



## 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 among all Californians.*

- 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 should support and integrate standardized collection, exchange, and use of data related to social and environmental determinants of health, such as food and housing insecurity, which account for 80-90 percent of an individual’s health status.
- We should design health information collection, exchange, and use policies and programs to serve and meet the diverse needs of all Californians, without barriers or diminished function or quality for some, including: 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 that health care and human service organizations who serve historically marginalized populations have the opportunity for full and equal access to the health information they need to support electronic health information exchange and use to support patient and population health.

**Principle 2: Make Data Available to Drive Decisions and Outcomes:** *We must exchange actionable and timely information within and across health and human service sectors to better understand and manage conditions at the level of the individual, within our communities, and across populations; to evaluate and the impact of our programs; and to 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.
- 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.

- We should design and use electronic health information exchange to improve individual health care and its quality, safety, efficiency, and efficacy for all Californians, and to enable all patients to be full and equal partners in their health care.
- We should design and use electronic health information exchange to improve health for the public and communities at large, such as reducing and preventing chronic diseases, epidemics, and health disparities; promoting public and population health and health equity; measuring and reporting the comparative effectiveness of treatments; and reducing the cost of health care.
- We must design and use electronic health information exchange that serves and meets all users where they are, without digital divides nor diminished access or functionality for some.
- We must practice data reciprocity, sharing health information with other requesting organizations as readily as we receive it.
- 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 design and build health information exchange to integrate maintain technology and data exchange arrangements that facilitate the timely bidirectional and multidirectional exchange of data, such as patients' contributing patient-reported outcomes or remote monitoring data to their health records; community and social service organizations contributing screening, diagnosis, and intervention data for a complete record after a referral; multidirectional exchange with public health agencies in real time to manage public health emergencies; and multidirectional exchange of care plan updates among all care teams for dynamic, longitudinal shared care planning and coordination for multiple patients simultaneously based on a submitted or requested patient panel.

**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 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

**Commented [MS1]:** Do these repeat some of the more targeted bulletpoints below under principles 4-6? Not a problem if/that they do, because principles overlap and work together.

**Commented [MS2]:** This seems to me like a natural place to drop a bullet on individual health benefits and a bullet on population/public health benefits. In light of COVID, it is smart to list some of these highly relevant public health benefits.

**Commented [MS3]:** You may want to prune or simplify the examples for these principles—or not—but I include to illustrate the range of important use cases.



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 data across organizations and sectors.

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

- All 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.
- 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.
- We should design health information collection, exchange and use policies and programs that enable, not impede, patients’ easy access to and use of their longitudinal health data, and facilitate all Californians’ active engagement and partnership in their health care. 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 promotes trust, 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 one’s health~~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 avoid or address new risks.
- Participants shall not use compliance with privacy and security laws as a pretext for information blocking nor impeding or burdening any patient’s access to and use of one’s health information. To that end, wWe should also establish policies, procedures and educational programs that clarify data sharing privacy requirements, and correct~~debunk~~ misleading claims and myths about data sharing, ~~and reduce burdensome or restrictive standards for compliance with privacy laws or regulations as pretext for not exchanging health information.~~
- 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: Make Health Data Policies and Uses Transparent to All Users Establish Clear & Transparent Data Use:** *We must adopt and communicate clear policies and procedures so*

**Commented [MS4]:** I think this is what the draft sentence was intending? Note that this re burden also complements the bullet on burden under privacy and security.

**Commented [MS5]:** Trying an alternative approach to replace the language at the end.

**Commented [MS6]:** Not sure this adds anything new?



that all Californians and the organizations that serve them ~~can~~ understand both the purposes and practices 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 especially sensitive health and human service information such as behavioral health information.

**Principle 7: Adhere to Data Exchange Standards:** *We must adhere to federal, state and industry recognized standards, policies, best practices, and procedures in order to advance interoperability and usability.*

- Data exchange participants must adhere at a minimum, to applicable standards for electronic health information collection, exchange, and use that have been identified by CalHHS's DxF, drawing from those adopted by the U.S. Department of Health and Human Services (HHS), the U.S. Office of the National Coordinator (ONC), the U.S. Office for Civil Rights (OCR), 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.

**(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.*

- 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 or violations are available.
- We should establish and enforce policies that protect against misuses of health data, such as the use of health data for unlawful discrimination or redlining or to deny or restrict health care or insurance coverage.

**Commented [MS7]:** I agree we do not want nor need an exhaustive list, but suggest adding OCR because it handles the HIPAA Privacy and Security Rules (as well as regulations implementing section 1557 of the Affordable Care Act on non-discrimination).