



Community Data Sharing

Key Considerations



Why set up Data Sharing?

In many communities children receive services from multiple organizations, but the organizations do not know what services are provided to the child outside their own. And communities use multiple providers to deliver a program or leverage a common community assessment tool. Ideally, organizations share data to collaborate to improve common goals; some even envision a comprehensive, longitudinal community database supported through the efforts of *Partner Organizations* that work together in a *Community Data Sharing Initiative*.

For example, in-school academics and after school enrichment may benefit if they share report cards, test results and program outcomes.

Only data sharing can enable outcome measurement across organizations. So, if an after school program and a school want to measure if their collective work has a positive impact on school attendance and academic outcomes, and to determine which programs are effective and to fund, data sharing is essential.

Considerations for Data Sharing

Who owns the data within COMET?

The organization that has directly contracted with COMET for services (the “Client”) is the owner. This is true regardless of who enters the data whether it is Client personnel, partners, such as community based organizations (CBOs), or COMET personnel on behalf of the Client.

How does COMET control data access?

Typically, COMET Users are provided “roles” within COMET where they can access the subset of the children they serve and have permission to view their data. When Users access a child’s record they have access to all the information pertaining to that child, providing them with up-to-date, relevant data that can help inform their professional practices. However, Users’ access to some data elements can be restricted based upon their roles.



Client Considerations

Who determines who may use COMET and what privileges they may have?

It is the responsibility of the Client to properly vet who will be COMET Users and what data those Users can access.

What is the role of data sharing agreements between the Client and the partner(s)?

Such agreements outline the conditions of who owns the data, what happens to data stored in COMET and under what conditions it will be shared. Partners and their employees who use COMET, including the longitudinal nature of COMET data and COMET system outputs, must understand such agreements.

For example, if a child moves from Partner1 to Partner2, the child’s history will move as well, and Partner2 will by default be able to see the data recorded by Partner1.



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COMET Considerations

Compliance responsibilities to specific regulations like HIPAA or FERPA:

COMET is responsible for providing privacy notices and is legally bound to make sure the database and its personnel follow FERPA and HIPAA regulations. COMET's personnel (e.g.: support) access client's records on a need to know basis to conduct their professional duties for the Client. COMET is **not** responsible for the actions of the Client, its personnel or those Users authorized by the Client to access COMET.

COMET recommendations:

- When a Client is enabling a partner to access their database, the Client should include legal and confidentiality obligations within the partner agreement.
- Each partner should extend their legal and confidentiality obligations to their staff, including employees, volunteers and contractors.
- Be sure to obtain a valid consent from parents or guardians to record and share information among all organizations that have access to the database, including COMET Informatics LLC.
- Engage a legal representative in the data sharing process, agreement development and review to keep the process as efficient as possible. Verify operations are within legal requirements and ensure that it supports the collective goals of the community.

Third-Party Access Considerations

When data is owned outside of COMET by other organizations, particularly government agencies with their own regulations and data systems, such as counties, school districts, cities, public health, etc., the following data sharing methods should be considered:

- **Data sharing agreement with a third party evaluator:** Designed for program evaluation purposes at the organization level, this agreement allows a third party evaluator, such as the Children's Institute, receives identifiable records from the various parties, performs its study and provides the results in a de-identifiable manner (commonly aggregated statistics) to answer the questions of the program evaluation. The interested parties (*for example, the Client, the county and the school district*) do not have access to the records of the other parties. Such agreements are well suited for ongoing program evaluations.
- **Data sharing agreement to inform the practice:** This kind of agreement can help the receiving organization to conduct their daily activities, i.e., work processes.
For example, an after school organization may have a program that follows specific steps when a child is absent in school such as contacting parents, working issues with the child, etc.
Such a data sharing agreement usually implies that the parties share "identifiable" records. This means parents have provided informed consent to share such data.