



CALIFORNIA'S HEALTH DATA EXCHANGE FRAMEWORK: ADVANCING HEALTH EQUITY

Beginning in January 2024, all health plans, hospitals, physicians, clinics, and other health care providers throughout California will be required to have the capability to share (through electronic health record systems) demographic and other data about their members/patients. All individual data will continue to be protected by privacy and confidentiality laws as "personal health information" that can only be accessed and used by the individual and their health care providers.

SHARING DEMOGRAPHIC DATA

Historically, the collection of demographic data has been limited and inconsistent, and challenges persist today. Being able to access member/patient demographic and social needs data can help ensure culturally and linguistically appropriate health care services, and can assist health plans, hospitals, providers, researchers, policymakers, and community advocates identify health care disparities and inequities, and make the case for increased attention and resources to reduce those disparities.

Demographic Data:

Race, ethnicity, language, and other socio-demographic variables that are used to address disparities in health outcomes due to systemic racism, discrimination, and exclusion.

Under the Data Exchange Framework, health care providers will be required to share information using standardized categories.

Data about health-related social needs (food and housing insecurity, transportation needs, etc.) also may be collected and shared. In the future, it is expected that data about a member/patient's disability status, tribal affiliation, and other characteristics will be required to be shared.

A major benefit of this data is that health care providers will be able to tailor their care appropriately to the patient. For example, a health care provider who knows in advance that their patient's preferred language is Tagalog can arrange for a trained medical interpreter to be present at the appointment.

DATA EXCHANGE FRAMEWORK DEMOGRAPHIC DATA CATEGORIES

Race and Ethnicity	Preferred Language	Sex Assigned at Birth	Gender Identity	Sexual Orientation
900 disaggregated race and ethnicity options, e.g. Chinese, Vietnamese, Korean, etc. rather than Asian	Hundreds of spoken languages, and American Sign Language	<ul style="list-style-type: none"> • Male • Female • Unknown 	<ul style="list-style-type: none"> • Transgender male/trans man • Transgender female/trans woman • Genderqueer, neither exclusively male or female • Additional gender category, or other • Choose not to disclose 	<ul style="list-style-type: none"> • Straight, or heterosexual • Lesbian, gay, or homosexual • Bisexual • Something else • Don't know • Choose not to disclose

Aggregated data will be available to researchers in order to advance the understanding of health disparities. Additionally, with more entities collecting robust demographic data, and doing so with standardized categories, there is an opportunity for governmental agencies to further their equity programs. For example, if state health insurance regulators, under their own authority, require health plans to submit quality and equity data, the health plans will be better positioned to access and provide more complete demographic data that can be compared and analyzed.

SHARING HEALTH INFORMATION

People of color are least likely to have a usual source of health care, such as a personal doctor. Without providers exchanging health information, patients must bear the responsibility of keeping track of their health information and carrying it from provider to provider. Under the Data Exchange Framework, health information will be exchanged directly between providers. For example, if a patient is referred to a specialist (cardiologist) for a heart condition, the cardiologist would be able to access that patient's medical history (what diseases and health conditions they currently have) and medications currently prescribed from that patient's primary care physician's electronic health record. Eventually, data may also be collected by and shared with social services and other providers to better address the social drivers of health such as housing, food, transportation needs.

EMPOWERING ALL CALIFORNIANS

The Data Exchange Framework also requires patients to provide informed consent for the sharing of their personal information, have access to their own health records, and to be able to correct inaccuracies or add self-reported health data. Engagement in one's own health is a key determinant of health outcomes.

References

- <https://www.chhs.ca.gov/data-exchange-framework/>
- https://www.chhs.ca.gov/wp-content/uploads/2022/07/Executive-Summary_DxF_7.1.22.pdf
- <https://cpehn.org/publications/california-needs-standards-for-demographic-and-social-needs-data-to-reduce-disparities-and-advance-health-equity/>

USE CASES

How can California state agencies and departments leverage the Data Exchange Framework demographic data sharing requirements to advance health equity?



In implementing Assembly Bill 1204, the California Department of Health Care and Information will be finalizing a list of hospital quality measures that all California hospitals will be required to report, stratified by demographic data, beginning in 2025. The Data Exchange Framework demographic data sharing requirements provide potential standards for hospitals to stratify their performance on the hospital quality measures by race, ethnicity, preferred language, sex assigned at birth, gender identity, and sexual orientation.

A historic lack of investment in California's public health systems has resulted in technological stagnation including an overreliance on antiquated communication methods such as fax and phone to transmit important health data. California's Data Exchange Framework will improve the sharing of health information across medical, behavioral, public, and social services systems to prevent the further spread of communicable diseases like COVID-19.



The Department of Health Care Services (DHCS) and Covered California are tying payment to the achievement of year-over-year health equity goals including a reduction of disparities in well-child visits and immunizations, maternity care, maternal and adolescent depression screening, mental health and substance use disorder, and children's preventative care measures. The Framework's demographic data sharing requirements provide potential standards for health plans to stratify their performance data in order to improve health care quality and reduce disparities in these priority areas.

In implementing Assembly Bill 133, the California Department of Managed Health Care will be finalizing a list of health plan quality measures that all California health plans will be required to report, stratified by demographic data, beginning in 2024. The Data Exchange Framework demographic data sharing requirements provide potential standards for the stratification of their performance on health plan quality measures by race, ethnicity, preferred language, sex assigned at birth, gender identity, and sexual orientation.

