, Investigator(s), and current contact information
 - b) Progress report, including a summary of current work, project titles, and brief justification for continued access to the data
 - c) Detail of changes or modifications in the research
 - d) Citations for any papers, publications or presentations using the WLS Restricted Data
 - e) Proof of current IRB or equivalent Ethics Committee review for projects using WLS Restricted Data, which must be renewed annually.
 - f) Updated list of authorized users under this agreement. A new Supplemental User Agreement must be completed and signed for each new user. The list should include access termination dates for those no longer requiring access to the WLS Restricted Data.
19. The Investigator shall have a permanent, faculty-level or scientist-level appointment at the Receiving Agency, and the Co-Investigator(s), if any, shall have faculty-level or scientist-level appointments at the Receiving Agency.
20. All Supplemental Users signing Supplemental Agreements have an employment or agency relationship with the Receiving Agency and are listed as personnel on the research project described in the Research Plan, and will have access to WLS Restricted Data only under the supervision of the Investigator(s). The Supplemental Agreements with Supplemental Users are incorporated by reference into this Agreement.
21. The Research Plan shall be reviewed by the Receiving Agency's Institutional Review Board/or equivalent Ethics Committee, using the standards and procedures for live human subjects, and a certification of that approval or determination that the study is exempt has been provided to WLS.
22. The Receiving Agency represents that it has in place a Code of Ethics governing its employees that prohibits and provides sanctions for the unauthorized disclosure of confidential information, and policies and procedures on scientific integrity and misconduct. The Receiving Agency recognizes that certain violations of this agreement might constitute actions covered by such policies and procedures and Code of Ethics, as well as constituting violations of applicable federal or state laws protecting individual privacy. If the WLS notifies the Receiving Agency that a violation of this agreement has occurred and alleges that the violation constitutes an ethical breach or scientific misconduct, the Receiving Agency will handle the allegation according to its policies and procedures applicable to ethical behavior, scientific integrity and misconduct.
23. The representative signatory of the Receiving Agency is a person authorized to enter into contractual agreements on behalf of the Receiving Agency.
24. If WLS determines that this Agreement has been violated, WLS may:
 - a) prohibit any of the signatories of this Agreement, and of any Supplemental Agreements from obtaining access to any WLS restricted data

- b) report the violation(s) to the Receiving Agency and request that sanctions be imposed on the person(s) responsible for the violations
- c) where the violation pertains to data obtained from a federal agency or used in connection with a federally-funded project, report directly or indirectly the violation(s) to funding agencies with a recommendation that current funding be terminated, and future funding denied, to the Investigator(s), the Researchers and any other person implicated in the violation(s)
- d) utilize such other remedies as may be available to it under law

SAMPLE

Signature Page for Investigator and Co-Investigator

By signing this Agreement, I certify that I have reviewed the Agreement and that I agree to abide by its terms:

Investigator Signature & Date

Co-Investigator Signature & Date

Typed/Printed Name

Typed/Printed Name

Title

Title

Phone

Phone

Email

Email

SAMPLE

Signature Page for Receiving Entity Signatory, WLS Representative, and
University of Wisconsin System Signatory

Receiving Entity Signatory

Wisconsin Longitudinal Study Representative

Typed/Printed Name

Carol Roan
Study Director
Department of Sociology, Room 4412
1180 Observatory Drive
Madison, WI 53706
Phone: 608.265.6196
Carol.Roan@wisc.edu

Title

Institution

Building Address

Board of Regents of the UW System Signatory

Street Address

Typed/Printed Name

City, State, Zip

Phone

Email

Exhibit A: Supplemental User Agreement

By signing this Exhibit A, I certify that I have reviewed the Agreement and that I agree to not use or disclose the WLS Restricted Data except as authorized in this Agreement. I understand that any unauthorized use or disclosure may result in further access to the WLS Restricted Data being denied and may further result in discipline or other sanctions as outlined in the Agreement.

Supplemental User Name and Date

Typed/Printed Name

Title

SAMPLE