

Challenges, Impacts, and Policy Options for a 21st Century Health System

Assembly Health Committee Hearing

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Access to timely and complete electronic physical, behavioral health and social service information is limited. Without it, California's pandemic, emergency response, and health care policy and program needs and priorities cannot be met.

The pandemic laid bare the reality that the lives and wellbeing of every Californian are jeopardized by our inability to safely and securely share information. Three critical data exchange issues need to be resolved:

- **Clinical data fragmentation:** There is incomplete provider participation in regional and national HIE activities, with many rural and underserved communities not supported by data exchange initiatives.
- **Exclusion of exchange sectors:** Payers, purchasers, public health, social service, behavioral health, and in most cases, emergency response providers and agencies can't participate in most HIE activities that were designed primarily to exchange physical health data.
- **Complex and onerous data exchange rules and regulations.** Restrictive, ambiguous and misaligned state and federal laws result in many organizations electing not to participate in data exchange activities.

The Impact of California's Deficient HIE Ecosystem

Four scenarios help illustrate the human toll of our limited HIE infrastructure, which have been particularly devastating to our African American, Latinx and Native American communities



Disaster Response

Wildfires have displaced hundreds of thousands of residents. Without capabilities to share data, emergency response, health and social service providers have incomplete information about patient needs, and limited means to electronically share what they know.



Pandemic Response

Public health institutions can't access real time lab, ICU, ventilator, vaccine, and other information needed to rapidly mobilize responses. Without it, they can't link records and direct physical, behavioral and social service resources to the people and institutions that need them most.



Serving Patients with Complex Needs.

Patients with complex needs often have chronic medical, behavioral and social needs; the network of providers serving them have no way of sharing vital information to treat the whole person, resulting in uncoordinated care, increased morbidity and mortality.



Quality Reporting and Value-Based Care

Payers, health plans and their members don't have complete access to health information, preventing identification of high-quality providers, developing value-based care programs, and limiting consumer empowerment to make informed decisions.

The scenarios evoke a complex set of HIE challenges and highlight significant gaps in California's information exchange capabilities that have serious implications for our residents, the providers who care for them, and the public and private agencies who cover and support them.

Stakeholder interviews and extensive research suggest that comprehensive statewide HIE is best supported when a range of policy, contracting, and financing levers are used together to advance data exchange; specifically that states with more robust HIE have:

- ✓ Established strong leadership structures within government to guide policy and program actions, address HIE gaps and overcome barriers;
- ✓ Created HIE advisory bodies to guide priorities, policies, and programs;
- ✓ Enacted new laws and promulgated rules to encourage or require HIE;
- ✓ Established HIE contracting provisions in public purchasing programs;
- ✓ Directed state investment in technology, services and training.
- ✓ Prioritized a set of HIE activities or “use cases” driven by and linked to the above actions

Options to Align Leadership across State Purchasing, Regulatory, Health and Social Service Agencies

- 1. Establish an Office and Advisory Board within state government charged with advancing HIE through alignment of financing, contracting and policy levers across state agencies.**
 - ✓ The Office could be charged with establishing the state's vision, goals and priorities for advancing health information exchange.
 - ✓ The Office could be endowed with rulemaking authority that aligns regulatory, contracting, licensing and financing levers available to state government agencies to advance HIE.
 - ✓ It could also be charged with developing recommendations to harmonize state law that conflicts with federal law, and to develop clear HIE guidance and technical assistance to state agencies and stakeholders.*
 - ✓ It could be guided by a multi-stakeholder Health Information Exchange Advisory Board with state and county agencies, physical, behavioral, social service providers, consumers and others to develop recommendations.

*This could build upon existing efforts initiative by the California Health & Human Services Agency to develop the State Health Information Guidance (SHIG), and the CalDURSA a set of standardized data sharing and use agreement documents.

Options to Address Clinical Data Fragmentation

2. Establish statewide health information exchange requirements, incentives and penalties to encourage broad HIE participation by health plans and providers in health care, social service, emergency response and public health programs.

- ✓ Enact new law requiring hospitals, providers and health plans to participate in health information exchange activities that meet specified state health care, public health social service and emergency response goals.

Requirements could be designed by the new Office with input from its Advisory Board that align with and reinforce federal rules established under the 21st Century Cures Act and elsewhere.

Evidence from other states suggest that mandates on their own are insufficient; they should be coupled with:

- ✓ Purchaser contracting and incentive requirements and programs to stimulate HIE participation.
- ✓ Incorporation of HIE measures into quality collaborative programs, such as the Integrated Healthcare Association's "Align. Measure. Perform" program.

Options to Address Exclusion of Exchange Sectors

3. *Establish financing programs that support statewide physical, behavioral and social service data exchange*

- ✓ Establish financing programs to help other physical, behavioral health and social service providers implement information technology that supports secure data sharing with providers, payers, consumers and government agencies (e.g., public health).
- ✓ Direct the new Office and its Advisory Board to identify financing streams and align program requirements to maximize their impact.

4. *Upgrade California's public health and emergency response information exchange infrastructure*

- ✓ Leverage and supplement federal funding (e.g., from the Centers of Disease Control and Prevention), with state resources to upgrade state and county surveillance, reporting and emergency response systems.
- ✓ Incentivize providers to share patient information with emergency response, public health and syndromic surveillance systems.
- ✓ Provide funding to train public health workforce on the use of the required infrastructure.

Options to Overcome Complex and Onerous Data Exchange Rules and Regulations

5. *Harmonizes state privacy rules and regulations with federal law.*

- ✓ Enact law based on recommendations made by the new Office and its Advisory Board to identify conflicting and ambiguous state health information privacy and security rules, and update California Health & Safety code to harmonize it with federal law.

6. *Establish statewide, universal consent policies.*

- ✓ Define requirements for a statewide universal informed consent model and set of standard consent authorization forms.
- ✓ Use contracting and licensing levers at the disposal of state and county agencies and private purchasers to incentivize and require consent policy use by health plan, provider and other contractors and licensed entities.
- ✓ Require participation in the California Trusted Exchange Network (CTEN) to support exchange between California HIOs and national networks and adopt the CalDURSA data sharing agreement as part of a broader set of data sharing and consent policies.

Thank you
