



Using Data to Improve Child & Adolescent Mental Health

Legal Considerations

Introduction

Prior to asking for data for public health surveillance purposes, health departments might want to consider the key components of the legal framework for collecting data related to CAMH that are maintained by preschools and elementary and secondary schools. In collaboration with the Network for Public Health Law (NPHL), PHII developed a guide to support agencies in the process of requesting CAMH data. Much of this information is discussed in greater detail in the [Summary of Laws Related to Child and Adolescent Mental Health](#) PHII also produced with NPHL in 2020.

Key points from the summary include the following:

- 1. A complex legal landscape governs data collection and sharing, especially regarding sensitive health information related to adolescents and children.** Data sharing is governed by federal, tribal, state, and local laws. The first step in collecting or sharing data is to identify applicable laws, which depend on the data type and source and how it will be used. Multiple laws may apply to each type or source of data, and these laws differ in permissible and prohibited disclosures and data sharing conditions and limitations.
- 2. Law is a real and perceived barrier to collecting and sharing data but not a complete barrier, especially to collecting and sharing meaningful disaggregated data.** Law is often cited as a substantial barrier to data collection and use because of the effort it takes to analyze various laws that apply to data. Those who withhold data sometimes indicate that they can't share because of the Health Insurance Portability and Accountability Act (HIPAA); however, this is often incorrect. While it is true that law, including HIPAA, places limits on data sharing, these limits are not complete barriers.
- 3. It is possible to navigate law to facilitate data sharing.** To navigate legal issues that govern data collection, use, and disclosure, an individual or agency that wants to obtain or share data could start by providing or collecting factual information, as discussed below in *A Process for Gaining Access to CAMH Data*.
- 4. When law is not clear on data collection and/or sharing, it is important to define, weigh, and communicate the potential risks and benefits.** While there are risks in sharing data, there are also risks in not sharing data including failure to promote the health of children and adolescents because of lack of data to inform policies and programs, measure their effectiveness, and advocate for funding. Agencies and organizations from many sectors, and their attorneys, need to appreciate the crucial role that data play in promoting the health of children and adolescents so that they are willing to invest the time and effort to find a legal pathway to share data.

All laws that were reviewed for this project (HIPAA, Privacy Act, E-Government Act, OPEN Government Data Act, Family Educational Rights and Privacy Act, Individuals with Disabilities Education Act, and Every Student Succeeds Act) allow de-identified data to be disclosed. De-identified, aggregated data might work well to identify trends and inform the development of policies.

A Process for Gaining Access to CAMH Data

Prior to contacting an attorney or legal counsel within the health department, it can be useful to think through the objectives for data sharing. The following questions provide an outline of the kind of information that will be useful to public health professionals and their attorney at the beginning of a project.

Step One: Gather Information¹

1. What is the purpose of collecting or using the data?

a. Is the purpose research?

Yes

No

If the purpose is research, the [HHS Common Rule](#) or state law governing research may apply.

b. What are your objectives?

¹ A similar, but more general, checklist in a downloadable format may be helpful.

<https://www.networkforphl.org/resources/checklist-of-information-needed-to-address-proposed-data-collection-access-and-sharing/>



Step One: Gather Information (continued)

2. What data are needed?

Data with a greater degree of identifiability are typically more protected, and thus more difficult to access, than de-identified or aggregated data. Determining the type of data needed will shape where the data can be accessed and the applicable laws governing access, use, and sharing.

a. What data elements are needed for the project?

b. Does the project require raw data?

Yes

No

c. Does the project require identifiable data?

Yes

No

i. What degree of identifiability?



Step One: Gather Information (continued)

3. Who has the data?

a. Does a federal agency have the data?	Yes	No
b. Does a state agency have the data?	Yes	No
c. Does a school or school district have the data?	Yes	No

4. Are the data already accessible?

a. Are the data publicly available?	Yes	No
b. Are there multiple sources of the data?	Yes	No
c. What is the easiest source of the data to access?		



Step One: Gather Information (continued)

5. What is the source of funding for the data collection?

- *If there is federal funding, data may be required to be public and simplify access. Other funding sources may simplify or complicate ease of access.*
- *Some online datasets have information near the bottom of the file or in an “About” or “Frequently Asked Questions” document on the website. If the source of funding is unclear, it could be helpful to contact the agency or organization that owns the data.*

a. Are the data federally collected?	Yes	No
<i>If data are federally collected, laws applicable to the federal government must be followed. For example, the federal privacy act has provisions of linking data.</i>		
b. Is there any federal, state, or local funding?	Yes	No
<i>Usually funding comes with provisions for privacy and security.</i>		
c. Is the data entirely privately funded, for example, data collection funded by a foundation or nonprofit community organization?	Yes	No

6. What is the health department’s internal policy for making a data sharing request?

a. Is approval required prior to making a data request?	Yes	No
i. For any request?	Yes	No
ii. Depending upon the form of the request?	Yes	No
iii. From whom?		



Step Two: Seek Approval/Assistance if Needed

If the needed data are publicly available, health departments can access the data in the same way as any member of the public without assistance of legal counsel. If the data are not publicly available, health departments might need to consult an attorney or privacy officer. Health departments should first consult their internal policies to understand any procedures and requirements. Then, using the answers to the questions from step one above, assistance of counsel could be requested to determine the applicable law and any exceptions or limitations. An attorney may also assist in making a case to gain access to restricted use data or in negotiating with another agency or organization that has denied a prior request for data.

When restricted use data files or data with particular elements or identifiability is required, health departments might benefit from following their internal policies and seeking guidance from the appropriate agency representative. That representative could be your attorney, a privacy officer, a supervisor, or governance board. The following questions provide an overview of how to ask for assistance, but specific questions may vary depending on internal policies and the jurisdiction.

1. Is permission or approval required prior to filing a data sharing request?	Yes	No
2. Is the assistance of an attorney or privacy officer required to file a data sharing request?	Yes	No
If so, health departments could provide or request the following:		
a. Explain the need for data and the objectives of the project.		
b. Ask for assistance navigating the law to meet data use needs.		
c. Ask for the criteria for accessing and using the data.		
d. Ask for assistance framing the request to meet the criteria, including any exceptions (the legal and factual justification for the intended use).		
e. Ask if there is an existing memorandum of understanding (MOU) or data sharing agreement that applies to the request.		
f. Ask for assistance drafting a data sharing agreement or MOU or ask for assistance reviewing the one offered by the data holder.		

