



California's Health Data Sharing Needs Strong Oversight to Benefit Consumers

California's health care system is highly fragmented, presenting myriad challenges for health care consumers. At the same time, the health care delivery system operates separately from human services and public health systems. As a result, health data is siloed and often not available to address either individual health concerns or population health.

When health data is held independently and not shared among medical and other providers, it is difficult to provide high quality, linguistically and culturally responsive, person-centered care. Currently, individuals bear the burden of reporting their own health information from provider to provider, and ensuring that their health history, prescriptions, allergies and medical conditions are known to various medical providers. In addition, health data is not shared with public health systems, which proved catastrophic during the COVID-19 pandemic when, for example, it was nearly impossible to ensure that early vaccines reached those at the greatest risk.

Consumer health data should be available to improve the health of consumers and of communities.

This is why we support California's Data Exchange Framework, which requires all health plans, hospitals, physicians, clinics, and other health care providers to have the capability to share (through electronic health record systems) data about their members/patients. Not only does the Data Exchange Framework have the potential to improve the health of all Californians, it is also critical for advancing health equity. With the Data Exchange Framework, providers will have access to information that enables them to tailor individual clinical care to be culturally and linguistically responsive. In addition, the Data Exchange Framework will enable the sharing of demographic data, including disaggregated race and ethnicity data as well as language, sexual orientation, and gender identity data, in order to advance population health and health equity.

Consumers must be able to trust that their health information is being shared safely and securely, and for the benefit of their health.

For that reason, we urge the creation in state statute of a strong, accountable, independent, public governing entity for California's health data sharing infrastructure, including the Data Exchange Framework. In order for consumers to put their trust into health data sharing, there must be a transparent, public entity that is free of conflicts of interest, includes consumer representation and guarantees ongoing opportunities for consumer voice and input, is reflective of the diversity of Californians, and has the authority to issue and enforce rules that ensure data sharing is done with appropriate safeguards and with the express goal of ensuring public health and safety and improving health outcomes for all Californians.

Health data sharing is imperative to advance health equity, and requires transparent and accountable oversight.