

California Health & Human Services Agency Center for Data Insights and Innovation Data Exchange Framework Guiding Principles (v2v3)

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 develop and implement data exchange policies, processes and programs to better understand and address health inequities and disparities among all Californians. Advancing health equity requires filling disproportionate gaps in data completeness and quality for historically underserved and underrepresented populations and information sharing infrastructure capable of consolidating and curating individual demographic and health information.*

- 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 in alignment with federal standards and at an actionable level of disaggregation to identify gaps in care and health disparities and support quality improvement.
- We should design health and human service information collection, exchange, and use policies and programs to serve and meet the diverse needs of all Californians, 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 should prioritize the analysis of health and human service information to reduce health disparities among Californians and increase health equity.
- We must ensure health care and human service organizations ~~who serves~~ serve historically marginalized populations have the ~~opportunity~~ resources and support needed to participate in data collection, exchange, and use, and have for full and equal access to the ~~health~~ information they need to ~~support electronic health information exchange to~~ support the care of all Californians ~~patient health~~.

Principle 2: Make Data Available to Drive Decisions and Outcomes: *We must collect, exchange, and use actionable and timely information within and across health and human service sectors, to the greatest extent allowable by law, to: better understand and manage ~~the~~ health needs of and manage conditions at the level of the individual, within our communities, and across our populations; ~~and assess~~ the impact of our programs, operations, and payment arrangements so that we may identify opportunities and implement solutions new strategies*

that to improve quality, experience and outcomes of care and services and advance new payment models that support population health improvement and the delivery of value-based care.

- We must ~~use~~ ensure the tools we have are compatible with federal and state interoperability standards and used to exchange ~~patient~~ electronic health and human service information ~~when doing so has the potential~~ to benefit the consumer, to the greatest extent ~~and is~~ allowable by law.
- We must not treat ~~patient~~ an individual's data as a strategic or competitive asset that may be withheld to protect its value.
- We must practice data reciprocity and share ~~requested~~ patient ~~electronic health~~ information with individuals, and, other ~~their~~ health and human service organizations or their data intermediary proxies to support the collection, exchange, and use of data for ~~defined~~ all purposes allowable by law, including but not limited to treatment, payment, and health care operations, to the extent allowable by law and in accordance with individuals' preferences.
- We must work toward the comprehensive collection, exchange and use of human services data allowed by law, prioritizing consistent and comprehensive collection, exchange and use of clinical data that are more immediately accessible
- ~~We must advance meaningful health and human service data exchange as it is available, while we collectively work towards the robust system of exchange envisioned by AB-133.~~
- ~~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 or arrangements that can collect, exchange, provide access to, analyze, and use information necessary to advance the DxF's vision and goals and patient preferences.~~
- We must establish reasonable financial conditions, and incentives and value-based payment arrangements that foster and support data exchange, including the development of critical infrastructure required for it to occur.
- We must design, build invest in and maintain technology and data exchange arrangements that are compatible with interoperability standards and facilitate the timely bidirectional exchange of data for multiple patients ~~individuals~~ simultaneously based on a submitted or requested patient panel and cohorts of individuals, one-to-many individual record exchanges, and that support data linkage for individual records across multiple sources.
- We must work to ensure that health and human service care data managed by the state and local public agencies (e.g., CURES, CAIR, and CalREDIE) will be available to health and human service providers through seamless, bidirectional exchange, to the extent allowed by law.

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, to the greatest extent allowable by law and in alignment with federal- and state recognized standards.

- We must support the standardized collection exchange and use of demographic, clinical, administrative, behavioral health, social and environmental and social determinants of health (e.g., food insecurity, housing instability (SDOH)), and other health and human service data to identify individuals' whole person care needs and to facilitate connections with and collaboration among health ~~care~~ and human service organizations capable of addressing them.
- We should design and support programs and policies that support enable active engagement of ~~patients individuals~~, family members, and caregivers and enable the coordination of an individual patient's care amongst diverse health and human service providers and systems.
- We should ensure hHealth and human service information collection, exchange, and use should support whole person care goals and programs that identify and manage high risk individuals and population healths; improve transitions of care; track and report quality; improve health equity; and coordinate care and services.
- We should develop and implement data sharing arrangements and programs that facilitate the reliable collection, exchange, and use of patient health and human service data across organizations and sectors, to the greatest extent allowable by law.

Principle 4: Promote Patient Individual 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.*

- We should design and support policies and programs to ensure that all Californians ~~should~~ have ready and complete electronic access to their health and human service data, to the extent allowed by state and federal law, as well as relevant including access to tools and educational resources, in their primary ~~or preferred~~ languages, to make meaningful use of that 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.
- We must ensure the burden of health information exchange must not rest solely with ~~patients individuals~~.

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

- We must support and honor individual patient's' preferences regarding the collection, exchange, access, and use of their information, as informed by balanced messaging of its benefits and risks, and consistent with the services being provided and to the greatest extent permitted under federal and state law.

- 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 in alignment with federal and state law, 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 in alignment with federal and state law, that incorporate innovations that can enhance individual privacy and security and avoid or address new risks.
- We should establish policies, procedures and educational programs that clarify data sharing privacy requirements, ~~debunk misleading~~ provide accurate information about how data will be shared and used ~~claims about data sharing~~, and reduce overly burdensome ~~or restrictive~~ standards for under the pretext of compliance ~~with privacy laws or regulations as pretext for~~ not to restrict the exchanging health and human services information.
- We should facilitate health information exchange that is governed by federal and state data stewardship privacy and security rules ~~and fair information practices advanced by federal and state government~~.

Principle 6: Establish Clear & Transparent Terms and Conditions for Data Collection, Exchange, and Use: *We must conduct all exchange and operations openly and transparently, and 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 make terms, conditions, and data sharing agreements that govern the exchange of health and human services data easily and publicly available.~~
- We should establish policies that help individuals know understand what personal health and human services information exists about them, and learn how it may be exchanged and used, ~~accessed, exchanged and maintained~~.
- ~~The purposes for which personal health and human services data are collected, exchanged and used should be known or specified at the time they are acquired; only information that is reasonably necessary for specified purposes should be collected, exchanged, and used, as required by federal and state law.~~
- We should establish policies that, consistent with federal and state laws, ~~make it as easy~~ facilitate ~~for~~ individuals' ability to authorize the disclosure and use of sensitive health and human service 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 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, or industry 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 act as responsible stewards of individuals' health and human service information and should be held accountable for realizing the benefits of utility of this health information exchange for to benefit all Californians.*~~

- ~~• We should establish policies enforcing existing laws and legal requirements and that align with existing industry standards 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 legal protections of health information exchange for all Californians.~~
- ~~• We must ensure reasonable legal and financial remedies to address breaches or violations are available.~~