DATA SECURITY AND PRIVACY

Required reference materials

- Existing protocols concerning the data protection and confidentiality of the families and children your organization serves

- Materials pertaining to the organization's ethical commitments to program participants, communities, and staff members

What topics and questions will this module explore?

- Understanding the key principles of data security and privacy and ensuring these are upheld in your data governance protocol

- How does the organization currently perform with regard to security and privacy of data, and in what ways can these principles be incorporated more strongly into your data protocol?

How does this relate to data governance?

A crucial component of any data governance protocol requires an organization to outline how data security and privacy will be upheld. There are five key principles of data security and privacy that you should take into account, which will help ensure that your organization's approach to data governance respects the identities and information of program participants.

KEY PRINCIPLES FOR DATA SECURITY AND PRIVACY

Reviewing these key principles for security and privacy will help you discuss some of the main components that need to be a part of your organization's data ethics protocol. Work in groups to discuss these five principles, while writing down ideas reflecting on how you currently fulfill each principle as well as ideas for how you could do better.

1. Limited Access

Access to data should be limited to staff members who need to work directly with those data. In addition, data should be stored securely (e.g., on password-protected devices, on locally accessible networks or in encrypted files).

2. Confidentiality

Data collection records, including notes, should only contain personally identifiable information if absolutely necessary. If necessary, personally identifiable information should be obscured or stored separately from sensitive information whenever possible.

3. Informed

Staff should be trained on appropriate data collection practices, in addition to federal, state and local laws regarding data collection and storage.

4. Documentation

Maintain an updated list of internal practices and principles regarding data security and privacy, and ensure all members of the organization have access to this document to refer to whenever needed. This document should be circulated throughout staff levels: frontline, administrative and executive.

5. Respect

When collecting and maintaining data, staff should take special consideration to note how comfortable the participant is in the process. This involves ensuring explicit and continued consent while working with the participant, being sensitive toward particular personal issues and being cognizant of any cultural standards that may shape one's work with the participant.

Implementation

Reflecting on the five key principles and your notes, work through the following exercise. First, rate your organization's current performance for each statement. Then, write down at least three ways that you could do better, as well as what principle your improvement pertains to. These responses can be used to develop specific practices for your data governance policy.

Our organization has a standardized data collection practice, which our leadership and designated frontline staff consistently review and update at least twice a year.

☐	☐	☐	☐	☐
Strongly Disagree	**Disagree**	**Not Sure**	**Agree**	**Strongly Agree**
We don't have a practice to execute this principle, or the practice we have needs to be completely revised.	Our current practice on this idea does not meet the standard in the statement, but we could get there with a few revisions.	We haven't really thought about this idea, but it may be a part of our current practices.	We do quite well to meet the statement, but there are a few areas where we could do better.	We meet or exceed the standard exemplified in the statement.

Three ways we could do better (and what principle they correspond to) are…

1.

Which principle?

2.

Which principle?

3.

Which principle?

We ensure that prior to any data collection participants are provided with information on all risks and implications of the process and that they provide explicit informed consent, ideally written using a standardized form.

☐	☐	☐	☐	☐
Strongly Disagree	**Disagree**	**Not Sure**	**Agree**	**Strongly Agree**
We don't have a practice to execute this principle, or the practice we have needs to be completely revised.	Our current practice on this idea does not meet the standard in the statement, but we could get there with a few revisions.	We haven't really thought about this idea, but it may be a part of our current practices.	We do quite well to meet the statement, but there are a few areas where we could do better.	We meet or exceed the standard exemplified in the statement.

Three ways we could do better (and what principle they correspond to) are…

1.	*Which principle?*
2.	*Which principle?*
3.	*Which principle?*

Staff are regularly trained on data collection practices and any materials used. Intake sheets are revised regularly to ensure only absolutely necessary personal information is being collected and that cultural sensitivity standards are being upheld.

☐	☐	☐	☐	☐
Strongly Disagree	**Disagree**	**Not Sure**	**Agree**	**Strongly Agree**
We don't have a practice to execute this principle, or the practice we have needs to be completely revised.	Our current practice on this idea does not meet the standard in the statement, but we could get there with a few revisions.	We haven't really thought about this idea, but it may be a part of our current practices.	We do quite well to meet the statement, but there are a few areas where we could do better.	We meet or exceed the standard exemplified in the statement.

Three ways we could do better (and what principle they correspond to) are…

1.	*Which principle?*
2.	*Which principle?*
3.	*Which principle?*

We store our data in secure ways; for example, on password-protected devices, in encrypted files or on only locally accessible networks (or some combination).

☐	☐	☐	☐	☐
Strongly Disagree	**Disagree**	**Not Sure**	**Agree**	**Strongly Agree**
We don't have a practice to execute this principle, or the practice we have needs to be completely revised.	Our current practice on this idea does not meet the standard in the statement, but we could get there with a few revisions.	We haven't really thought about this idea, but it may be a part of our current practices.	We do quite well to meet the statement, but there are a few areas where we could do better.	We meet or exceed the standard exemplified in the statement.

Three ways we could do better (and what principle they correspond to) are…

1.	*Which principle?*
2.	*Which principle?*
3.	*Which principle?*

If our data were to be publicly shared by mistake, participants would not be at risk of becoming personally identified. They would not face theft or identity theft because of a data breach or face stigmatization or any other kind of harm.

☐	☐	☐	☐	☐
Strongly Disagree	**Disagree**	**Not Sure**	**Agree**	**Strongly Agree**
We don't have a practice to execute this principle, or the practice we have needs to be completely revised.	Our current practice on this idea does not meet the standard in the statement, but we could get there with a few revisions.	We haven't really thought about this idea, but it may be a part of our current practices.	We do quite well to meet the statement, but there are a few areas where we could do better.	We meet or exceed the standard exemplified in the statement.

Three ways we could do better (and what principle they correspond to) are…

1.	*Which principle?*
2.	*Which principle?*
3.	*Which principle?*

DATA GOVERNANCE PROTOCOL TEMPLATE:
DATA SECURITY AND PRIVACY

Finally, use the improvement measures you have highlighted for each core principle of data security and privacy to develop language for a data security and privacy protocol. You could consider organizing your thoughts in a table like the one below.

Key data security and privacy principle	How do we plan to improve on this principle? Reflect on the concrete plans you just identified in the activity above.	Notes on how we plan to frame this in our data security and privacy protocol. Work together to develop the language that reflects the ideals and practices you have established.
LIMITED ACCESS	1. 2. 3.	
CONFIDENTIALITY	1. 2. 3.	
INFORMED	1. 2. 3.	
DOCUMENTATION	1. 2. 3.	
RESPECT	1. 2. 3.	

This is useful content to include as a part of your final data governance protocol.

DATA GOVERNANCE PLANNING TOOL KIT — DISCUSSION NOTES

Please use this space to take notes on important points you and your team discussed. You may also want to include a list of any references or additional resources you used to complete this module or that you think are relevant to developing a data governance protocol based on this module.

Notes:

Resources and references:

1
2
3
4
5
6
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8

Notes:

Resources and references:

1
2
3
4
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