



**California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework Guiding Principles (v2)**

The CalHHS Data Exchange Framework (DxF) principles will be core expectations or “rules of the road” that: guide and govern the design and implementation of the DxF and electronic health information exchange in California; support the deliberations and formulation of Advisory Group and its subcommittees’ DxF and DxF Data Sharing Agreement recommendations; and, build trust among data exchange partners. Principles were informed by the [CalHHS Guiding Principles](#), [Consumer and Patient Protection Principles for Electronic HIE in CA](#), and [ONC’s TEFCA Principles for Trusted Exchange](#) and developed to align with AB-133 requirements.

Principle 1: Advance Health Equity: *We must develop and implement data exchange policies, processes and programs to better understand and address health inequities and disparities.*

- We should support the standardized collection, exchange and use of data that allows us to identify underserved and underrepresented populations, including demographic information about race, ethnicity, preferred spoken and written language, sexual orientation, gender identity, and disability.
- We recognize that advancing health equity requires filling disproportionate gaps in data completeness and quality for historically underserved and underrepresented populations and being proactive in reaching out to these individuals. This will require broad information sharing and infrastructure for combining and curating health information into the unified person-centered records needed for public health and population health management.
- We should design health information collection, exchange, and use policies and programs to meet the diverse needs of all Californians; older and younger residents, people from diverse cultures and communities, people with diverse abilities and disabilities, and people across a range of income levels, languages spoken and health literacy.
- We must ensure health care and human service organizations who serve historically marginalized populations can meet data exchange requirements and have the opportunity for full and equal access to the health information they need and the means to derive insights from it, to support electronic health information exchange to support patient health. This will require technical support and assistance.

Principle 2: Make Data Available to Drive Decisions and Outcomes: *We must exchange, analyze and use -actionable and timely information within and across health and human service sectors to better understand conditions at the level of the individual, within our communities, and across populations, and the impact of our programs so that we may identify opportunities and implement solutions that improve quality, experience and outcomes of care and services.*

- We must use the tools we have to exchange patient electronic health information when doing so has the potential to benefit the consumer and is allowable by law.
- We must not treat patient data as a strategic or competitive asset that may be withheld to protect its value, or is only shared for a subset of allowable purposes.

Commented [CW1]: There are a lot of important health data uses that are needed for healthcare payment and operations and public health but may only indirectly “benefit the consumer”

Commented [CW2]: Recommend deleting – this is a repeat of the third bullet

- We must share requested electronic health information with individuals, other health and human service organizations, or their proxies to support the collection, exchange, and use of data for all defined purposes allowable by law, including treatment, payment, public health, patient access and health care operations, to the extent allowable by law and in accordance with individuals' preferences.
- We must practice data reciprocity, sharing health information with other requesting organizations as readily as we receive it.
- We must decrease the cost, burden and complexity of exchange, including by relying on standards and data exchange intermediaries and networks already in use.
- We should support implementation of systems that can collect, exchange, provide access to, and use information necessary to advance the DxP's vision and goals and patient preferences.
- We must establish financial conditions that foster and support data exchange.
- We must maintain technology and data exchange arrangements, networks and infrastructure that facilitate the timely bidirectional exchange of data for multiple patients simultaneously based on a submitted or requested patient panel, that support one to many exchange (e.g., a provider shares data once with a network, and the network facilitates sharing that data with many other entities), and that support aggregation and curation of data from many sources to create the unified patient-centered records needed for both treatment and population health.
- Data held by the state including public health data and data in public systems, should be available to providers, health plans and the networks that serve them.

Principle 3: Support Whole Person Care: *We must promote and improve data collection, exchange, and use across health and human services organizations so that we may gain greater insight into the needs of the people we serve and can better meet individuals' whole person care needs.*

- We must support the standardized collection, exchange and use of demographic, clinical, administrative, behavioral health, social determinants of health (SDOH), and other health and human service data to identify individuals' whole person care needs and to facilitate connections with collaboration among health care and human service organizations capable of addressing them.
- We should design and support programs and policies that support active engagement of patients, family members, and caregivers and enable the coordination of a patient's care amongst diverse providers and systems.
- Health and human service information collection, exchange, and use should support whole person care goals and programs that identify and manage high risk individuals and populations; improve transitions of care; track and report quality; improve health equity; and coordinate care and services.
- Whole person care must be enabled by whole person records—information that is updated and combined into unified records that allow care teams and service providers to see the complete picture for their patient and client populations.

Commented [CW3]: We have not discussed or decided that information will only be shared in response to requests. There are many instances when it should be shared proactively.

Commented [CW4]: This is really important. HIEs and other intermediaries will be designated as the data sharing partners for providers and plans. We need to embrace these entities in the framework

Commented [CW5]: It is problematic to make required information sharing more restrictive or conditioned than what is allowable by law by adding new patient consent steps or requirements that purposes be specifically defined.

This creates a narrower definition of what information must be shared than is established in federal regulations through the information blocking rules. Here is an excerpt from an ONC info blocking fact sheet:

"This exception recognizes that if an actor is permitted to provide access, exchange, or use of EHI under a privacy law, then the actor should provide that access, exchange, or use. However, an actor should not be required to use or disclose EHI in a way that is prohibited under state or federal privacy laws."

It will also open up a new way for providers to block information sharing by saying they don't agree with the purposes named by the requesting party

Using the "allowable by law" frame ensures we are not re-interpreting HIPAA or going sideways with information blocking regulations which impose substantial penalties for holding back information that can be legally shared

Commented [CW6]: Already addressed under transparency. Also this language "in accordance with patient preferences" implies we are adding a consenting step for all TPO data exchange that is not required by HIPAA. That it a really bad idea

Commented [CW7]: Duplicates this principle below: "We should develop data sharing arrangements and programs that facilitate the reliable collection, exchange, and use of patient data across organizations and sectors."

Commented [CW8]: Panel based exchange is not necessarily bidirectional



- We should develop and use data sharing arrangements, networks and infrastructure and programs that facilitate the reliable collection, exchange, aggregation, curation, analysis and use of patient data across organizations and sectors, to create unified whole-person records.
- In addition to the need for incentives and technical assistance to support universal data sharing as established by AB 133, we recognize that we must develop and fund the data aggregation and curation infrastructure that is needed to reach the goals of the Data Exchange Framework. This infrastructure is required to create the unified whole-person records that are vitally important for the success of California's public health, equity and Medi-Cal transformation efforts.
- We must prioritize the pursuit of federal and other funding to support universal data sharing and this infrastructure, leveraging the networks that already serve California.

Principle 4: Promote Patient Data Access: *We must ensure that all Californians easily have full and equal access to their electronic health information.*

- Californians should have ready and complete electronic access to their health and human service data as well as relevant tools and educational resources, in their primary or preferred languages, to make meaningful use of that information.
- Californians' information must accompany their journey across health and human service systems and be continually updated as a single unified record that encompasses their history and is readily available for use by themselves and their care teams.
- We must support equal access to health information for California's low-income communities, communities of color, people speaking primary languages other than English, people with disabilities, seniors and youth, immigrant residents, rural and inner-city, and LGBTQI communities.
- The burden of health information exchange must not rest solely with patients.

Principle 5: Reinforce Patient Privacy & Security: *We must collect, exchange, and use health and human service information in a secure manner that ensures data integrity and adheres to federal and state privacy law and policy.*

- ~~We must support a patient's preferences regarding the collection, exchange, access, and use of their information. We must collect, exchange, and use data in compliance with state and federal data sharing technological and secure transmission requirements.~~
- We should establish strong and clear privacy and security policies to ensure that health information exchange promotes trust and protects the privacy, security confidentiality and integrity of health data.
- We should establish policy and support technologies that incorporate innovations that can enhance individual privacy and security and address new risks.
- We should establish policies, procedures and educational programs that clarify data sharing privacy requirements, debunk misleading claims about data sharing, and reduce burdensome or restrictive standards for compliance with privacy laws or regulations as pretext for not exchanging health information.

Commented [CW9]: This content is already addressed by principle 6. Also see note above about consent



- We should facilitate health information exchange that is governed by data stewardship rules and fair information practices advanced by federal and state government.

Principle 6: Establish Clear & Transparent Data Use: *We must adopt and communicate clear policies and procedures so that all Californians and the organizations that serve them can understand both the purpose of data collection, exchange, and use.*

- Data collection, exchange, and use policies and practices should be open and transparent to patients and all other data exchange participants.
- We should establish policies that help individuals know what personal health information exists about them, and how it may be used, accessed, exchanged and maintained.
- The purposes for which personal health data are collected, exchanged and used should be specified at the time they are acquired. ~~only information that is reasonably necessary for specified purposes should be collected, exchanged, and used.~~
- We should establish policies that make it as easy for individuals to authorize the disclosure and use of ~~information that by law requires proactive patient consent such as substance abuse treatment information, or health data sharing with non HIPAA-covered entities. Patient data should not be blocked (not shared) if it is allowable to be shared under state and federal law. sensitive health and human service information.~~

Commented [CW10]: We should stick to “allowable by law” rather than trying to reinterpret HIPAA

Commented [CW11]: The term sensitive is not meaningful in our experience

Not all of the info that requires consent is sensitive. Some sensitive info does not by law require consent. And sensitive is subject to interpretation.

Would define the subset as information that by law requires proactive patient consent

Principle 7: Adhere to Data Exchange Standards: *We must adhere to widely adopted and used federal, state and industry recognized standards, policies, best practices, and procedures.*

- Data exchange participants must adhere to applicable standards for electronic health information collection, exchange, and use that have been identified by CalHHS’s DxP, drawing from those adopted by the U.S. Department of Health and Human Services (HHS), the U.S. Office of the National Coordinator (ONC), and other relevant federal agencies.
- Where federal or state standards do not exist, we must establish data sharing standards that are necessary to meet the state’s Data Exchange Framework’s goals.

Commented [CW12]: Many entities we work with hold back information they deem sensitive even though the information can be shared under TPO and is not subject to legal restrictions

(NEW) Principle 8: Accountability: *Entities that collect, exchange, or use health data, and the governmental agencies that oversee them, must act as responsible stewards of individuals’ health information and should be held accountable for realizing the benefits for all Californians of sharing this information of health information exchange for all Californians.*

- We should establish policies that hold data sharing participants accountable for safeguarding its collection, exchange, and use of health and human service data.
- Entities that collect, access and use health and human service data and the government organizations that oversee them must be held accountable for enforcing protections of health information exchange for all Californians.
- ~~We must ensure reasonable legal and financial remedies to address breaches of violations are available.~~

Commented [CW13]: HIPAA already addresses this through breach notification requirements and fines. It is over-reaching to suggest we need new law in this space. Recommend deleting