



## 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 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 have the opportunity for full and equal access to the health information they need to support electronic health information exchange to support patient 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 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.
- 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 must begin by prioritizing consistent and comprehensive exchange of clinical data that are more immediately accessible, while still working toward exchange of human services data as described above.

**Commented [LK1]:** Although we agree that all health and human services data is important, we are far from that now and believe prioritization or phasing should be acknowledged. We recommend stating that data such as ADT and ORU, and other clinical data that are more immediately accessible be prioritized initially



- 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 DxF'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 that facilitate the timely bidirectional exchange of data for multiple patients simultaneously based on a submitted or requested patient panel.

**Commented [LK2]:** This bullet and the last one appear to be references to HIEs and the 'how' data exchange should occur. Instead, we recommend developing a separate principle on adopting data exchange technologies. See proposed new principle 9 below.

**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 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 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.
- 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 standard exchange of data from all, to all, honoring the personal preferences of individuals to opt out, after being presented with a balanced message of benefits and risks, 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 align with privacy and security statutes, regulations, or policies ~~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.
- We should facilitate health information exchange that is governed by data stewardship rules and fair information practices advanced by federal and state government.

**Commented [LK3]:** The rationale for this change is that although we absolutely agree with patient choice and preference, we believe opt out approaches should be leveraged, otherwise we will not have complete data to accomplish the vision laid out in this document.

**Commented [LK4]:** Alignment with existing rules should be referenced throughout this document. We should only establish new rules or policies insofar as existing rules do not address our priorities or are deemed inadequate.

**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-align with industry standards and 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 sensitive health and human service information.

**Commented [LK5]:** We suggest that instead of establishing policies, we align with CTEN and Cal DURSA which already have policies in use today.

**Commented [LK6]:** Existing privacy laws (e.g., HIPAA) that should be referenced in lieu of the language in this bullet.

**Principle 7: Adhere to Data Exchange Standards:** *We must 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 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), 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 [LK7]:** We recommend this be the first principle. Alignment with federal and state standards is critical.



**(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-align with existing industry standards and 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.

Principle 9: Technology. We shall support the adoption of technologies that enable real-time exchange of health information and build upon existing local or regional infrastructure that has proven value, and the State's role in breaking down real and perceived barriers.

**Commented [LK8]:** What does this mean? It does not seem to relate to the bullets below which are accountability around safeguarding and protection. This clause seems to speak to proving outcomes which is a different principle from accountability.

**Commented [LK9]:** These already exist through CTEN and DURSA. Suggest alignment.

**Commented [LK10]:** Bullets under Principle #2 acknowledge technology, however, there are no principles that speak to how information exchange should occur. While we understand that dictating the "how" is outside of the scope of AB 133, we believe there should be a principle that acknowledges the need for adoption of data exchange technologies.

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