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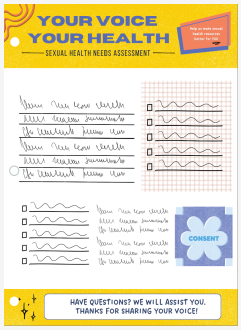
A partnership between
Child Trends & Chapin Hall

A Practical Tool for Building Data Collection and Data Use Capacity in Youth-Supporting Organizations

Module 3: Protecting Privacy and Confidentiality



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Protecting Sensitive Information

Mina is a case manager at a school reengagement program. Over the past two weeks, Mina has been hard at work developing a sexual health needs assessment for the young people the program serves. When young people are asked to complete the assessment, they voiced some concerns. One young person approaches Mina and says, "This is really personal information. I don't mind sharing it with you, but what's going to happen with it afterward? Are other people going to see my answers to these questions?" Mina isn't sure what to say. The staff had agreed to keep the sexual health data safe but were still figuring out how exactly to do that.

Youth-supporting organizations that collect sexual and reproductive health data have an obligation to protect the privacy of the young people whose data they collect and the confidentiality of those data.

Privacy is the ability to control access to one's personal information.[17] Young people should be able to decide whether they want to share information about their sexual and reproductive health and what information they want to share. Protecting privacy involves, but is not limited to:

- Explaining the data collection process.
- Avoiding unnecessary data collection.
- Collecting data in a private setting.

Confidentiality is the duty to protect data that have been shared from unauthorized disclosure or breach.[18] Maintaining confidentiality involves, but is not limited to:

- Physically or digitally protecting data (e.g., storing data in locked filing cabinets; password protecting data files).
- Limiting data access to those who need it.
- Removing identifying information (e.g., names, addresses) from data files.
- Reviewing any documents before they are published to ensure that individuals cannot be identified.

See the following resources for more information about safeguarding data:

- 10 Ways to Safeguard Data in the Nonprofit Sector (Arizona State University)
- Cybersecurity Assessment Tool (Ford Foundation)

Having an *informed consent* process may be required in some circumstances, such as in the context of a research study or before undergoing a medical procedure.[a] While informed consent requirements may not apply to many youth-supporting organizations, it is still best practice to give youth the opportunity to opt out of data collection activities. This can be done by establishing transparent processes for collecting, protecting, using, and sharing data and discussing the processes with young people before data collection. These processes may be described in a written document that is reviewed with youth prior to data collection. This document, which may be referred to as a *Client Confidentiality Statement* or *Client Privacy Notice*, should be written at an appropriate reading level using language youth will understand rather than jargon or technical terms.

Youth should also have the opportunity to ask any questions they might have about the protection and use of their data. Having transparent processes can help youth-supporting professionals build trust with youth and empower youth to make informed decisions about whether they want to share information related to their sexual and reproductive health.[16]

Module Takeaways

- Protecting privacy and confidentiality is a core responsibility for youth-supporting organizations that collect sexual and reproductive health-related data.
- Explaining to young people how their data will be collected, protected, shared, and used allows them to make informed decisions and builds trust with them.

Reflection Questions

- How does your organization protect young people's privacy during data collection, and how is the confidentiality of the data your organization collects maintained?
- How could those privacy and confidentiality protections be improved?
- What do young people need to know about how your organization protects, shares, and uses data?



[a] Informed consent is the process by which a person voluntarily agrees to participate in a study, receive a medical procedure, or share personal information after being given clear, complete, and understandable information about what that participation involves.

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