



California Pan-Ethnic
HEALTH NETWORK



June 2, 2022

Submitted via email: CDII@chhs.ca.gov

RE: Data Exchange Framework Comments

Dear Secretary Ghaly,

Thank you for the opportunity to serve as members of the Data Exchange Framework Stakeholder Advisory Group, and to serve as a voice for diverse consumers in this process. The California Pan-Ethnic Health Network (CPEHN) and Health Access are strongly supportive of the development and implementation of a statewide health information exchange, and are grateful for the thoughtful, inclusive process conducted by CalHHS.

Importance of a Data Exchange Framework

The Data Exchange Framework (DxF) is a critical opportunity to advance health equity, empower consumers to have optimal health outcomes, and provide whole person and integrated health care.

The current patchwork system of data collection, sharing, and use is detrimental to advancing the central goal of improving the health of Californians. The holders of health data must be given both the tools and the responsibility to share data, in accordance with the needs and preferences of their patients.

Over the course of the COVID-19 pandemic, the importance of strengthening our state's crumbling data infrastructure became all the more evident. Communities of color continue to suffer the most severe impacts of the pandemic as a result of poor access to primary and preventive care, prevalence of chronic health conditions, and insufficient ability to address the social determinants of health. Health care delivery systems, social services, and public health departments have been unable to coordinate and collaborate to the extent needed. The deep health inequities that drove these devastating consequences could have been prevented with greater access and integration of health care and social services in vulnerable communities.

The DxF is an opportunity to ensure that we are better prepared in the future to address public health emergencies, but also that we have the tools needed to drive meaningful advances in health equity. California simply cannot afford to wait any longer to embrace this transformational innovation.

Governance

Our organizations strongly support the proposed governance structure, including the creation of a Health Information Exchange Policy Board with specified functions. Increased sharing of health data has tremendous potential to improve care and outcomes. Advancing data sharing requires the trust of the consumers whose personal health data is being shared and exchanged. The system must be set up to foster trust, which includes being transparent, accountable, and accessible to the public. The Policy Board should be comprised of those who are free from any conflicts of interest, possess expertise related to health equity, health quality, data privacy, and are fully able to commit to participation.



We urge the state to establish the Policy Board as soon as possible, balancing the importance of a thorough, thoughtful and transparent creation process that may take time.

Finally, we recommend the addition of “Consumer Engagement and Inclusion” as a governance function. The Policy Board should be tasked with proactively seeking, evaluating, and incorporating the input of consumers regarding the function of data exchange in California.

Data Sharing Agreement

We recommend that the data sharing agreement, or associated policies and procedures, be revised to fully incorporate the DxF guiding principles, particularly 1 (Advance Health Equity), 4 (Promote Individual Data Access), 5 (Reinforce Individual Data Privacy and Security), and 8 (Ensure Accountability). While we understand that the agreement is for entities that will be exchanging data, it should lay out standards which fully reflect the purpose of the data exchange framework: to improve the health of Californians. We recommend that the data sharing agreement be revised in order to accomplish the following:

1. Ensure that participants are required to utilize the data standards that best advance health equity:

The first Guiding Principle in the Framework is to "advance health equity", defined as: "*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 creating information-sharing infrastructure capable of consolidating and curating individual demographic and health information.*"¹

Fortunately, there are federal standards for comprehensive demographic and social needs data that can be incorporated into the Framework. The federal Office of National Coordinator for Health IT U.S. Core Data for Interoperability (USCDI) Version 1 (adopted July 2020) include race, ethnicity, and language data, with comprehensive granularity/disaggregated categories.² USCDI Version 2 (adopted July 2021) add sexual orientation and gender identity and social determinants of health data.³ And the pending USCDI Version 3 (to be finalized July 2022) will add tribal affiliation, disability, functional status, and mental status data.⁴

The Framework should fully adopt these federal standards, through USCDI Version 3, immediately rather than phasing or delaying any implementation.

Some note that these federal data standards have yet to be fully implemented by EHR vendors, and these data have yet to be collected by California hospitals and providers using EHRs. However, these standards have existed for many years, even if they are only more recently being incorporated into the USCDI

¹ https://www.chhs.ca.gov/wp-content/uploads/2022/02/CalHHS-DxF-Guiding-Principles_Final.pdf

² https://www.healthit.gov/isa/sites/isa/files/2020-10/USCDI-Version-1-July-2020-Errata-Final_0.pdf

³ <https://www.healthit.gov/isa/sites/isa/files/2021-07/USCDI-Version-2-July-2021-Final.pdf>

⁴ <https://www.healthit.gov/isa/sites/isa/files/2022-01/Draft-USCDI-Version-3-January-2022-Final.pdf>



standards. And one the primary purposes of the Framework is to move all data collectors toward collecting and exchanging standardized data, including data that have not been collected or exchanged.

Finally, there are both legislative mandates and voluntary administrative efforts by California health care departments and agencies to identify - and work to reduce disparities - based on sexual orientation, gender identity, and disability in addition to disparities based on race, ethnicity, and language. For example, AB 133's charge to DMHC is to address health equity across all these dimensions through quality and equity measures for managed care plans. Similarly, AB 1204's charge to HCAI is to address "vulnerable populations" including people with disabilities and people identifying as LGBTQ through hospital equity reports. By requiring comprehensive demographic and social needs data, the Framework can help support standardization and exchange of these demographic and social needs data and alignment of these efforts to improve quality, and identify and reduce disparities.

This comment also applies to the draft policy and procedure on "data elements to be exchanged".

2. Provide for bidirectional consumer data access:

The fourth guiding principle in the Framework is to "promote individual data access", including "*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.*"

Numerous bodies of research clearly demonstrate that the more consumers understand and are involved in their own health care and health decisions, the more positive their health outcomes will be. For that reason, the Framework appropriately views the consumer not as a passive recipient of care, but as an active participant in their own health care.

We strongly recommend that CalHHS formalize the standard of bidirectional consumer access either through the data sharing agreement or through another implementation mechanism. This requirement could exist either on individual participating entities or through the use of intermediary, consumer facing technology.

- a) **Consumer/patient access and use of one's longitudinal health record:** Consumers should have access to their longitudinal health information across providers. Consumers must be provided with education and support to engage in their own health care, including shared care planning and coordination for long-term and post-acute care through use of the data sharing.
- b) **Bi-directional consumer access:** Allowing consumers, as well as authorized family members and caregivers within appropriate confidentiality constraints, to view their electronic health record is necessary, but not sufficient. Consumers must also be able to add self-reported health information and correct inaccurate information, with a process of reconciling discrepancies in the record to ensure accuracy. Indeed, *multi*-directional access is needed, as we also integrate community and social service organizations which, along with patients and family caregivers, can contribute critical data and care missing from current clinical care.



- c) **Fully accessible technology:** Consumer health data must be fully accessible for all Californians, including language access and readability, disability access, and access for those Californians who have limited access to technology or broadband. Digital divides and limited access or inferior platforms for many Californians are not acceptable. Attention to health literacy and health IT literacy is also critical.

This comment also applies to the draft policy and procedure on “individual access services”.

3. Ensure data privacy and security by improving informed consent:

The fifth guiding principle in the Framework is to “reinforce individual data privacy and security”, which means “*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.*”

In order for data exchange to meet the intended goals, the trust of consumers is central. Consumers may have questions about increased data exchange, and may not have full information about the potential for data exchange to assist in improving health outcomes. In fact, a recently published study showed that those consumers with the greatest social needs are the most wary of having social determinants information included in medical records.⁵ Reasons included concern about privacy as well as minimal confidence that the health care system would be able to use the information to help. The best way to engender trust is to actively engage consumers and ensure robust education.

The data sharing agreement should include a responsibility for providers to proactively educate their patients about the benefits of data sharing and patients’ rights. The state should provide tools, resources, and technical assistance to facilitate this, including messaging about benefits of information sharing, tools for obtaining informed consent, and an independent ombudsperson to assist consumers with additional questions or concerns.

In light of expected changes in rights to gender, sexual, and reproductive health care nationally, the data sharing agreement also must carefully consider and limit sharing of related information and with providers outside of California.

This comment also applies to the draft policy and procedure on “privacy standards and security safeguards”.

4. Establish an enforcement scheme to guarantee accountability:

The final guiding principle in the Framework is to “ensure accountability”, which means that “*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*”

⁵ <https://assets.researchsquare.com/files/rs-1597212/v1/1fe59b5d-db8b-4d6e-8d53-fec1ad5b582e.pdf?c=1652802053>



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other than for authorized purposes in accordance with state and federal law and California's Data Sharing Agreement and Data Exchange Framework policies."

While AB 133 does not establish enforcement mechanisms, **CalHHS and the Health Information Exchange Policy Board must be empowered by statute to ensure participation in the data sharing agreement and to hold participants responsible for complying with data exchange standards.** Clear and robust enforcement mechanisms are essential for consumers to trust the framework. Without enforcement authority, it is not clear that consumers can have confidence in the standards outlined by the DxF. In addition, we currently have disparate authority over health data which creates a complex maze of accountability. The Health Information Exchange Policy Board is an important opportunity to align both expectations and accountability in order to reduce burden and advance the shared goal of using data to improve the health Californians.

Additional Policies and Procedures

We would like to ensure that the policies and procedures allow for full and open public input on future deliberations related to the data exchange framework and data sharing agreement. As drafted, the policies and procedures related to amending the data sharing agreement and modifying policies and procedures allow only for framework participants to engage in the process. We recommend that both of these be modified to guarantee transparent processes that require consumer input and allow for public engagement on an equal footing as data exchange participants.

Thank you for your consideration of these comments. Please contact ksavage@cpehn.org with any questions or to discuss.

Sincerely,

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