

National Survey of Child and Adolescent Well-Being (NSCAW) Restricted Release Data License

National Data Archive on Child Abuse and Neglect

The Investigator accepts the definitions as described and agrees to follow the terms and conditions outlined in this License:

I. DEFINITIONS

- a. **Investigator** The person who serves as the primary point of contact for all communications involving this License. The Investigator is the person primarily responsible for analysis and other use of Restricted Data obtained through this License. The Investigator must have a research-related affiliation with the Investigator's Institution or be granted an exception from NDACAN, when allowed by NDACAN procedures.
- b. **NDACAN** The National Data Archive on Child Abuse and Neglect at Cornell University acting on behalf of the Children's Bureau, Administration for Children, Youth and Families, U.S. Department of Health and Human Services.
- c. **Promise of Confidentiality** A promise to a Research Subject that the information the respondent provides will not be disseminated without the permission of the respondent; that the fact that the respondent participated in the study will not be disclosed; and that disseminated information will include no linkages to the identity of the respondent. Such a promise encompasses traditional notions of both confidentiality and anonymity. Names and other identifying information regarding respondents, proxies, or other persons on whom the respondent or proxy provides information, is presumed to be confidential.
- d. **Investigator's Institution** The organization employing the Investigator. The Investigator's Institution must have an Institutional Review Board/Human Subjects Review Committee registered with the United States Office for Human Research Protections.
- e. **Representative of the Investigator's Institution** An individual who is authorized by the Investigator's Institution to enter into contractual agreements on behalf the institution. Examples include President, Vice President, Dean, Provost, Vice Provost for Research, Vice Chancellor for Research, Director of Sponsored Research, or an attorney for the institution.
- f. **Research Staff** All people other than the Investigator who have been authorized to access the Restricted Data. Research Staff must be affiliated with the Investigator's Institution as employees, students, consultants, or subcontractors.
- g. **Research Subject** A person, family, household, or organization observed for purposes of research and to whom a promise of confidentiality has been given. A Research Subject includes any person providing information to a study or on whose behalf a proxy provides information.
- h. **Restricted Data** The original data provided by NDACAN and any variables derived from the original data. Data resulting from merges or matches to the original or derived variables are included in this definition. Aggregated statistical summaries of data and analyses, such as tables and regression statistics, are not considered restricted derived data for the purposes of this License.
- i. **Statistical Purposes** The description, estimation, or analysis of the characteristics of groups, without identifying the individuals that comprise such groups; and includes the development, implementation, or maintenance of methods, technical or administrative procedures, or information resources that support the aforementioned purposes.

II. ITEMS INCORPORATED BY REFERENCE

- a. The Research Staff Supplement is incorporated by reference into this License.
- b. The Data Protection Plan, if required, is incorporated by reference into this License.

III. DURATION OF THIS LICENSE

- a. This License will go into effect upon approval of the License by NDACAN and will remain in effect for 36 months or until the completion of the research project, whichever comes first. If, at the end of 36 months, access to the Restricted Data is still desired, the Investigator must submit a new application to NDACAN.

IV. PRIVACY OF RESEARCH SUBJECTS

Any intentional identification of a Research Subject or unauthorized disclosure of confidential information violates the Promise of Confidentiality given to the providers of the information. Therefore,

- a. The Restricted Data will be used solely for research or statistical purposes.
- b. No attempt will be made to identify Research Subjects.
- c. The Restricted Data will be used to generate statistical summary information only and may never be released, alone or in combination with other known data, in a manner that would allow a Research Subject to be identified.
- d. If the identity of any Research Subject is discovered inadvertently, no use will be made of this knowledge; NDACAN will be advised of the discovery; the identifying information will be safeguarded or destroyed as requested by NDACAN; and no one else will be informed of the discovered identity.

V. ACCESS TO THE RESTRICTED DATA

- a. Access to the Restricted Data will be limited to the Investigator and the Restricted Data will not be given to other people.
- b. The Restricted Data will be protected from loss, theft, or unauthorized access.
- c. NDACAN will be notified immediately if the Investigator's Institution, Investigator, or Research Staff receive any demand for disclosure of the Restricted Data. NDACAN is authorized to revoke this license and take possession of the Restricted Data, or take any other action necessary to protect the absolute confidentiality of the Restricted Data.
- d. If the Research Subjects in the Restricted Data are protected by a Federal Certificate of Confidentiality issued by the National Institutes of Health, the Investigator's Institution, Investigator, and Research Staff may refuse to disclose identifying information on the research participants in any civil, criminal, administrative, legislative, or other proceeding, whether at the federal, state, or local level.

VI. LINKING TO OTHER DATA

- a. Linking to the Restricted Data is not allowed unless all three of the following conditions are met: (1) linking to the requested dataset is not prohibited by NDACAN, (2) the dataset to be matched has been specifically identified in the Application for Restricted Data, and (3) linking has been approved in accordance with NDACAN procedures.

VII. REPORTING AND PUBLICATION REQUIREMENTS

- a. The Investigator will provide NDACAN with annual reports which include a copy of the annual approval of the project by the Investigator's Institution's Institutional Review Board; copies of published works or reports based wholly or in part on the Restricted Data; and a listing of presentations at professional meetings based upon the Restricted Data.
- b. All books, articles, conference papers, theses, dissertations, reports, or other publications that employed the Restricted Data or other resources provided by NDACAN will acknowledge both NDACAN and the original collectors of the Restricted Data. A disclaimer must also be provided, stating that the information and opinions expressed in the work reflect solely the position of the author(s) and not NDACAN, the original collector of the Restricted Data, or the agency that funded the research.

VIII. OWNERSHIP OF THE DATA

- a. Permission to use the Restricted Data may be revoked by NDACAN at any time, at its discretion. The Investigator and Investigator's Institution must return all originals and destroy all copies of the Restricted Data, on whatever media they exist, within 5 days of written request to do so. Failure to comply may be considered a material breach of the License.

- b. The Investigator and Research Staff will not make any claim to copyright ownership of the Restricted Data and accompanying documentation.

IX. DISCLAIMER

- a. The original collector of the Restricted Data, NDACAN, Cornell University, and the agency that funded the research bear no responsibility for use of the data or for interpretations or inferences based upon such uses.

X. VIOLATIONS OF THIS LICENSE

- a. If NDACAN determines that the terms of this License may have been violated, NDACAN will inform the Investigator and Investigator's Institution of the allegations in writing and will provide an opportunity for a written response within 10 days. Sanctions for violating the License may include the following:
- b. NDACAN may revoke the existing License, demand return of the Restricted Data, and deny all future access to NDACAN data.
- c. The violation may be reported to the Investigator's Institution's Institutional Review Board and to the Investigator's funding agency with a request for an investigation.
- d. If the confidentiality of Research Subjects has been violated, the case may be reported to the Federal Office for Human Research Protections, which may result in an investigation of the user's institution.
- e. A court may award the payment of damages to any individuals or organizations harmed by the breach of the License.

Note: If you are unable to sign this document digitally, you may email a scan of a hand-signed copy to NDACAN@cornell.edu.

Signature of the Investigator

I certify that all information that has been submitted in association with this request for the Restricted Data is truthful. Furthermore, I acknowledge that I am legally bound by the covenants and terms of this License.

Investigator Signature: _____ Date: _____

Investigator Name: _____

Signature of the Representative of the Investigator's Institution

By signing this License, this institution agrees that access to these confidential data will be restricted to authorized persons whose names appear on this License and the Supplemental Agreements with Research Staff, and that this institution is legally bound by the covenants and terms of this License.

Representative Signature: _____ Date: _____

Representative Name: _____

Representative Title: _____

Representative Institution: _____

Representative E-mail address: _____

Signature of the NDACAN Representative

NDACAN Signature: _____ Date: _____

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Bronfenbrenner Center for Translational Research
Cornell University