

Comments re: Data Exchange Framework Guiding Principles (V4)

- I appreciate CalHHS restoring Principle 8 related to accountability in this version. Consumers are placing great trust in health systems and other participating entities to use their data appropriately and the state should play an active role in overseeing the appropriate use of data, including taking any steps necessary to address instances of misuse of data.
- Principle 8 could be further strengthened by adding focus on ensuring that participating entities use the data available to them to further both individual health outcomes and population health. Line edits are provided below.
 - “All entities participating in the collection, exchange, and use of health and human service information must act as responsible stewards of that information, utilize available data to the fullest extent possible to further individual health outcomes and population health, 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.”
 - New suggested sub-bullet: “The state and all participating entities shall foster a culture of data use, including making training and technical assistance available on using data to improve individual and population health, establishing quality metrics that assess the extent to which providers are effectively using data, and holding participating entities accountable for utilizing demographic data to improve access to care (for example, using language data to arrange interpreter services).”
- Principle 4 should clearly state that individual data access must be bidirectional, enabling consumers to add patient-reported health information to the record and to correct errors made by participating entities. This principle should clarify that individuals should have access to their longitudinal health information. Finally, principle 4 should include a sub-bullet that reads:
 - “We must ensure that all barriers to consumer access are addressed and that all Californians have equitable access to their own health information. This includes addressing the digital divide and building consumer interface options that account for different needs such as limited digital literacy, language access, and limited access to technology.”
- I suggest clarifying that Principle 1, Advance Health Equity, should not be presumed to be the totality of health equity considerations. Rather, health equity must be addressed in each of the following principles and in every aspect of the data exchange framework.

Comments re: Gaps and Opportunities Slide Deck

- As mentioned in the meeting, it is striking that the currently considered gaps and opportunities related to technical infrastructure do not include any consumer-facing issues. In order to meaningfully advance health

equity and ensure that consumers can be active participants in their own healthcare, the discussion must include consideration of the technical infrastructure gaps for consumers. To remedy this, I suggest an additional gaps, with corresponding opportunities, be added to the list:

- Universally accessible consumer interface options:
 - Build consumer interface options that account for limited literacy and limited digital literacy, language preferences, and technological limitations.
 - Provide capacity building support and supplementary funding to health navigators, community health workers, and other support professionals with the capability to provide training and assistance to consumers in order to ensure access their health information.
 - Expand the Emergency Broadband Benefit (EBB) Program via California LifeLine to ensure that all Californians have access to phone service and broadband sufficient to access, and engage with, their own health records.