California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework Guiding Principles (~~v3~~v4)

The CalHHS Data Exchange Framework (DxF) 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 and formulation of the Advisory Group's and its subcommittees' DxF and DxF Data Sharing Agreement recommendations; and, build trust among data exchange ~~partners~~stakeholders. 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 identifying and redressing disparities in health and health care ~~filling disproportionate gaps in data completeness and quality~~ for historically underserved and underrepresented populations, including filling disproportionate gaps in data completeness and quality for those populations and ensuring 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 allow~~s~~ 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 support and integrated 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 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 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~~ and use of 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 the greatest extent allowable by law, to: better understand and manage*

Commented [MS1]: More inclusive in ways important here.

Commented [MS2]: Much more than data gaps.

Commented [MS3]: "Data" is plural.

Commented [MS4]: I do not understand what this phrase intends to address. Normally, for proper health care and identifying disparities, one needs individual patient-level data (not aggregated). One needs to know the individual's precise disability status, race and ethnicity for CDS, sexual orientation and gender identity for proper care, etc. "Actionable level of disaggregation" suggests to me that there is some significant level of aggregation, which hides the individual-level data needed for proper, equitable care of the individual. True, providers, policymakers, researchers, etc., ALSO look at and make comparisons within aggregated, population-level data, but individual-level data are also essential. Not knowing more, I would delete this phrase. If this is some round-about reference to a deidentified database under HIPAA for population-level analysis of health disparities, then that is already covered by the preceding reference to "federal standards."

Commented [MS5]: I recommended this addition here in my last comment, but it was not included. I recommend it again. I appreciate the reference to SDOH in the principle below about whole-person care, but SDOH also have distinct, critical health equity components as well. I recommend including this fuller statement here, beyond the simple mention below under whole-person care.

health needs and manage conditions at the level of the individual, within our communities, and across our populations;~~,~~ to assess the impact of our programs, operations, and payment arrangements; and ~~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 used to exchange electronic health and human service information to benefit the consumer, to the greatest extent allowable by law.
- We must not treat an individual's data as a strategic or competitive asset that may be withheld to protect its value to the data holder.
- We must practice data reciprocity and share electronic health information with individuals, their health and human service organizations or their data intermediary proxies to support the collection, exchange, and use of data for 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~~health data that are more immediately accessible
- We must establish reasonable financial conditions, incentives and value-based payment arrangements that foster and support data exchange infrastructure required for it to occur.
- We must design, build and maintain technology and data exchange arrangements that are compatible with national interoperability standards and facilitate ~~the~~ timely exchange of data among all authorized users~~for individuals and cohorts across multiple sources~~.
- We must design and build health information exchange to integrate bidirectional and multidirectional exchange of health data~~work to ensure that health and human service data managed by state and local public agencies will be available to health and human service providers through seamless, bidirectional exchange~~, to the extent allowed by law, so that all authorized users can contribute as well as access and use health data as needed.

Commented [MS6]: Not just clinical data in the EHR, but health data from all important sources, e.g. CBOs, patients, public health, payers, etc.

Commented [MS7]: What's the "it"? Referent unclear.

Commented [MS8]: The need for bidirectional/multidirectional exchange covers far more than state and local public agencies, e.g. PGHD and PROs, payers sharing data with providers, CBOs sharing data with providers and payers, etc. Edited accordingly.

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 standards.*

- We must support the standardized collection, exchange, and use 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 amongst 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 and secure collection, exchange, and use of health and human service data across organizations and sectors, to the greatest extent allowable by law.

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 and their personalized, longitudinal health records.*

- We should design and support policies and programs to ensure that all Californians have ready electronic access to their health and human service data, to the extent allowed by state and federal law, including access to personalized, longitudinal health records, 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, and LGBTQI communities.
- ~~We must ensure the burden of health information exchange must not rest solely with individuals.~~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..
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Principle 5: Reinforce 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 individuals' preferences regarding the collection, exchange, access, and use of their health information, including~~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 that~~in~~ align~~ment~~ with federal and state law and~~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, provide accurate information about how data will be shared and used, and ~~reduce~~ prevent employing ~~overly~~ burdensome requirements and standards, under the pretext of compliance, to restrict authorized ~~the~~ exchange

Commented [MS9]: This principle should explicitly call out patients' access to their longitudinal health record. That is what the California Legislature did in AB 133: "patient access to personalized, longitudinal health records." AB 133 leverages national standards, and that is what Congress mandated in the 21st Century Cures Act: "offering patients access to their electronic health information in a single, longitudinal format that is easy to understand, secure, and may be updated automatically." This principle should be clear that it is not enough to expect patients to log into 5, 10, or 20 different portals for multiple providers, payers, human services, etc., and attempt to stitch it all together for a comprehensive snapshot and care coordination. California's patients should be able to use the state health information exchange for authorized access to their longitudinal health record, whole-person care, shared care planning, etc., just like providers, payers, public health, etc.

Commented [MS10]: Repeating a prior recommendation. As written, this bullet is satisfied if patients have almost all of the burden ("must not rest solely") and providers, payers, etc., have a little burden. I know that was not the intention, so I tried and try again to capture what I assume the draft sentence was intending? This articulates the expectation positively, not negatively, in terms of patient access and engagement for better care.

Commented [MS11]: The referent of "its" is unclear.

health and human services information.

- We should facilitate health information exchange that is governed by federal and state data privacy and security rules.

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 communicate clear policies and procedures so that all Californians and the organizations that serve them can understand the purposes and practices of data collection, exchange, and use.*

- We should make easily and publicly available the 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.
- 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, 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'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, 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.

Principle 8: 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~~ national 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.

Commented [MS12]: I still think that, as written, this does not capture what we mean. Trying a different suggestion.

Commented [MS13]: The why and the how.

Commented [MS14]: I think we should keep this from version 2 of the principles.

Commented [MS15]: Wholeheartedly agree that we should restore and keep this principle, not delete it. These principles are not just words: we mean what we say.

- 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 reasonable legal and financial remedies to address breaches or violations are available.