

Public Health Data Disclosure or Request Readiness Assessment

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Introduction

Organizations that want to share or request data to support public health work should take several preparatory steps. An organization's data sharing efforts will develop more quickly and smoothly if certain considerations have been analyzed, or actions taken before negotiations begin on a data sharing agreement.² The same is true for organizations trying to obtain data to support their public health efforts.

Consider the following prompts and questions before initiating data sharing or a request for data to prepare for a more efficient and effective negotiation for the data's disclosure. That consideration will identify barriers to data sharing as well as result in greater clarity around organizational data sharing needs and data governance.

For those seeking data, what data do you need?

- What type of public health work is on the table and what data is needed to achieve the related public health goals?
 - Identify which entity has the needed data
 - Identify the required data elements
 - Specify the type of data needed (e.g., line level, identifiable, Limited Data Sets, de-identified, aggregated)
 - Having identified the data elements and type of data needed will help later in the legal analysis of which laws apply to the disclosure of data

Pre-Negotiation Considerations

- Review organization's existing written data sharing or data governance policy. Determine whether the project is covered by it and whether any related data disclosures or uses would comply with it.

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² Data sharing agreement is the term used in this writing to refer to all forms of legal documentation of data sharing, which includes data use agreements, memoranda of understanding, and data sharing agreements.

- If there is no such policy, consider developing one for adoption. That process will clarify and/or resolve many issues, including data governance guidelines, which could become barriers during data sharing agreement negotiation.
- Having an organizational “champion” in a position of authority to support a data project may help overcome internal obstacles. Identify a champion – or develop one.
- Identify and get to know the people who play key roles in data sharing agreements (data stewards, leadership, legal counsel) to facilitate project communication.

Pre-Negotiations Review of Legal Issues

- Collect (copies of) and review existing data sharing/use agreements.
 - Reviewing existing agreements will identify existing terms already considered to be agreeable, which could save time in agreement negotiations.
- Determine whether legal barriers (federal or state laws or regulations) to the disclosure of the data exist.
 - If the law does not permit releasing the requested data, re-evaluate the project goals to see if an alternative to the requested data would still be beneficial (e.g., using a Limited Data Set in lieu of fully identifiable data or using aggregated instead of identifiable data)

Other Pre-negotiation Considerations for Those Disclosing Data

- Evaluate the answers to these questions about disclosing the data at issue:
 - *Can I?* (i.e., does the law permit the data’s disclosure?)
 - *Must I?* (i.e., does the law require disclosure?)
 - *Should I?* (i.e., is disclosing the data the right call when considering legal, policy, and equitable factors)
- When considering the risks of disclosing data, also consider the risks of not disclosing it for public health purposes; consider what public health efforts will not succeed without the data.