

Data-Sharing Agreements

What is a data-sharing agreement?

A data-sharing agreement outlines the terms that guide the sharing of any type of data between two organizations. In researcher-practitioner partnerships, data-sharing agreements help clarify expectations among partners and promote the security of data exchanged between them. A data-sharing agreement may be a standalone document or it may supplement a broader Memorandum of Understanding (MOU) between the partners. The formality and level of detail contained in these agreements can vary.

When is a data-sharing agreement needed?

Data-sharing agreements may be required by a funding agency, an Institutional Review Board (IRB), or the policies of one or both involved organizations. Even if not required, a data-sharing agreement can protect both the agency sharing the data and the agency receiving the data by ensuring that data will not be misused.

How is a data-sharing agreement created?

The process of creating a data-sharing agreement relies on positive communication and collaboration. Even when using a template or required format (e.g., one provided by a university IRB), both partners should have opportunities to provide input and make changes. Effective planning for data-sharing agreements takes a long-term view of questions that may arise, from the initial point of sharing data, to conducting data analyses, disseminating the results, and then terminating the study. The final agreement should be signed by the proper authorities in each organization.

What should be considered in drafting a data-sharing agreement?

Consider the following questions when drafting the agreement.

Who is involved, and what are their roles?

- What is the name of the organization that is sharing the data?
- What is the name of the organization that is receiving the data?
- Who, within the sharing organization, is responsible for transferring the data?
- Who, within the receiving organization, will have access to the data?
- Who will manage the data analyses?
- Who is responsible for overseeing the security of the data?
- What training will be required for anyone with access to the data?
- Who retains ownership of the original dataset?
- Who has intellectual property rights to the findings of the study?

What data will be shared and for what purpose?

- What specific data will be shared?
- What IRB or other approvals are needed before data may be shared?
- What restrictions are there on how the data can be used (e.g., for internal review only, shared with board members)?
- What are the requirements for using the data (e.g., aggregating individuals into groups or de-identifying data)?
- What is the plan for analyzing the data?
- What research questions will guide the analyses?
- What steps will be taken if additional research questions or analyses are identified in the course of the project and there is interest in expanding the work?

How will data be shared while meeting safety, legal, ethical, and confidentiality requirements?

- How will data be transferred securely from the sharing agency to the receiving agency?
- Will there be costs involved in sharing the data, and how will those be covered?
- How will the confidentiality of the data, including the privacy of individuals whose personally identifiable information (PII) is included, be safeguarded? (If the data were already collected, what privacy assurances were participants given, and how will those assurances be upheld?)
- What is the plan for maintaining the security of the data throughout the project timeframe?
- How will any electronic and/or paper-based copies of the data be stored securely?
- What are the legal or organizational policies relevant to the confidentiality of the data, and how are these accounted for within the data-sharing agreement?
- If the data was collected for a specific purpose, or with specific consent, confidentiality or use assurances, what data protection or approval requirements apply to the parties of this agreement?
- If the research is being supported by government or private grant funding, what approval or copyright requirements involved in that funding apply to the researcher?

When will planned activities be completed?

- When will the data be shared (only one time, or will updated datasets be shared)?
- How long does the receiving organization have access to the data?
- When does the data-sharing agreement expire?
- When the data-sharing agreement expires, are the data returned or destroyed?

Where will the research findings be communicated at the end of the study?

- How will both parties be involved in the interpretation of the results of the study?
- Through what publications or forums will the findings be published or shared?
- What are each partner's expectations regarding the publication and dissemination of findings based on the shared data?
- Is permission from the data-sharing agency required before any public sharing of the findings?



[The Colorado Clinical and Translational Sciences Institute](#) at the University of Colorado, Denver, created a resource to assist researchers in developing data-sharing agreements within the context of community-academic partnerships.



Child Trends offers [a research brief](#) entitled, "Guidelines for Developing Data Sharing Agreements to use State Administrative Data for Early Care and Education Research."

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Sample Data-Sharing Agreement

- A. This agreement outlines the terms of data-sharing for the research project, "Understanding the needs of clients seeking services at Family Violence Crisis Agency," which is being conducted by Dr. Jane Smart at State University. This research project is being conducted so that the leaders of the Family Violence Crisis Agency can gain a deeper understanding of the needs of their client populations in order to guide future programming decisions.
- B. The timeline for this agreement is planned as follows:
1. The agreement will be signed by January 10, 2020.
 2. IRB approval will be secured by February 28, 2020.
 3. The data outlined below will be shared by the Family Violence Crisis Agency with Dr. Smart by April 30, 2020.
 4. All data analyses will be conducted by December 31, 2020. Following that time, Dr. Smart will retain access to the data until December 31, 2021, to allow the data to be accessed if revisions are required to any publications resulting from this study.
 5. Unless a written extension is granted, this data-sharing agreement will terminate on December 31, 2021, at which time Dr. Smart will return any data she continues to have in her possession to the Family Violence Crisis Agency, and/or she will provide written confirmation to the Family Violence Crisis Agency that she has destroyed any remaining data in a secure manner.
- C. In order to carry out this study, Family Violence Crisis Agency will provide Dr. Smart with de-identified client record data for clients seeking services for the past two calendar years (i.e., from January 1, 2018, through December 31, 2019). All personally identifiable information and potential client identifiers will be excluded from the data provided to Dr. Smart. The specific data to be shared include the following:
1. Client demographic data (i.e., age, racial background, occupation, home address ZIP code only, marital status, and income level)
 2. Client services received (i.e., a summary of the number of services and the types of services provided to each client during that timeframe)
 3. Narrative client information from the initial agency intake form
- D. No data will be provided by the Family Violence Crisis Agency until the following conditions have been met:
1. The study has been approved by the State University Institutional Review Board (IRB)
 2. All data have been de-identified such that there are no identifiable details about any clients of the Family Violence Crisis Agency.
 3. A password-protected dataset has been created to be shared securely with Dr. Smart.
- E. Within State University, only Dr. Smart is granted access to the data provided by the Family Violence Crisis Agency. Within the Family Violence Crisis Agency, the Data Manager, Joe Sharp, will be responsible for preparing the de-identified, password-protected dataset that will be provided to Dr. Smart. Once the data have been transferred, Dr. Smart is responsible for ensuring that all the data usage, security, and research dissemination plans outlined below are carried out.
- F. Data Usage Plans: The Family Violence Crisis Agency data will be used by Dr. Smart as follows:
1. The overall goal of the research/analysis is to develop a data-driven understanding of the needs of clients seeking services at the Family Violence Crisis Agency in order to guide future programming decisions by the Agency.
 2. Dr. Smart will conduct a quantitative analysis of the client demographic and client services data provided by the Family Violence Crisis Agency to identify and describe patterns in met and unmet needs for various client demographic groups.

3. Dr. Smart will conduct a qualitative analysis of the narrative client information provided by the Family Violence Crisis Agency to identify and describe themes and nuances about met and unmet needs of clients.
 4. Should Dr. Smart identify during the course of the research additional lines of inquiry to achieve the overall goal of the research, she must consult with the Family Violence Crisis Agency and obtain the Agency's approval before pursuing those analyses.
 5. Data provided by the Family Violence Crisis Agency should not be used for purposes other than meeting the goal of the research specified in section F.1. or the provisions of section I. of this Agreement.
- G. Data Security Plans: Both Dr. Smart and the Family Violence Crisis Agency agree to the following procedures to ensure the safety and confidentiality of the data to be shared:
1. As stated above, all data will be de-identified prior to being shared with Dr. Smart.
 2. The dataset will be stored electronically with password protection. Dr. Smart will ensure that any additional files associated with the shared data will be password-protected.
 3. Any paper versions of the data, including the qualitative data, will be stored in a locked filing cabinet in Dr. Smart's locked office.
 4. No other individuals within State University will be granted access to the shared data without prior approval of the Family Violence Crisis Agency.
- H. Research Dissemination Plans:
1. It is the responsibility of Dr. Smart and the State University to protect the privacy rights of individuals and the confidentiality of their data in compliance with all relevant State and Federal laws and regulations and this Agreement. In any public communications about the findings of this research study—whether in written, verbal, or electronic form—data should be redacted to strip all individual identifiers, and effective strategies should be adopted to prevent the disclosure of an individual's identity. All findings must be reported at the aggregate (i.e., group) level, and any information provided about individuals, such as quotations from the qualitative analyses, must be disguised so as not to be identifiable.
 2. Prior to sharing any public communications about this research study, Dr. Smart will provide the Family Violence Crisis Agency with a minimum of two weeks to review any publications or any other public communication products that result from this study. The Family Violence Crisis Agency has the right to refuse permission to disseminate findings in any format if the agency determines that the publication may be detrimental to the agency or its clients.
- I. Intellectual property considerations: Throughout the entire process of this study, the Family Violence Crisis Agency maintains ownership of the data provided to Dr. Smart. However, Dr. Smart has intellectual property rights—including the right to publish the findings of this research in peer-reviewed scholarly publications—to the research findings of this study, provided the research dissemination plans as stated above are followed. Any publication or public dissemination of research findings by Dr. Smart must include 1) statements acknowledging the federal funder of the study (including the award or grant number) and the Family Violence Crisis Agency as the data provider; and 2) a disclaimer stating that the content is solely the responsibility of the author and does not necessarily represent the views of the funder or the Family Violence Crisis Agency.
- J. This data-sharing agreement may be terminated at any time by either party for any reason. In order to request a termination or modification of this agreement, either party must provide a written request with an explanation for the reason for requesting the termination or modification.
- K. This data-sharing agreement must be signed by Dr. Smart, the President of the Family Violence Crisis Agency, and the State University IRB Coordinator in order to take effect.

Dr. Smart: _____

Date: _____

President of Family Violence Crisis Agency: _____

Date: _____

State University IRB Coordinator: _____

Date: _____