Agreement for the Use of Confidential Data from the Community Tracking Study/Health Tracking Surveys in the Health and Medical Care Archive at the Inter-university Consortium for Political and Social Research (ICPSR)

I. DEFINITIONS

A. "Investigator" is the person primarily responsible for analysis and other use of Confidential Data obtained through this Agreement.

B. "Research Staff" are all persons at the Investigator's institution, excluding the Investigator, who will have access to Confidential Data obtained through this Agreement. Research Staff include project staff or students conducting dissertation or thesis research.

C. "Institution" is the university or research institution at which the Investigator will conduct research using Confidential Data obtained through this Agreement.

D. "Representative of the Institution" is a person authorized to enter into contractual agreements on behalf of Investigator's Institution.

E. "Confidential Data" consist of identifiable private information, linkable to a specific individual either directly or indirectly, for which the individual (whether a person or organization) has the expectation that the information will not be released in a manner that allows public identification of the individual or causes some harm to the individual.

F. "Private Person" means any individual (including an individual acting in his official capacity) and any private (i.e., non-government) partnership, corporation, association, organization, or entity (or any combination thereof), including family, household, school, neighborhood, health service, or institution.

G. "ICPSR" is the Inter-university Consortium of Political and Social Research.

H. "Restricted Data Contracting System" ("RDCS") is the web-based system for data contracts at ICPSR.

I. "Data Security Plan" is a component of the Agreement which specifies permissible computer configurations for use of Confidential Data through Investigator responses to a series of questions, and records what the Investigator commits to do in order to keep Confidential Data secure.

J. "Deductive Disclosure" is the discerning of an individual’s identity or confidential information through the use of known characteristics of that individual. Disclosure risk is present if an unacceptably narrow estimation of an individual’s confidential information is possible or if determining the exact attributes of the individual is possible with a high level of confidence.

K. "RWJF" is the Robert Wood Johnson Foundation.

L. "HSC" is the Center for Studying Health System Change.

M. Derivative is a file or statistic derived from the Confidential Data that poses disclosure risk to any Private Person in the Confidential Data obtained
through this Agreement. Derivatives include copies of the Confidential Data received from ICPSR, subsets of the Confidential Data, and analysis results that do not conform to the guidelines in Section VI.G.

II. DESCRIPTION OF DISCLOSURE RISK

Deductive disclosure of an individual's identity from research data is a major concern of federal agencies, researchers, and Institutional Review Boards. If a person is known to have participated in ANY survey or study or whose information is known to be included in a database from which the Confidential Data were obtained, then a combination of his or her personal characteristics may allow someone to determine which record corresponds to that individual. Investigators and Institutions who receive any portion of Confidential Data are obligated to protect the individual's confidential information from deductive disclosure risk by strictly adhering to the obligations set forth in this Agreement and otherwise taking precautions to protect the Confidential Data from non-authorized use.

III. REQUIREMENTS OF INVESTIGATORS

A. Investigators must meet the following criteria:
   1. Have a PhD or other terminal degree; and
   2. Hold a faculty appointment or research position at Institution.

B. The Investigator assumes the responsibility of completing the RDCS online application and required documents, reports, and amendments. The Investigator agrees to responsibly manage and use Confidential Data and implement all Confidential Data security procedures per the Data Security Plan.

IV. REQUIREMENTS OF INSTITUTION

The Institution must meet the following criteria:

A. Be an institution of higher education, a research organization, a research arm of a government agency, or a nongovernmental, not for profit, agency.

B. Have a demonstrated record of using Confidential Data according to commonly accepted standards of research ethics and applicable statutory requirements.

V. OBLIGATIONS OF ICPSR

In consideration of the promises made in Section VI of this Agreement, ICPSR agrees to:

A. Provide the Confidential Data requested by the Investigator in the Confidential Data Order within a reasonable time of execution of this Agreement by appropriate ICPSR officials and to make the Confidential Data available via download or removable media.

B. Provide electronic documentation of the origins, form, and general content of the Confidential Data sent to the Investigator, in the same time period and manner as the Confidential Data.

C. Provide a new version of the Confidential Data upon written request of the Investigator if a new version becomes available.
ICPSR MAKES NO REPRESENTATIONS NOR EXTENDS ANY WARRANTIES OF ANY KIND, EITHER
EXPRESSED OR IMPLIED. THERE ARE NO EXPRESS OR IMPLIED WARRANTIES OF
MERCHANTABILITY OR FITNESS FOR A PARTICULAR PURPOSE, OR THAT THE USE OF THE
CONFIDENTIAL DATA WILL NOT INFRINGE ANY PATENT, COPYRIGHT, TRADEMARK, OR OTHER
PROPRIETARY RIGHTS. Unless prohibited by law, Investigator and Institution
assume all liability for claims for damages against them by third parties that
may arise from the use or disclosure of the Confidential Data.

VI. OBLIGATIONS OF INVESTIGATOR, RESEARCH STAFF, AND INSTITUTION

Confidential Data provided under this Agreement shall be held by the
Investigator, Research Staff, and Institution in strictest confidence and can
be disclosed only in compliance with the terms of this Agreement. In
consideration of the promises in Section V of this Agreement, and for use of
Confidential Data from ICPSR, the Investigator, Research Staff, and Institution
agree:

A. That the Confidential Data will be used solely for research or statistical
purposes relative to the research project identified on the Application for
Obtaining Confidential Data accompanying this Agreement, and for no other
purpose whatsoever without the prior consent of ICPSR. Further, no attempt will
be made to identify private persons, no Confidential Data of private person(s)
will be published or otherwise distributed, and Confidential Data will be
protected against deductive disclosure risk by strictly adhering to the
obligations set forth in this Agreement and otherwise taking precautions to
protect the Confidential Data from non-authorized use.

B. To supply ICPSR with a completed RDCS online Application for Obtaining
Confidential Data that will include the following:

1. A signed Agreement
2. Data Security Plan
3. Confidential Data Order Summary specifying which files and
documentation are requested
4. Supplemental Agreement with Research Staff signed by each Research Staff
member
5. Pledges of Confidentiality for the Investigator and each Research Staff
member
6. A copy of a document signed by the Institution’s Institutional Review
Board (IRB) approving or exempting the research project
7. Investigator curriculum vitae

C. To comply fully with the approved Data Security Plan at all times relevant
to this Agreement.

D. That no persons other than those identified in this Agreement or in
subsequent amendments to this Agreement, as Investigator or Research Staff and
who have executed this Agreement, be permitted access to the contents of
Confidential Data files or any files derived from Confidential Data files.
E. That within one (1) business day of becoming aware of any unauthorized access, use, or disclosure of Confidential Data, or access, use, or disclosure of Confidential Data that is inconsistent with the terms and conditions of this Agreement, the unauthorized or inconsistent access, use, or disclosure of Confidential Data will be reported in writing to ICPSR.

F. That, unless prior specific approval is received from ICPSR, no attempt under any circumstances will be made to link the Confidential Data to any individual, whether living or deceased, or with any other dataset, including other datasets provided by ICPSR.

G. To avoid inadvertent disclosure of private persons by being knowledgeable about what factors constitute disclosure risk and by using disclosure risk guidelines, such as but not limited to, the following guidelines in the release of statistics or other content derived from the Confidential Data.

1. No release of a sample unique for which only one record in the Confidential Data obtained through sampling (e.g., not a census) provides a certain combination of values from key variables. For example, in no table should all cases in any row or column be found in a single cell.

2. No release of a sample rare for which only a small number of records (e.g., 3, 5, or 10 depending on sample characteristics) in the Confidential Data provide a certain combination of values from key variables. For example, in no instance should the cell frequency of a cross-tabulation, a total for a row or column of a cross-tabulation, or a quantity figure be fewer than the appropriate threshold as determined from the sample characteristics. In general, assess empty cells and full cells for disclosure risk stemming from sampled records of a defined group reporting the same characteristics.

3. No release of a population unique for which only one record in the Confidential Data that represents the entire population (e.g., from a census) provides a certain combination of values from key variables. For example, in no table should all cases in any row or column be found in a single cell.

4. No release of the statistic if the total, mean, or average is based on fewer cases than the appropriate threshold as determined from the sample characteristics.

5. No release of the statistic if the contribution of a few observations dominates the estimate of a particular cell. For example, in no instance should the quantity figures be released if one case contributes more than 60 percent of the quantity amount.

6. No release of data that permits disclosure when used in combination with other known data. For example, unique values or counts below the appropriate threshold for key variables in the Confidential Data that are continuous and link to other data from ICPSR or elsewhere.

7. No release of minimum and maximum values of identifiable characteristics (e.g., income, age, household size, etc.) or reporting of values in the "tails," e.g., the 5th or 95th percentile, from a variable(s) representing highly skewed populations.

8. Release only weighted results if specified in the data documentation.

9. No release of ANOVAs and regression equations when the analytic model
that includes categorical covariates is saturated or nearly saturated. In
general, variables in analytic models should conform to disclosure rules for
descriptive statistics (e.g., see #7 above) and appropriate weights should be
applied.

10. In no instance should data on an identifiable case, or any of the kinds
data listed in preceding items 1-9, be derivable through subtraction or
other calculation from the combination of tables released.

11. No release of sample population information or characteristics in greater
detail than released or published by the researchers who collected the
Confidential Data. This includes but is not limited to publication of maps.

12. No release of anecdotal information about a specific private person(s) or
case study without prior approval.

13. The above guidelines also apply to charts as they are graphical
representations of cross-tabulations. In addition, graphical outputs (e.g.,
scatterplots, box plots, plots of residuals) should adhere to the above
guidelines.

H. That if the identity of any private person should be discovered, then:

1. No use will be made of this knowledge;

2. ICPSR will be advised of the incident within five (5) business days of
discovery of the incident;

3. The information that would identify the private person will be safeguarded
or destroyed as requested by ICPSR; and

4. No one else will be informed of the discovered identity.

I. Unless other provisions have been made with ICPSR, all originals and copies
of the Confidential Data, on whatever media, shall be destroyed on or before
completion of this Agreement or within five (5) days of written request from
ICPSR. Investigator will complete and notarize an Affidavit of Destruction,
attesting to the destruction of the Confidential Data. Investigators requiring
the Confidential Data beyond completion of this Agreement should submit a
request for continuation three months prior to the end date of the Agreement.
This obligation of destruction shall not apply to Investigator's scholarly work
based upon or that incorporates the Confidential Data.

J. To ensure that the Confidential Data are managed and used in compliance
with the terms and conditions of this Agreement and with all applicable
statutes and regulations. Noncompliance with this Agreement by any Research
Staff hereto shall be deemed noncompliance and a breach by Investigator and
Institution for purposes of section VIII below.

K. To notify ICPSR of a change in institutional affiliation of the
Investigator. Notification must be in writing and must be received by ICPSR at
least six (6) weeks prior to Investigator's last day of employment with
Institution. Investigator's separation from Institution terminates this
Agreement. Investigator may reapply for access to Confidential Data as an
employee of the new institution. Re-application requires:

1. Execution of a new Agreement for the Use of Confidential Data by both
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the Investigator and the proposed new institution;

2. Execution of any Supplemental Agreement(s) with Research Staff and Pledges of Confidentiality by Research Staff at the proposed new institution;

3. Preparation and approval of a new Data Security Plan; and

4. Evidence of approval or exemption by the proposed new institution’s IRB.

These materials must be approved by ICPSR before Confidential Data or any derivatives or analyses may be stored or accessed at the new institution. Investigator must also, prior to the date of relocation, destroy all electronic and paper files containing Confidential Data or derivatives or analyses thereof at the original institution. This obligation of destruction shall not apply to Investigator’s scholarly work based upon or that incorporates the Confidential Data.

L. That if the Investigator who is changing institutions is unable to establish and gain approval for the new institution, Investigator will contact ICPSR to arrange the return to ICPSR for storage of all electronic and paper Confidential Data and any derivatives or analyses. Upon approval of the new RDCS online application, ICPSR will return these stored files to the Investigator. The Investigator will assume all costs associated with the shipping and storage of these Confidential Data and any derivatives or analyses. Although the Confidential Data and any derivatives or analyses will be stored in a secure location, ICPSR staff assumes no responsibility for these items.

M. That any books, articles, conference papers, theses, dissertations, reports, or other publications that employed the Confidential Data or other resources provided by ICPSR reference the bibliographic citation provided by ICPSR in the study description.

N. That use of the Confidential Data will be consistent with the Institution’s policies regarding scientific integrity and human subjects research.

O. To respond fully and in writing within ten (10) working days after receipt of any written inquiry from ICPSR regarding compliance with this Agreement.

VII. VIOLATIONS OF THIS AGREEMENT

A. The Institution will treat allegations by ICPSR/RWJF/HSC or other parties of violations of this Agreement as allegations of violations of its policies and procedures on scientific integrity and misconduct. If the allegations are confirmed, the Institution will treat the violations as it would violations of the explicit terms of its policies on scientific integrity and misconduct.

B. In the event Investigator or Institution breaches any provision of this Agreement, they shall be jointly and severally responsible to promptly cure the breach and mitigate any damages. Investigator and Institution hereby acknowledge that any breach of the confidentiality provisions herein may result in irreparable harm to ICPSR/RWJF/HSC not adequately compensable by money damages. Investigator and Institution hereby acknowledge the possibility of injunctive relief in the event of breach, in addition to money damages. In addition, ICPSR/RWJF/HSC may:

1. Terminate this Agreement upon notice and require return of the
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Confidential Data and any derivatives thereof;

2. Deny Investigator future access to Confidential Data; and/or

3. Report the inappropriate use or disclosure to the appropriate federal and private agencies or foundations that fund scientific and public policy research.

C. Institution agrees, to the extent permitted under the law, to indemnify, defend, and hold harmless The University of Michigan, ICPSR, and the sources of Confidential Data from any or all claims and losses accruing to any person, organization, or other legal entity as a result of Investigator's, Research Staff's, and/or Institution's acts, omissions, or breaches of this Agreement.

VIII. CONFIDENTIALITY

The Institution is considered to be a contractor or cooperating agency of ICPSR; as such, the Institution, the Investigator, and Research Staff are authorized to protect the privacy of the individuals who are the subjects of the Confidential Data by withholding their identifying characteristics from all persons not connected with the conduct of the Investigator's research project. Identifying characteristics are considered to include those data defined as confidential under the terms of this Agreement.

IX. INCORPORATION BY REFERENCE

All parties agree that the following documents are incorporated into this Agreement by reference:

A. The Application for Obtaining Confidential Data

B. A copy of the Institution's IRB approval or exemption of the Research Project

C. The Data Security Plan proposed by the Investigator and approved by ICPSR

X. MISCELLANEOUS

A. All notices, contractual correspondence, and return of data under this Agreement on behalf of the Investigator shall be made in writing and delivered to the address below:

Restricted Data Manager  
ICPSR  
P.O. Box 1248  
Ann Arbor, MI 48106-1248

B. This agreement shall be effective for 24 months from execution.

C. The respective rights and obligations of ICPSR and Investigator, Research Staff, and Institution pursuant to this Agreement shall survive termination of the Agreement.

D. This Agreement may be amended or modified only by the mutual written consent of the authorized representatives of ICPSR and Investigator and Institution. Investigator's research project, Data Security Plan, or Research Staff may be amended or modified only by submitting such amendments or modifications to the RDCS and receiving approval from the authorized
representatives of ICPSR. This Agreement may be extended only by submitting an extension request to the RDCS and receiving approval from the authorized representatives of ICPSR. Investigator and Institution agree to amend this Agreement to the extent necessary for ICPSR to comply with the requirements of any applicable regulatory authority.

E. The persons signing this Agreement have the right and authority to execute this Agreement, and no further approvals are necessary to create a binding agreement.

F. The obligations of Investigator, Research Staff, and Institution set forth within this Agreement may not be assigned or otherwise transferred without the express written consent of ICPSR.
Institutional Signatures (please do not use black ink)

Investigator
Signature ________________________________________________
Date ______________________________________________________
Print Name _______________________________________________
Title ______________________________________________________
Institution ________________________________________________
Building/Room Number ___________________________________
Street Address ____________________________________________
City/State/ZIP ____________________________________________
Telephone ________________________________________________
Email ______________________________________________________

The below signer represents and warrants that he or she is duly authorized and has legal capacity to execute and deliver this Agreement on behalf of the Institution. He/she represents and warrants that the execution and delivery of the Agreement and the performance of such party’s obligations hereunder have been duly authorized and that the Agreement is a valid and legal agreement binding on such party and enforceable in accordance with its terms.

Representative of Your Institution
Signature ________________________________________________
Date ______________________________________________________
Print Name _______________________________________________
Title ______________________________________________________
Institution ________________________________________________
Building/Room Number ___________________________________
Street Address ____________________________________________
City/State/ZIP ____________________________________________
Telephone ________________________________________________
Email ______________________________________________________