**Accessing Center for Prevention Research and Development (CPRD) Data for Research**

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**Purpose**: As the research involving CPRD’s datasets may benefit the public good, this memo outlines procedures for requesting such data. Data requests will typically only be granted to qualified researchers, referred to hereafter as “requesters,” who are trained to protect human subjects’ rights and able to carry out the proposed analyses.

**Overview**: In general, the following steps should be followed for accessing CPRD data, including:

1. The requester will review the codebook for the study for which they seek to access data.
2. The requester will submit a Data Sharing Request Form (see Attachment 1).
3. CPRD staff will review the request form, determine feasibility of the analysis, and, if necessary, acquire approval of the funding source for each request.
4. The requester will sign a business associate’s agreement, allowing the use of the data, confirming their completion of IRB training, and confirming their intent to protect human subjects’ rights (see Attachment 2).
5. The requester will supply CPRD with documentation that their secondary analysis was reviewed by the human subjects research committee at their institution.
6. CPRD will share the data.
7. The requester will acknowledge CPRD and the funding source in any products (i.e., presentations and publications) resulting from their analyses.
8. The requester will notify CPRD of any products resulting from their data requests.

**Codebook Review:** Because CPRD staff members’ time is directly charged to various funding sources, there is minimal time for providing support on the content of our datasets. Thus, the onus of understanding our survey items, and the project’s broader research design, rests squarely on the data requester. Reasonable efforts will be made by CPRD to have accessible codebooks and survey administration descriptions for available datasets. Requesters are expected to be familiar with the project for which they intend to submit a request prior to doing so.

**Data Sharing Request Form:** The Data Sharing Request Form permits CPRD to ensure the following safeguards are being met, including: 1) requesters have a clear vision of the analysis they want to do and are not just generally exploring the data; 2) requesters are not proposing a study that is currently planned by CPRD or already being done by a prior requester; 3) requesters have research questions that address significant problems and the knowledge generated is likely to benefit the public; and 4) the study is feasible with CPRD data.

**CPRD Feasibility Review:** A staff member at CPRD will review any data sharing request forms that are submitted. **Please allow approximately 2-4 weeks for your feasibility review.** Some may take longer if there are specific concerns by the funders of the affected projects.

**Business Associate’s Agreement:** CPRD is part of the School of Social Work, which is a unit within the University of Illinois system that is compliant with the Health Insurance Portability and Accountability Act (HIPAA). As such, we are able to provide limited datasets to qualified requesters for research purposes. The Business Associate’s Agreement outlines the data that we are unable to share per the HIPAA legislation and the human subjects rules we expect requesters to observe (i.e., no re-releasing of data, using data only for specified purposes, no efforts made to identify individual participants or organizations providing data, or any breaches of confidentiality as defined in the project’s IRB applications). **Data will not be shared unless requesters are willing to comply with these HIPAA and human subjects’ safeguards.**

**IRB Approval:** Although we expect many of the analyses that requesters will submit to be deemed as exempt from human subjects review, we want all requesters to provide CPRD with assurances from their Institutional Review Boards that a) they have completed IRB training; b) their study was reviewed and approved, and c) their study was reviewed and deemed exempt from review. A letter from the requester’s IRB on their letterhead is preferred documentation.

**Data Sharing:** De-identified data will be shared via a HIPAA-compliant online Box folder that is password protected. The password will be shared with the requester once all requirements specified above have been met. The limited dataset will be provided via encryption standards specified by the HIPAA and Health Information Technology for Economic and Clinical Health Act (HITECH) policies.

**CPRD and Funding Source Acknowledgment:** Presentations or publications that result from any requester’s analyses should be appropriately acknowledged. The format for such an acknowledgment will be as follows:

*Data for this study were provided by the Center for Prevention Research and Development (CPRD, a unit within the School of Social Work at the University of Illinois at Urbana-Champaign). Data were collected under Contract # (XXXXX) from the (Funding Source). The opinions in this (presentation/article), however, reflect those of the authors and do not reflect official positions of CPRD or the funding source.*

**Notify CPRD of Products Related to Your Analysis:** We will contact you six months and 1 year following your receipt of the data to inquire about products resulting from your request. You may also notify us by emailing smithdc@illinois.edu and using the subject line: CPRD Data Sharing Product. Please give us the full APA-formatted citation in your email, and attach a copy of the actual presentation or publication.

**Attachment 1. CPRD Data Sharing Request Form**

 **Illinois Youth Survey**

Request for Use of the Illinois Youth Survey Dataset

**1) Please provide your name, highest degree achieved, current affiliation, and contact information (Email, address, phone):**

**2) Provide the names and contact information of any individual on your research team with whom you would like to share the data (Only individuals listed will be permitted access to the dataset). Each individual will be required to sign and return a Business Associate’s Agreement to CPRD.**

**3) Specify specific variables you are requesting:**

**4) Provide a summary of your plans for analysis:**

What is the purpose of analyzing the dataset (or the purpose of your study)? Please comment on the novelty/originality of analyses, significance of the study, analytic plans, and public health relevance to Illinois youth.

**5) Describe your plans for dissemination and publication.**

**6) Please include a copy of the Institutional Review Board’s approval of your research and your human subjects training documentation.**

*If Applicable, please complete:*

Grant Program: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Grant No.: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Attachment 2. Business Associate’s Agreement**

**Model Data Use Agreement**

**For Receiving Analytic Files**

**(3. CPRD Limited, version 06-27-19)**

This Data Use Agreement (the “Agreement”) is entered into as of \_\_\_\_\_\_\_\_\_\_\_, 20\_\_,

(the “Effective Date”) by and between the University of Illinois School of Social Work’s Center for Prevention Research and Development (CPRD) (the “Covered Entity”) and

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_,

(the “Recipient”), (collectively, the “Parties”).

WHEREAS, CPRD is a “Covered Entity” and has received limited

data sets from other covered entity, as that term is defined in the Health Insurance Portability and Accountability Act Privacy Rule, 45 C.F.R. §160-164, as amended from time to time (the“Privacy Rule”);

WHEREAS, [*Insert Name of Recipient*]

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

is a recipient of a Limited Data Set from the Covered Entity;

WHEREAS, pursuant to the Privacy Rule, the Recipient must agree in writing to certain

mandatory provisions regarding the use and disclosure of the Limited Data Set; and

WHEREAS, the Parties wish to enter into this Agreement to comply with the

requirements of the Privacy Rule.

NOW, THEREFORE, in consideration of the mutual promises and covenants contained

herein, the receipt and sufficiency of which is hereby acknowledged, the Parties agree as follows:

1. Limited Data Set means a data set that has had the following Protected Health

Information for the individual, his/her relatives, employers or household members

removed:

\_ Names of participants;

\_School names and building codes

\_Student ID#’s provided by schools or the State of Illinois

\_School-level data with low frequency, identifiable information

\_ Street or Postal address information (other than town/city, state, zip code)

\_ Telephone numbers

\_ Fax numbers

\_ Electronic mail addresses

\_ Social Security numbers

\_ Medical record numbers

\_ Health plan beneficiary numbers

\_ Account numbers

\_ Certificate/license numbers

\_ Vehicle identifiers and serial numbers, including license plate numbers

\_ Device identifiers and serial numbers

\_ Web Universal Resource Locators (URLs)

\_ Internet Protocol (IP) address numbers

\_ Biometric identifiers, including finger and voice prints

\_ Full face photographic images and any comparable images.

2. The Limited Data Set may include the following identifying information:

\_ The town or city, state and zip code of the individual, his/her relatives, employers

or household members *(Data on the town/city/county may, however, be stripped if there are too few schools/individuals in a town or county which make the school/county/individual identifiable.)*

\_ Dates, including dates of behaviors or services converted to days before or after

intake and the federal fiscal year of intake

\_ Age (in years) at intake

\_ A unique research identifying number, characteristic or code

3. The Limited Data Set may also include non-identifying information, including the type of treatment or service received or randomly assigned and the amount of services received as well as the facility location.

4. The Recipient will not have access to the linkage file that will connect the Limited Data Set back to the PHI. The Covered Entity should destroy the linkage file per IRB guidelines, unless there is an extension of follow-up and a subsequent consent signed.

5. Recipient may use or disclose the Limited Data Set only for purposes of research, public health or health care operations. Research is the systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge. All other capitalized terms not defined herein shall have the same meaning as in the Privacy Rule.

6. Recipient agrees not to use or disclose the Limited Data Set if such use or disclosure by the Covered Entity would be a violation of the Privacy Rule.

7. Recipient agrees it will not use or further disclose the Limited Data Set other than as

permitted or required by this Agreement or as required by law.

8. Recipient agrees to use appropriate safeguards to prevent use or disclosure of the Limited Data Set other than as provided for by this Agreement.

9. Recipient agrees to report to the Covered Entity, in writing, any use or disclosure of the Limited Data Set not provided for by this Agreement of which it becomes aware.

10. The Recipient agrees to not provide the Limited Data Set to a third party, including any individual outside of the research team doing the analyses specified in the data request.

11. Recipient will not (re)identify or contact the individuals who are the subjects of the

information.

12. This Agreement shall remain in effect for as long as Recipient maintains the Limited

Data Set. **The recipient shall delete the dataset once the analyses are completed, or no longer than 2 years, whichever comes first. In the event of requirements to archive the dataset for replication/verification, the recipient will contact Doug Smith (****smithdc@illinois.edu****) at CPRD for guidelines on proceeding. No data may be archived in open science platforms without additional permissions from an authorized CPRD representative.**

13. Recipient shall indemnify and hold the Covered Entity harmless from and against all

claims, liabilities, judgments, fines, assessments, penalties, awards or other expenses, of any kind or nature whatsoever, including, without limitation, attorney’s fees, expert witness fees, and costs of investigation, litigation or dispute resolution, relating to or arising out of any breach of this Agreement by Recipient as determined by a court of competent jurisdiction.

14. None of the provisions of this Agreement is intended to create, nor shall any be construed to create, any relationship between the parties other than that of independent entities contracting with each other solely to effectuate the provisions of the Agreement.

15. The Parties agree to take such action as is necessary to amend this Agreement from time to time as is necessary for the Covered Entity to comply with the requirements of the Privacy Rule or the Security Rule or any other applicable federal or state regulations. Any amendment shall require the mutual written consent of the parties.

16. This Agreement shall not in any manner whatsoever confer any rights upon or increase the rights of any third-party.

17. The Parties shall each be solely responsible for their own compliance with all applicable law.

18. The Parties acknowledge that this Agreement represents the entire understanding between the Parties regarding the Limited Data Set and that there are no other agreements, either oral or written, between them.

IN WITNESS WHEREOF, the parties have executed this Agreement as of the day and

year written below.

*CPRD Representative:*

Douglas C. Smith, Ph.D.

Title:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

*Recipient:*

*Name:*

Title:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_