Address Obstacles to Accessing Data

Agencies and institutions, such as public health departments or law enforcement, routinely gather data that could help you better understand suicidal behaviors in your state or community. However, sharing data can be challenging, as there are many concerns around data use and privacy/confidentiality. Once you identify key data keepers whose information you would like to access, present a compelling case for why they should share data with you, as well as directly addressing any potential data-sharing barriers. Plan what you will say in advance, and be sure to tailor your case to the particular interests and perspective of your partner.

This worksheet, which has been adapted from the resource [Breaking Down Barriers: Using Youth Suicide-Related Surveillance from State Systems](), can help you prepare to discuss data sharing with partners.

Articulate the need

1. Articulate your need for data, and develop a clear vision of how it will be used.
   a. What kind of suicide-related data are you hoping to access (e.g., deaths, attempts, ideation, demographic, other information)?

   b. How would you like to use the information (e.g., for planning, quality improvement, impact assessment? Will it be presented for internal or public review)?

2. Assess your capacity to handle incoming data.
   a. In what format does the partner maintain the data and how could it be most easily shared? Are your data systems compatible (or can they be made compatible) with the partner's systems?

   b. What is your existing capacity for accessing, analyzing, and using the data? Where are your gaps? How can these gaps be filled?

Gain buy-in & support

1. Describe the benefits of data sharing for you and the partner agency. Consider the different ways you can frame these benefits (e.g., programmatic priorities, benefits to leadership, and benefits to individuals being served).

2. Which stakeholder/agency leaders from the partner agency or organization need to be brought on board to obtain needed approvals for data sharing or to facilitate data-sharing agreements (e.g., are there in-system champions or agency personnel with connections to the suicide prevention field)?

Provide clarity & reassurance

1. What is the estimated cost of establishing and sustaining a data-sharing system between the partner system and the suicide prevention system? Who will be responsible for the expenses?

2. What challenges exist in data sharing between the partner system and the suicide prevention system without violating privacy regulations? This resource from the U.S. Department of Health & Human Services offers guidance surrounding the HIPAA privacy rule. Using this resource, you can provide clarity around HIPAA and why and how data *can* **be** shared.

3. What technical challenges might exist in sharing this data (e.g., difficulties matching identifiers)?

Be transparent

1. Which parties will be involved in data sharing? Who else can use the data?

2. How will the data be transmitted? In what form? From whom to whom? How often?

3. How will security and confidentiality be addressed?
   a. Who will have access to the data?

   b. What data cannot be shared?

   c. Where and how will the data be stored?

   d. How will the data be de-identified prior to sharing?

   e. How and when will the data be destroyed (at the end of the agreement, or if the agreement is ongoing, after how long)?

4. Are there conditions about disseminating the data? For example, is there a specific citation that should be used when the data are used in a report?