Data Sharing Worksheet

Are you interested in requesting data from another entity, or linking your data with other external data? To do so often requires that you develop a data sharing agreement or a memorandum of agreement, which outlines which data will be shared and how. To develop the data sharing agreement, an important first step is to identify your data needs and approach for obtaining and using the data. This worksheet can be used to identify your data needs, data sharing considerations and next steps to an agreement. You can complete this worksheet within your own organization first, or in collaboration with other organizations. Then information from this worksheet can be used to draft a data sharing agreement with collaborating organizations. We recommend that you complete this worksheet for each organization from which you are requesting data.

Remember that this worksheet is a tool for your organization and should be used in the way that works best for you. You may prefer to break this work up into several meetings instead of doing it all at once or complete it in collaboration with other data stakeholders. If terms in this worksheet are unfamiliar to you, consult the Data Lingo resource. You can also contact the Child Trends team at NCITSupport@ childtrends.org for additional support and guidance.

STEP 1: IDENTIFYING THE DATA YOU NEED

1. **What is the purpose or reason for requesting these data? What question(s) are you are trying to answer?**

2. Who is your population of interest? (e.g., teenage parents, families receiving home visiting services, infants and toddlers in certain neighborhoods, etc.)

3. What data will you need?

Do you need data about parents, providers, or maybe referrals? For example, you might need data on how many childcare providers took part in a behavior management training, and how many completed the entire series.

The following are some common categories of data elements to consider:

Demographics (e.g., race, ethnicity, gender, age, marital status, education level, employment status)

Eligibility for Services: (e.g., program enrollment data (e.g. who? when?), disability status, income level, other eligibility requirements (e.g. first-time parent, teen parent, Medicaid recipient))

Date or timing (e.g., school year, calendar year, date or duration of services)

4. Do you need the data at an individual level, or an aggregate level?

This is important as requesting data at the individual level often requires more data security and approval processes to be put in place.

DATA LEVEL	EXPLAIN (WHICH DATA ELEMENTS?)
☐ Individual	
☐ Aggregate	

5. Is there someone in your community collecting this data?

Make sure they're collecting the type and form of data you need. Sometimes an entity will say they are collecting these types of data, but then they are in a different format or are collected in a different way than what you need.

Does a codebook exist to help you identify specific elements? If an entity says they collect the information you need, make sure to ask them if there is a codebook or any documentation on the specific data elements so you can confirm these data will be helpful to you.	
Who do you need to speak with to learn more about these data and how they are collected?	

STEP 2: IDENTIFYING THE STEPS NEEDED TO SHARE DATA

Now that you've identified the data you need, it's time to think about building your data sharing partnership. The next set of questions will help you think through the different topics you will need to address both internally as well as with collaborating organizations. Answers from these questions will also help you draft the data sharing agreement.

1. Who owns the data?

Is this a public records request? If so, there should already be an established process within that organization or state to request public records data. Instead of developing a data sharing agreement, you should work with that organization to follow their process	
Are the data housed by one organization, or multiple organizations? Which are they? What type of organization is it (public, not-for-profit, private)?	
Who makes decisions about the data (e.g. agency leadership, contract and legal staff)?	
Who are the day-to-day people involved in the collection and storage of the data? Include project managers, data collectors, IT staff, and anyone who can help you understand the data.	

2. What are the benefits to the organizations you will be working with?

How will data analysis and reporting benefit their organization? Is there something you can offer to the organization such as additional analysis or a report to them to help them answer their own questions?	
Will you need to compensate them for their time and effort? Consider how much effort will be involved on their end to share the data.	
What may be a disincentive or risk for the organization to sign on to the data sharing agreement? What would be some ways to mitigate that risk? For instance, perhaps they are nervous about sharing data and what findings and conclusions you will draw from them. Could you offer to share the findings and any conclusions or recommendations with them before information is publicly available?	

3. How often do you need the data?

If your data are stored in two different places, how will you plan to coordinate the schedules of each organization?	
Are the data going to be received all at once, or over a period of time? Or are you requesting the data be sent on an ongoing basis (such as annually, biannually, or monthly)?	
How long will you be using the data?	
How will you receive the data? That is, how will the data be sent to you and in what format?	

4. What are the data security considerations?

What are the data security policies of the organizations you'll be working with?	
What are your own organization's data security policies?	
What are the state and federal regulations surrounding your data?	
Who do you need to speak with to ensure you are meeting, or will be able to meet, data security requirements?	
What are the requirements for all involved organizations/entities for dealing with a security breach should it occur? • Note: These data security considerations and policies will need to be written into a data sharing agreement, specifying how you will abide by them.	

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5. How will you manage the data?

Who will have access to the data?	
Where will it be stored?	
How will you maintain privacy and confidentiality of the data? • Note: your organization or your collaborating organization should have policies on this for you to follow.	
Are you required to destroy the data at a certain time point? If so, how and when will it be destroyed, and do you need to document this destruction of data?	

6. Do you plan to link the data with other datasets?

Is linking allowed? Are there additional restrictions on linked data?	
If yes, how will you link the data? Will you use as the common identifier across datasets, or a matching algorithm?	

7. What is the scope of your data sharing agreement?

Will there be smaller projects and data exchanges involved in this project?	

8. What are the roles of those involved of the data sharing agreement?

What are the individual roles and responsibilities of the parties to the agreement?	
Who are the lead staff who will be signing the agreement? What are their positions?	

9. What are your deliverables?

What reports or publications do you anticipate resulting from this agreement?	
Will you be publishing reports (or any other products/outputs) in collaboration with these organizations? If so, how and to whom? • If so, who needs to review and approve the reports before they are released?	
Who will own the findings and reports? Who is ultimately responsible for the content of the report?	

10. What are the terms of the data sharing agreement?

What period of time will the agreement cover? When will it need to be renewed or revisited?	
How will you communicate any modifications or changes to your plan for data analysis and/or reporting?	
What is the process for making other changes to the agreement? For instance, what if you decide in a year to add a new data element, or a new series of data?	
If approvals are necessary, including Institutional Review Board (IRB)[1], who is required to obtain approvals? Are approvals from one organization reciprocal at the other organization?	

11. Who needs to sign the final contract?

Which legal representatives from each organization are required to sign the data sharing agreement?	
Who are the key authorizing personnel from each organization? What will happen if they change positions?	

COMMON ELEMENTS OF A DATA SHARING AGREEMENT

No two data sharing agreements are exactly alike. Different organizations, agencies, and municipalities will have different regulations, terms, requirements, and standards. There are, however, common elements of data sharing agreements, such as the ones listed below.[2] Using the completed worksheet above, you should be able to draft sections of the data sharing agreement. This worksheet can also be brought to initial discussions with collaborating organization(s). Typically, one data sharing agreement is made per organization. However, you may decide to create an integrated system and develop one agreement that encompasses all sharing instead. Keep in mind that data sharing agreements take time! Make sure to plan ahead and involve everyone early on who needs to be part of this process. Also, it is important to be aware of any policies, or privacy and security requirements that may have changed during the development of this agreement that could impact this data sharing.

List who:

1. The organization and/or authorized individual who can share the data and sign the agreement
2. The organization and/or individual(s) who are requesting the data and will sign the agreement
3. The main project contacts
4. The researchers, analysts, and staff who will be involved in the data analysis and reporting
5. Any other key personnel

Detail what:

1. The purpose for the request to use data? [Be specific]
2. The process for revising the list of key staff and/or authorizing individuals
3. The specific aspects of the data you are requesting
4. Your plan for linking data [if applicable]
5. The project timeline and period of use
6. The data security measures in place, whether required by law or institutional policy
7. Any reporting guidelines and expectations, including acknowledgments, authorship, review of publications, and approval for release/dissemination
8. The roles and responsibilities of each person listed in the agreement
9. Other approvals necessary for the data sharing, analysis, and reporting to occur, including an IRB application.

Explain how:

1. How will the data be shared, analyzed, and reported?
2. How will you determine ownership of reports?
3. How will you amend the people listed in the agreement?
4. How will you amend the agreement in other ways, including project timeline, aims, or roles?
5. How will each party involved be compensated for their time and the data?
6. How will each party handle breaches in data security?
7. How will the data be handled at the conclusion of the project?

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[1] An Institutional Review Board is an administrative group at an organization that works to ensure research is conducted ethically. The review research plans and ensure that rules about privacy and confidentiality are followed. They typically operate within a specific organization, so rules may be slightly different from one to the next.

[2] The guidance is adopted from the OPRE Research Brief #2018-67 Guidelines for Developing Data Sharing Agreements to Use State Administrative Data for Early Care and Education Research

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