

Center for Collegiate Mental Health (CCMH) Data Access Policy



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Introduction and Background

Thank you for your interest in the Center for Collegiate Mental Health (CCMH) data repository. Our mission is to bridge the gap between the science and practice of college student mental health. CCMH is a multi-disciplinary, member-driven research center focused on providing accurate and up-to-date information about the mental health of today's college students. CCMH leverages modern technology and the collaborative efforts of college counseling centers and key partners in business, academia, health-care, and member organizations. Since its conception in 2005, CCMH has become a recognized leader in college student mental health research by facilitating the pooling of standardized data from counseling centers and transforming this data into clinical tools and empirical knowledge.

CCMH is continually exploring new ways to inform practice through research. Examples of our work include: managing the Standardized Data Set (SDS) for participating counseling centers; developing the Counseling Center Assessment of Psychological Symptoms (CCAPS) instruments; developing the CCAPS profile and related reports for clinicians; delivering benchmarking data back to counseling centers; producing an annual report of findings from current data; providing professional development opportunities for counseling center staff; and presenting at conferences and publishing empirical and conceptual articles that address important topics for our field. Each of these activities is intended to make the raw pooled data *accessible* and *useful* to the field of college student mental health.

Because we know that many hands make light work, CCMH believes in making data available to qualified researchers after we have met the expectations of our stakeholders. This data sharing policy was created to provide basic information about the CCMH data repository along with a transparent and organized process through which qualified researchers can request access to data. The most up-to-date information about CCMH is available on our website at <http://ccmh.psu.edu>.

Eligibility

Principal Investigators

Only faculty members or post-doctoral researchers affiliated with a university or research institution may apply for access to data and serve as the Principal Investigator. Post-doctoral researchers who are working in a lab must have a letter of support from the lab director. Research may only be for non-commercial, no derivative use. Furthermore, access to data is limited to researchers whose projects have been vetted by a university or independent IRB.

All applications will be scrutinized for four criteria: privacy, security, ethical considerations, and value to the field of college student mental health.

Students

Graduate students may gain access to data under the supervision of a Principal Investigator. The Principal Investigator and institution will ensure that the student meets all conditions of the agreement. Approved graduate students must sign the Data Use Agreement with Research Staff.

Multiple Institutions

Multiple institutions working together on a research project should submit one application. This application should identify 1-2 Principal Investigator(s) who will serve as primary contact(s) for the entire research team. Within the application, a separate Data Use Agreement Form must be signed by each individual involved in the research.

Who is Not Eligible

Individuals not associated with a university or research institution may not have access to the CCMH Data or to output derived from these data and may not be a part of a research team submitting an application for the data. In addition, individuals associated with the following organizations and groups may not have access even if associated with a university or research institution:

- Law enforcement
- Undergraduate students
- Self-employed individuals
- Individuals representing for-profit institutions

These policies will be reviewed periodically.

Privacy Concerns

CCMH is committed to protecting the rights and privacy of all entities involved. Our data contains no individual identifiers and our data sharing policy requires that approved researchers agree to analyze and report in aggregate form only.

Data Ownership

Standardized data, gathered by a counseling center, is owned by that counseling center. Data submitted to CCMH is owned by CCMH. Upon request by any participating counseling center, CCMH will delete submitted data up until data has been distributed to researchers for analysis. At this point, CCMH assumes responsibility for data access and stewardship of remaining data.

Available Data

The CCMH Data Repository includes a variety of standardized data pertaining to students seeking treatment at college and university counseling centers, providers at said counseling centers, and center and institutional variables. CCMH reserves the right to ensure confidentiality by limiting access to or modifying data points. Information regarding variables included within the data can be found at: <http://ccmh.psu.edu/data/requesting-data/>

Datasets

The standard CCMH data files available to approved researchers include appointment data (date, type of appointments, attendance status, etc.) and survey data (CCAPS - symptoms, SDS- demographics and history, CLICC- clinician ratings, Case Closure form, etc.). By default, appointment data and survey data are stored on separate lines, so a CCAPS completed on the same day as an appointment does not appear on the same line as that appointment. This is true for single academic year files (e.g. 2016-2017) and for files spanning multiple academic years (e.g. 2015-2017). Because of this formatting, each client has multiple lines of data, potentially including multiple appointments (both attended and missed), CCAPS administrations, SDS administrations, and administrations of other measures from multiple time points throughout treatment. Some clients may also have multiple distinct episodes of treatment (something we typically define by a 90-day gap between appointments, but this does not come defined in the data set).

Each CCMH dataset is specifically cleaned by a member of the CCMH team for every data request. Datasets represent one year of data (July 1 – June 30). Researchers may request multiple years of data within one request. If a researcher requests more than two years of data, the data must be handled in R or sent in the form of multiple SPSS data sets. Variables do change from year-to-year, so limitations may apply.

Exceeding a Routine Request

Because of the complexity of the data, when it is typically distributed by CCMH it is not ready to use for studies of pre-treatment distress and client characteristics, pre-post change during treatment, or longitudinal analyses of change during treatment. These all require additional data cleaning before they can be performed.

CCMH's data analyst and research team of graduate students have extensive experience cleaning and manipulating the data to prepare it for analyses and can provide this data cleaning for an additional fee. Below are some estimates of time required for typical types of data cleaning.

- Selecting only first and last SDS and CCAPS (est. 1 hour)
- Creating variables to indicate the sequencing of appointments and total number of attended appointments (est. 1 hour)
- Longitudinal analyses linking CCAPS to appointments (est. 3+ hours depending on project complexity)
- Creating files with more than 2 years of data in SPSS- due to the size of the data, more than two years of uncleaned data is unworkable in SPSS and necessitates us creating multiple files (est. 1 hour)
- Estimates for other cleaning available after we've reviewed the request

Access to Data

How to Access Data

Access to CCMH data begins with completing a Data Request Application and completing and signing a Data Use Agreement Form.

Institutional Review Board Approval

An IRB determination from the researcher's institution is required as part of the Data Request Application.

Skills Required to Access Data

Each CCMH dataset contains over one million lines of data. To access data it is important to have someone on your research team with proficiency in statistical analysis and fluency in statistical software packages such as SPSS or R. Individuals must also be trained in social science research methods.

Data Access Levels

Due to the number of stakeholders involved in the larger data-pooling effort, CCMH maintains a tiered system of data access to ensure that our mission and goals are given the first priority, followed by stakeholders in descending order of investment. (Each school always has access to their own data, stored at their institution).

Level 1) Access for the purpose of meeting the mission, commitments, and/or goals of CCMH.

Examples include, but are not limited to, the Annual Report, conference presentations, related publications, research and development of the CCAPS, benchmarking, etc.

Level 2) Staff of member counseling centers and/or sponsoring agencies

Level 3) Independent Researchers. Examples include: staff at non-CCMH counseling centers, researchers employed by a college, university or research institution. (*data access fees apply*)

Data Access Timing

Given that CCMH is continually collecting data, data will be released in discrete time periods or waves. Aggregate data will be cleaned and made available at the end of a standardized period of time (e.g., a semester or academic year) to simplify requests and data processing demands. In addition, each data access level is assigned a time-period during which they may request data.

Level 1) Exclusive access for one year following closure of a given data period.

Level 2) Access begins one year after the closure of a given data period.

Level 3) Access begins two years after the closure of a given data period.

For example, if data period X ends on June 30th, 2014:

Level 1 would have exclusive access until July 01, 2015

Level 2 access would begin on July 01, 2015

Level 3 access would begin on July 01, 2016

Data Access Fees

Data access fees directly support the operations of CCMH. The current Data Access Fee is \$500.00 per request. This fee applies to those who fall into the Level 3 category of the Data Access Levels. All data fees must be submitted *prior to* CCMH sending out any requested data. Additional data cleaning costs \$50 per hour for CCMH members and \$100 per hour for non-members.

Data Request Scope

Each data request covers only the research project outlined in the data request, and data received from CCMH may not be used for research outside of the scope of the approved request. In order to use CCMH data for an additional project, a new data request must be submitted and approved.

Modifications to Data Requests

Once a Data Request Application has been approved, CCMH must be consulted if the researcher intends to change the direction or goal of the study.

Reporting to CCMH

Principal Investigators are required to report to CCMH upon completion of the research proposed in the Data Request Application by the anticipated completion date of the study.

Submission Process

1. Researcher submits Application including:
 - Research team
 - Project title and description
 - Data Management Plan (specific methodologies/analyses planned)
 - IRB approval through a university or independent IRB
 - Signed Data Use Agreement forms for each person on research team
2. Applications are reviewed by CCMH (Researchers may receive questions during review.)
3. Notifications of decision are sent to Principal Investigators within 2-3 weeks of confirmation of receipt
4. To gain access to data, approved research teams must submit
 - A Data Use Agreement for each individual involved
 - A Data Access Fee (when applicable)

Criteria for Approval

All applications will be scrutinized for four criteria: privacy, security, ethical considerations, and value to the field of college student mental health.

Given CCMH's limited resources, not all applications that pass security, privacy, and ethical requirements can be approved. Successful applications must indicate strong potential value to contributing to the field of college student mental health. Questions that the reviewers will ask include:

- Is the proposal in line with CCMH's mission?
- Are the needs of college students or those that serve them at the core of this research?
- Does the research develop, employ, and promote "best practices?"
- Will the information be useful to aid decision-making, planning, policy, clinical practice or prevention services?
- Does the research include collaboration with other staff and departments in order to maximize resources and increase efficiency?

Use/Sharing

Data, derivatives, research, algorithms, and all other outputs are strictly for non-commercial use. No commercial uses will be approved. Approved data for data requests shall not be shared with parties outside of the individuals listed on the Data Request Application.

Conflicts of Interest

CCMH will review and address potential conflicts of interest within each application. Principal Investigators that may have a potential conflict of interest must disclose this conflict to CCMH. Principal Investigators attest that they are not connected to any of the previously mentioned Non-Eligible groups. If a member of CCMH submits a proposal, he/she shall not be a part of the proposal review.

CCMH Rights

CCMH reserves the right to provide or retract data access at its sole discretion for the purposes of protecting the center, participating institutions, and all parties involved. CCMH data-sharing decisions are final and may not be appealed.

The Center for Collegiate Mental Health Data Use Agreement Form

As a condition of receiving from The Pennsylvania State University, by and on behalf of its Center for Collegiate Mental Health (CCMH) (“Provider”) the data requested in Recipient’s Data Request Application (“Data”), **[Recipient Research Institution name]** _____ (“Recipient”), by and on behalf of its investigator, **[Recipient researcher’s name]** _____, agrees that:

- 1) Recipient has read, understands, and agrees to comply with the CCMH Data Access Policy, which is hereby made part of this Agreement and attached hereto as Appendix A.
- 2) Recipient will use the Data in compliance with all applicable laws and regulations pertaining to the Data, including but not limited to laws and regulations governing the use of Data for human subjects research if applicable, and Recipient has obtained all necessary approvals and/or determinations by an Institutional Review Board or other ethics board as may be required thereunder.
- 3) The Data will only be used for the study described in the Data Use Agreement Form, and Data Request Application attached hereto as Appendix B, which is for the purpose of furthering the understanding of college mental health issues. Any new use of the Data will require a new Data Use Agreement Form and Data Request Application.
- 4) Recipient will not share the Data with, provide access to the Data to any third party, or anyone person within Recipient’s institution other than the investigator identified above and other researchers listed in Appendix C. Recipient is responsible for ensuring all persons provided access to the Data comply with the terms and conditions of this Agreement and applicable laws and regulations.
- 5) Recipient will return or destroy the Data, including any copies or Data contained in any derivative files, upon request of Provider.
- 6) Should the identity of any person or establishment from which the Data are derived be inadvertently discovered, then Recipient will ensure that:
 1. No use or disclosure, internal or to any third party, will be made of this knowledge;
 2. The Executive Director of CCMH will be immediately notified via email at ccmh@psu.edu.
 3. The information that would identify an individual or establishment will be immediately returned or destroyed, as requested by Provider;
- 7) Recipient will employ the following guidelines when presenting results and information regarding the sample (in any form or venue):
 1. Magnitude data (includes all continuous variables): Ensure that no cells/strata with $n < 5$ are produced
 2. Frequency data (includes all categorical variables): Ensure that no cells/strata with $n < 5$ are produced
 3. It is never admissible to describe the characteristics of any individual institution, center, or participant in any manner.
 4. In the context of null hypothesis statistical testing (NHST), measures of effect size (Cohen’s d , Pearson’s r , odds ratios, etc.) **must always be presented and discussed with the results of the NHST**, particularly when the sample size being analyzed is large. In the context of structural equation modeling or model comparison, the effects of sample size on goodness-of-fit indices and power to detect differences between models should be considered and discussed.
- 8) Aggregate statistical summaries of the Data and analyses (frequency tabulations, magnitude tabulations, means, variances, correlation coefficients, etc.) are approved under this Agreement and may be freely published by Recipient, subject to the provisions above (see Section 7 above).
- 9) Recipient will cite CCMH as the data source in any publication or research based on these data:
 1. In text: The CCMH XXXXX (data set, e.g., CCMH 2010-2011 data) was collected by the Center for Collegiate Mental Health

2. In references: Center for Collegiate Mental Health, XXXXX (data set). Produced and distributed by the Center for Collegiate Mental Health

- 10) Recipient will provide an electronic copy of any publication and/or presentation that results from the use of this data set to the Executive Director of CCMH at the time of the presentation, the article's acceptance for publication, or approval of the internal document (e.g., dissertation).
- 11) Recipient will maintain a secure computing environment for storage and use of the Data and any data sets that derive from it that is sufficient to prevent unauthorized use, access, or disclosure of the Data.
- 12) Recipient will immediately notify Provider of any unauthorized use, access, or disclosure of the Data, and will immediately take steps, at Recipient's expense, to remediate such breach, including but not limited to any return or destruction of the Data as requested by Provider.
- 13) THE DATA PROVIDED UNDER THE THIS AGREEMENT IS PROVIDED TO RECIPIENT WITHOUT WARRANTY OF ANY SORT, EXPRESS OR IMPLIED, INCLUDING BUT NOT LIMITED TO WARRANTY OF TITLE, MERCHANTABILITY, OR FITNESS FOR A PARTICULAR PURPOSE. PROVIDER MAKES NO REPRESENTATION THAT THE USE OF THE MATERIAL WILL NOT INFRINGE ANY PATENT, COPYRIGHT, TRADEMARK, OR OTHER PROPRIETARY RIGHTS OF ANY THIRD PARTY.
- 14) Provider, its trustees, officers, employees, and agents will not be liable for any use of the Data, breach of this Agreement, or negligence or willful misconduct by Recipient.
- 15) Recipient will hold harmless, defend, and indemnify Provider, its trustees, officers, employees, and agents from any claims or liabilities which may arise from Recipient's use of the Data, breach of this Agreement, or negligence or willful misconduct.
- 16) Recipient or Provider may terminate this Agreement at any time upon thirty (30) days' prior written notice, and Provider may terminate this Agreement immediately upon notice in the event Recipient's breach. Upon termination, Recipient will cease all use of the Data, and return or destroy the Data as requested by Provider. Sections 6-16 will survive termination of this Agreement.

Agreed to upon the date of signature below:

Signature:	Title:
Name (print):	Institution:
Date:	

Return this form to:

Alaina Henry, CCMH Project Manager: ccmh@psu.edu

The Center for Collegiate Mental Health Data Request Application

Date:	
Name of Principal Investigator:	
Title of PI:	
Institution:	
Address:	
Telephone:	
E-mail:	
Name of Supervising Person (if PI is a student):	
Title of the Study:	
Other names, titles, and affiliations of those involved in the project (please include everyone who will have access to the requested data, and have each individual sign a separate data use agreement form):	
Data set you are interested in obtaining:	
Anticipated Start Date of research:	Anticipated End Date:
Provide Brief Literature Review and research question:	

Please answer the following questions regarding your study:

1) Describe the type of study you intend to use the data for (dissertation study, article for publication, other).

2) Provide a description of the study (including rationale, research question(s), hypotheses, data analyses, etc). Please be as specific as possible including exactly which variables you will need and your proposed methodology.

3) Please describe how this study will contribute to college mental health and why this question is important to move the field forward;

4) Other comments:

Name (print)

Date

Signature

Date

Return this form to:

Alaina Henry, CCMH Project Manager: ccmh@psu.edu

APPENDIX C – List of Recipient Researchers

Name	Title	Email

Return this form to:

Alaina Henry, CCMH Project Manager: ccmh@psu.edu