CalHHS Data Exchange Framework
Technical Advisory Committee (TAC) Recommendations

Date(s): May 29, 2025 – July 10, 2025

Topic: Consent Management

Attendance

Facilitators: Rim Cothren, Cindy Bero

Committee Members (in attendance): Elison Alcovendaz, Irene Lintag Alvarez, Hans J Buitendijk, Adam Davis, Linda Deaktor, Diane Dooley, Kayte Fisher, Robby Franceschini, Eric Jahn, Jeff Jarrett, Alana G Kalinowski, David McCann, Eric Nielson, Derek Plansky, Ken Riomales, Sara Rogers, Shannon Rohall, Jessica Rougeux, Linette Scott, James Shalaby, Ambrish Sharma, Julie Silas, Debbie Spray, Joe Sullivan, Dr. Brian Thomas, Rita Torkzadeh, Daniel Wilson, Jennifer Womack

Recommendation(s)

The following recommendations were summarized by the Facilitators as the consensus of Committee Members. This summary may not reflect HCAI recommendations or intended actions.

1. **Consent management under DxF should allow collecting multiple types of consent, in multiple places, applied everywhere, and managed simply by the consumer.**

   There are different circumstances under which DxF Participants might be collecting consent, such as the type of data collected or disclosed or the type of services provided by the Participant organization, which make a one-size-fits-all approach to consent unworkable.

   Members recommended adopting a model that supports this complexity while still considering the consumer's ability to manage their own consent preferences however and wherever it is collected and stored.

2. **All consent forms should be structured using standardized templates, modular components, and/or model language to support interoperability and consistency in applying multiple types of consent.**

Acknowledging that applicable law has different consent requirements for different types of data and/or disclosing entities, the DxF should ensure that all consent forms can be consistently mapped to a common set of consent rules.

Members were divided equally on how best to implement this recommendation. Some preferred that Participants be allowed to continue using their own consent forms as long as they conform to standardized templates, modules, and language. Some preferred a unified consent form used by all Participants that offers multiple selectable options tailored to different data types and situations.

Some of those preferring a unified form felt it to be a long term, aspirational goal and noted using multiple forms may be more practical in the near term.

3. **Consent may be collected by any Participant so long as it follows a transparent process.**

   Members agreed that consent is and should continue to be collected in a variety of settings—clinical, community-based, and administrative—reflecting the real-world complexity of service delivery and the types of consent collected. Rather than requiring a single point of collection, the committee emphasized the importance of allowing consent to be gathered wherever it makes sense operationally - meeting the individual where they are - as long as it adheres to a transparent process that ensures trust, consistency, and interoperability.

   Members did not specify how the process for capturing consent should be developed or enforced. The conversation suggested that a single, consensus process might be most desirable.

4. **Consents should be stored and maintained in repositories that Participants must access when making disclosure decisions.**

   Members clearly rejected the current practice in nationwide networks and frameworks, which is to trust the assertion made by the requesting Participant that it is authorized to receive the data in a request for information and that consent, if required, has been obtained.

   Instead, Participants should be able to obtain a copy of the consent prior to making a disclosure. Members recommended that consent be stored in a repository that Participants can access prior to making a disclosure. A single consent repository was somewhat preferred to multiple repositories.

A minority preferred attaching consent to each request for information, a method investigated but not widely implemented by nationwide networks and frameworks.

5. **While members believed maintaining consent should be simple for the patient, they failed to come to consensus on the most practical method.**

   Both in-meeting and post-meeting poll results, and discussion during meetings, reflected varied preferences but a lack of consensus for how individuals should access and manage their consents under DxF.

   Approximately equal numbers recommended: (1) that all consents should be stored in a single repository providing a single point for consent management; (2) that individuals be allowed to choose one of many consent repositories for managing their consent, requiring each consent repository to query every other repository directly to find and retrieve consent(s) as needed; (3) that individuals work directly with each Participant where consent was given; or (4) that individuals use a directory, like a record locator, to locate their consents while managing them in the multiple locations where they reside.

6. **Implementation of a consent management under DxF should be incremental, starting with domains that have more mature data standards and processes.**

   Members emphasized the importance of starting with technically feasible areas (data types and/or organization types) to build momentum and reduce complexity. Behavioral health, reproductive health, homelessness, and food insecurity were frequently cited as candidates requiring progress in consent management. However, no single domain emerged as the clear starting point, reflecting the diversity of needs, the recognition that consent requirements vary widely across programs, populations, and data types, and the general lack of maturity in this area.