Community Data Sharing: *Architecture*

Key Concepts

Organizations leverage COMET's comprehensive, longitudinal community database offering through the efforts of *Partner Organizations* that work together on common goals in a *Community Data Sharing Initiative or Consortium*.

Data Owners

Data Owners (or data contributors) record their data within independent COMET databases that they fully configure and control, specifically regarding data access, data usage and data quality. As part of the community data sharing consortium, Data Owners may have agreed to track specific (common) information, using the same or similar tools or instruments.

Data Seekers

Data Seekers wish to access various records from various Data Owners - either at aggregated, de-identified or identifiable record levels, and are properly authorized to do so.

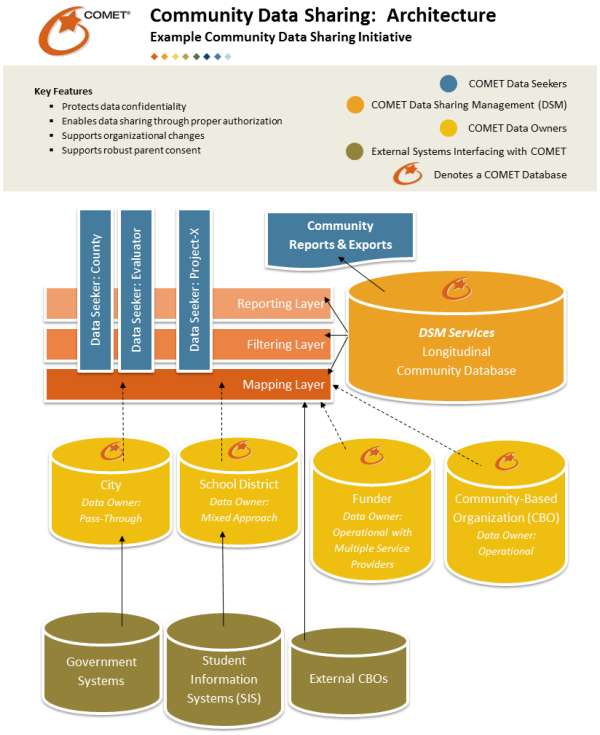
- Data seekers are usually one of the Data Owners, but not necessarily (e.g.: funding organizations such as United Way, County or City governments, etc.)
- Data Seekers must secure parent consent (in particular when seeking identifiable records) and/or data owner authorization to access child records at aggregated, de-identified or at identifiable levels.

Data Sharing Management

COMET Professional Services: Acting as a third-party Data Sharing Manager (DSM), the COMET service team continuously assesses Data Owners' databases and builds/maintains the mapping layer.

- Maintain demographics combining the various sources and will interact with the various data owners for data quality purposes.
- Manage/maintain parent consent for data sharing purposes as provided by the data seekers.
- Manage data seekers requests for data sharing (aggregated, de-identified or identifiable records) and obtain access authorization or denial from the various data owners involved

NOTE: The DSM - COMET personnel will NOT interact directly with children / families, and will limit interactions to the COMET Primary Administrator (CPA) of each Data Owner of the Community Data Sharing initiative.



Data Owners' Databases

Data Owners maintain their own records in personalized COMET databases for a variety of purposes. Each Data Owner will have a specific Master Service Agreement with COMET.

Pass-Through: Simple Data Repository from their own data systems; in this approach, the data provided is likely to be limited to the data that is agreed to be shared through the Community Data Sharing initiative

- *A school district may share student grades and attendance records. COMET may develop an interface with their Student Management System (SMS) and download student records, grades, attendance daily.*
- *A Community-Based Organization (CBO) with their own data system may agree to upload records manually (using Excel-like imports or manual data entry) on a quarterly basis*

Operational: Full operational / transactional database to manage Data Owner's daily operations. In that case, the data owner will provide a clear definition of what is "potentially shareable" with the other Community Data Sharing Initiative members and what will not be shared *(e.g.: operational records, data elements too sensitive to be shared)*.

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Operational with Multiple Service Providers: Some data owners may already integrate data from multiple data sources / service providers.

- *A United Way or a County may use COMET for a specific program (e.g.: after school academic support) and they may have contracted such services to a set of CBOs. In that case, the data owner could be the funder / integrator. This integrator must have already secured data sharing agreements and parent consent processes with their service providers and will validly provide access authorizations (or denial) to their records.*

Mixed Approach: Leverage COMET for a specific operational purpose in conjunction with other operational data systems.

- *A school district may use COMET to conduct a specific assessments or screenings that are not available within their SMS.*

Mapping Layer

When served by multiple organizations / Data Owners, the same child will have a specific record in each of the associated databases.

The *Mapping Layer* establishes equivalence between these records.

Example child record equivalence:
- *City database child "1234" is the same as*
- *County database child "2345" is the same as*
- *School District database child "3456"…*

As a DSM, COMET will maintain the mapping layer:

- Regularly identify and review all new child records
- Provide data quality services, in particular:
  - Identify possible duplicates within each Data Owner's database
  - Validate and correct with each Data Owner's differences in the child record, especially regarding child demographics.
- Build a COMET child profile in the Data Sharing Management database based upon agreed commonly used demographics.

NOTE: DSM records are created to facilitate Data Sharing Management by COMET personnel. These records and data elements are not shared with any Data Owner / Seeker without proper permission and are only used to build a reliable Mapping Layer between Data Owners

NOTE: The existence of the Mapping Layer does NOT imply any data sharing / data exchange between Data Owners and/or Data Seekers

Filtering Layer

The *Filtering Layer* will be used for:

- Enabling access by Data Seekers to either aggregated reports or de-identified records
- Managing parent consents and enabling access by Data Seekers to identifiable Data Owner records

As a DSM, COMET will support the filtering layer by helping to resolve open requests for data access.

Accessing Aggregated Reports

Reports will be defined and created per a mutually approved scope, combining data from multiple Data Owners, to report global statistics - *such as overall demographic, program registration, service delivery and other Key Performance Indicators (KPIs)*. The filtering layer will identify which Data Seekers are authorized to use which report.

Accessing De-identified Records

Typically, detailed de-identified records are used to perform more advanced data analyses, find correlation between activities and outcomes, monitor resource allocation and inform global decision makers regarding past or future decisions. The filtering layer will identify which Data Seekers are authorized to use which report.

Accessing Identifiable Records

Accessing an identifiable data owner record by a data seeker will be done through a COMET-supported two-step process:

Step 1: The Data Seeker should secure parent consent to access identifiable records from one or more Data Owners. When the parent consent is executed, the Data Seeker will record the consent in COMET including required data - *such as Consent "Until Date", a Scan of the Signed Document, etc.*

Step 2: Then COMET DSM personnel will secure an access authorization from each Data Owner involved through each Data Owner's COMET Primary Administrator (CPA).

One-Way vs Two-Way Consents

Some parent consent processes may include authorizing access to a specific Data Owner, skipping Step 1. For example, an after-school program may obtain parent consent to access academic records from the school district (Step 1 & 2); the same consent may also authorize the after school service provider to share its data with the school district (going directly to Step 2.) COMET's architecture supports both types of consents.

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Reporting Layer

The *Reporting Layer* is developed and maintained by COMET to support the community data sharing initiative's reporting requirements and corresponding access rights.

Data Seekers will be granted access to specific reports tailored to produce "acceptable" data without breach of confidentiality:

- *Aggregated Reports* at community, service provider or program level; such reports may require the program and/or the service provider be concealed.
- *De-identified Records* for statistical analysis; such reports may include requirements to remove names, change the birth date to age in months, hide zip code if have less than 10 children in that zip code, etc. These rules will need to be defined and approved.
- *Identified Records* when proper parent consent and access authorizations have been secured.

Data Seeker Access

Data Seekers are organizations that have one or more "COMET Users" accessing the community data sharing system for specific data needs. To be a Data Seeker, an organization will need a Master Service Agreement with COMET. All Users of a given Data Seeker will have the same access rights into the community data sharing system, consistent with the way parent consent is provided. If needed, specific access "scoping" for Users can be configured.

When Data Seekers are also Data Owners, their COMET Users will be provided with a choice at login:

- *Accessing their own database to conduct operations and access identifiable records,*
- *Accessing the community data sharing system to view aggregated reports or access authorized identifiable records.*

When authorized organizations are only Data Seekers, their COMET Users will login to COMET to access sharable data, record parent consents and review Data Owner authorization statuses.

Parent Access

COMET's community data sharing architecture can include an option that enables parents, through a *Parent Portal,* to access their children's records and view, from each Data Owner's perspective, which information was recorded for their child. In addition, parents will be able to file data update requests if they identify that a given Data Owner has inaccurate records for their child.

Legal Considerations

COMET recommends that the community data sharing initiative "consortium" secures a legal opinion regarding accessing identifiable records to produce aggregated reports and de-identified child-level reports.

In particular, define which precautions should be taken to assure:

- Data Seekers will not find a way to identify individuals through the aggregated counts *(e.g.: a zip code with a single person in it)*.
- Programs or service providers' identities will be protected *(e.g.: to protect fair competitive practices between providers)*.

COMET recommends creating a standard parent consent document to be reviewed and approved by legal counsel for data sharing purposes that will make the consent both efficient and effective.

In particular:

- Clearly inform the parents,
- Provide the ability to deny consent at any time, including after consenting and explain the consequences of such denial,
- Define if the consent is "forever" or valid until date,
- Consents should offer data sharing both ways *(e.g.: if a CBO provides a consent to access academic records from the school district, the consent should also offer the possibility to share CBO data with the School District)*.

COMET recommends clarifying how new members will be added to the consortium (Data Owners and/or Data Seekers) and which reports they will be granted access. Legal advice in this area is also recommended

COMET will have a specific Master Service Agreement (MSA) with each data sharing member defining the services provided, each party obligation, costs and payment schedules.

When a formal consortium exists as a legal entity, COMET may have an MSA with the consortium in addition to each individual member MSA.