



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 ~~and human services~~ 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 d~~Develop and implement data exchange policies, processes and programs to better understand and address health inequities and disparities.

- ~~We should S~~upport 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 ~~and align with federal standards being developed by the Centers for Medicare and Medicaid Services.~~
- ~~We should design~~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 e~~Ensure health care and human service organizations who serve historically marginalized populations have the ~~opportunity resources needed to participate in data collection, exchange, and use, and have for~~ full and equal access to the ~~health information information they need to support electronic health information exchange to support the care of all patient health~~ Californians.

Principle 2: Make Data Available to Drive Decisions and Outcomes: ~~We must e~~Exchange actionable and timely information within and across health and human service sectors to ~~the extent allowable by law 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 u~~Use the ~~tools~~existing and emerging standards and technology we have to exchange ~~patient electronic health and human services~~ 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. Replace with one of the following:~~

Commented [TG1]: Shift from negative to positive.



- ~~Ensure collaboration between stakeholders across the health and human services care continuum. or Data should be made available by entities in the health and human services care continuum to drive decisions that improve the quality, experience and outcomes of care and services.~~
- ~~Ensure that entities agree to the uses and disclosures related to~~We must share requested electronic health information with other health and human service organizations to support the collection, exchange, and use of data for defined purposes, including treatment, payment, and health care operations, to the extent allowable by law and in accordance with individuals' preferences.
- ~~Establish policies and procedures for~~ascertaining those entities have an applicable relationship with an individual prior to exchanging data.
- ~~We must practice data reciprocity, sharing health information with other requesting organizations as readily as we receive it.~~
- ~~We should~~Support the implementation of systems that can collect, exchange, provide access to, and use information necessary to advance the DxP's vision and goals and ~~patient individual~~ preferences.
- ~~We must establish~~Promote data exchange to support new payment models that can be utilized as a tool to advance population health improvement efforts and value-based care, financial conditions that foster and support data exchange.
- ~~We must~~Maintain technology and data exchange arrangements that facilitate the timely bidirectional exchange of data for multiple ~~patients individuals~~ simultaneously based on a submitted or requested ~~patient panel~~cohort of individuals.

Commented [TG2]: Policies will ensure that appropriate information is shared with entities to advance care.

Formatted: Font: (Default) Arial

Principle 3: Support Whole Person Care: ~~We must~~Promote and improve data collection, exchange, and use across health and human services organizations to the extent allowable by law and aligned with industry and federally recognized standards, policies, and procedures so that we may gain greater insight into the needs of the people we serve and can better meet individuals' whole person care needs.

Commented [TG3]: Language aligned with TECCA.

- ~~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 health ~~care~~ and human service organizations capable of addressing them.
- ~~We should~~Design and support programs and policies that support active engagement of ~~patients individuals~~, family members, and caregivers and enable the coordination of ~~an individual's a patient's~~ care amongst diverse health and human services 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.
- ~~We should~~Develop data sharing arrangements and programs that facilitate the reliable collection, exchange, and use of patient health and human services data to the extent allowable by law across organizations and sectors.



Principle 4: Promote Patient Data Access: *We must ensure that all Californians and their caregivers easily have full and equal access to their electronic health and human services 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. Replace with:~~
Ensure that entities collecting, exchanging and using information enable individuals to easily and conveniently access their information.
- ~~We must support equal access to health and human services 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.~~

Commented [TG4]: While ideal, use of the words "full and equal access" to health information runs counter to privacy restrictions.

Commented [TG5]: Electronic health records not available in multiple languages.

Formatted: Font: 11 pt

Formatted: Indent: Left: 0.75", No bullets or numbering

Formatted: Font: (Default) Arial

Formatted: Font: 11 pt

Principle 5: Reinforce Patient Privacy & Security: *We must collect, exchange, and use health and human service information in a secure manner that promotes patient safety, 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.~~
- ~~Establish procedures for sharing electronic consent between entities exchanging health and human services data, with the State developing a global opt-out policy for individuals.~~
- ~~We should establish strong and clear privacy and security policies to ensure that health information data 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 and human services information.~~
- ~~We should facilitate health information data exchange that is governed by data stewardship rules and fair information practices advanced by federal and state government statutes.~~

Commented [TG6]: Health care entities are subject to federal HIPAA laws and state CMIA statutes. Parameters and penalties are already in state and federal statute. May need to clarify that HIPAA, CMIA and other applicable laws take precedence over standards articulated in Data Sharing Agreement or fully align guiding principles and subsequent data sharing agreement with HIPAA, CMIA and other applicable privacy laws.

Commented [TG7]: Contradictory items.

Commented [TG8]: What is this referring to?

Principle 6: Establish Clear & Transparent Terms and Conditions for Data Exchange, Collection, and Use: *We must adopt Conduct all exchange and operations openly and transparently 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.*

- ~~Make terms, conditions, and data sharing agreements that govern the exchange of health and human services data easily and publicly available. Data collection, exchange,~~

and use policies and practices should be open and transparent to patients and all other data exchange participants.

- ~~We should e~~Establish policies that help individuals know what personal health and human services information exists about them, and ~~how it may be used, accessed, exchanged and maintained,~~ learn how their information is shared and used.
- ~~The~~ purposes for which personal health and human services data are collected, exchanged and used should be specified at the time they are acquired; ~~only~~ information data that is reasonably necessary for specified purposes should be collected, exchanged, and used.

Commented [TG9]: What does this mean?

Formatted: Font: (Default) Arial

Commented [TG10]: Contradictory to the first part of the sentence.

-
-

- ~~We should e~~Establish policies that ~~make it as easy~~ facilitate the ability for individuals to authorize the disclosure and use of sensitive health and human service information.

Principle 7: Adhere to Data Exchange Standards: ~~We must a~~Adhere to 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, or industry~~ standards do not exist, we must establish data sharing standards, through an agreed upon governance structure, that are necessary to meet the state's Data Exchange Framework's goals.

(NEW) Principle 8: Accountability: *Entities that collect, exchange, or use health data, and the governmental agencies that oversee them, must be held accountable for realizing the benefits of health information exchange for all Californians.*

Commented [TG11]: This section needs to be re-worked. This does not reflect accountability; it is fault finding. Data breaches, for example, may occur despite best efforts. Whose "fault" is it and who should be held "accountable?"

- ~~We should e~~Establish policies that hold data sharing participants, including state and local government, 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 e~~Ensure reasonable legal and financial remedies to address breaches or violations are available.

Commented [TG12]: State statute already exist for data breaches in health care.