

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

*The CalHHS Data Exchange Framework (DxF) Guiding Principles will be core expectations or “rules of the road” that guide the design and implementation of the DxF and electronic health and human services information exchange in California; support the deliberations the Stakeholder Advisory Group and Data Sharing Agreement Subcommittee as well as the formulation of the DxF and Data Sharing Agreement, and Policies and Procedures; and build trust among data exchange partners. Principles were informed by the [CalHHS Guiding Principles](#), [Consumer and Patient Principles for Electronic HIE in California](#), and [Office of the National Coordinator’s Trusted Exchange Framework: Principles for Trusted Exchange](#) and developed to align with AB133 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 gaps in data completeness and quality for historically underserved and underrepresented populations and developing 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 that allows us 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, preferred languages, and health literacy levels.
- We should prioritize the analysis of health and human service information to reduce health disparities among Californians and increase health equity.
- We must ensure that health care and human service organizations serving historically marginalized populations have the resources and support needed to participate in data collection, exchange, and use, and have full and equal access to the information they need to support the care of all Californians.

**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 better understand and manage health needs and manage conditions at the level of the individual, within our communities, and across our populations; assess the impact of our programs, operations, and payment arrangements so that we may identify opportunities and implement new strategies 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 ensure that the tools we have are compatible with federal and state interoperability standards and are used to exchange electronic health and human service information to benefit the individual.
- We must not treat 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 electronic health information with individuals, their health and human service organizations, or their data exchange intermediaries to support the collection, exchange, and use of data for all appropriate purposes, including but not limited to treatment, payment, and health care operations, in accordance with law and an individual's 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 is more immediately accessible.
- We must establish reasonable financial conditions, incentives, and value-based payment arrangements that foster and support data exchange to advance individual and population health improvement efforts and value-based care.
- We must design, build, and maintain technology and data exchange arrangements that are compatible with interoperability standards and that facilitate the timely exchange of data for individuals and cohorts across multiple sources.
- We must work to ensure that health and human service data managed by state and local public agencies will be available to every Californian and the health and human service providers that serve them through seamless, bidirectional exchange.

**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, in alignment with federal and state standards.*

- We must support standardized collection, exchange, use, and integration of demographic, clinical, administrative, behavioral health, environmental and social determinants of health (e.g., food insecurity, housing instability), and other health

and human service data to identify individuals' whole person care needs and to facilitate connections with and collaboration among health and human service organizations capable of addressing them.

- We should design and support programs and policies that enable active engagement of individuals, family members, and caregivers and the coordination of an individual's care among diverse health and human service providers and systems.
- We should ensure that health and human service information collection, exchange, and use should support whole person care goals and programs that identify and manage population health; 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 health and human service data across organizations and sectors.

**Principle 4: Promote Individual Data Access.** *We must ensure that all Californians and their caregivers have access to their electronic health and human services information.*

- We should design and support policies and programs to ensure that all Californians have bidirectional electronic access to their health and human service data, including the ability to update errors in their longitudinal health information – to the extent allowed by state and federal law – and access to tools and educational resources, in their primary languages.
- 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 populations, and LGBTQIA communities, including addressing the digital divide to account for different needs such as limited digital literacy, limited language access, and limited access to technology.
- We must ensure that the burden of health information exchange does not rest solely with individuals.

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

- We must support and honor individuals' preferences regarding the collection, exchange, access, and use of their information, 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 that include privacy rights of minors and others who may not want sensitive health information shared, 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 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, provide accurate information about how data will be shared and used, and reduce overly burdensome standards under the pretext of compliance that restrict the exchange of health and human services information.
- We should facilitate health information exchange that is governed by federal and state data privacy and security rules.
- We should establish procedures for sharing electronic consent, if and where consent is needed, between entities exchanging health and human services data in compliance with state and federal data sharing rules.

**Principle 6: Establish Clear and Transparent Terms and Conditions for Data Collection, Exchange, and Use.** *We must 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 the purpose of data collection, exchange, and use.*

- 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 understand what personal health and human services information exists about them, and learn how it may be exchanged and used.
- We should establish policies that, consistent with federal and state laws, facilitate individuals' ability to authorize the disclosure and use of 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 information collection, exchange, and use that have been identified by CalHHS'

DxF, drawing from those adopted by the U.S. Department of Health and Human Services (HHS), the U.S. Office of the National Coordinator for HIT (ONC), the U.S. Office for Civil Rights (OCR), and other relevant federal agencies.

- Where federal, 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 goals.

**Principle 8: Ensure Accountability.** All entities participating in the collection, exchange, and use of health and human service information must act as responsible stewards of that information and be held accountable for any use or misuse of information other than for authorized purposes in accordance with state and federal law and California's Data Sharing Agreement and Data Exchange Framework policies.

- All entities participating in the collection, exchange, and use of health and human service information should promote and improve data sharing practices 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 should establish policies enforcing existing laws (e.g., HIPAA, federal information blocking rules) and legal requirements that align with industry standards and stakeholder best practices, and that hold all data sharing participants accountable for safeguarding the 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 accountable for enforcing legal protections of health information exchange for all Californians in accordance with state and federal law and California Data Exchange Framework and Data Sharing Agreement policies.
- We must ensure that reasonable legal and financial remedies are available to address breaches or violations.