HIE and Public Health Webinar Session 2: Data Sharing to Promote Health Equity

April 28, 2021

EXECUTIVE SUMMARY

On April 28, 2021, Cal-IHEA and Connecting for Better Health convened a panel of experts for an interactive discussion on data sharing to advance health equity. The session highlighted the need for a statewide Health Information Exchange (HIE) in California to facilitate data exchange to improve care coordination and respond to public health emergencies. By securely collecting and sharing data related to race, ethnicity, and language, interventions can target vulnerable communities to effectively address health disparities.

Julia Adler-Milstein (UCSF), Alice Chen (Covered California), and Rhonda Smith (California Black Health Network) joined moderator Hector Rodriguez (Cal-IHEA) to discuss how a statewide HIE can improve health equity by leveraging race and ethnicity data. The panel also discussed the importance of establishing trust, and offered insights on how policy can support sustainable interoperability and data exchange.

The briefing is the second of a three part series on HIE and Public Health, and is co-hosted by Cal-IHEA and the Connecting for Better Health Coalition. Watch the webinar recording here.

Hector Rodriguez

> *"The national landscape suggests that California hospitals and other states with vulnerable populations are being hurt because of the lack of health information exchange."*

Hector Rodriguez, Faculty Director of Cal-IHEA, opened the webinar by highlighting how safety net hospitals caring for high risk populations are disproportionately affected by the lack of data exchange. Under CMS readmission reduction programs, safety nets are more likely to receive financial penalties for excessive hospital readmissions. Interoperable data exchange would reduce penalties and simultaneously promote care coordination for improved health outcomes among vulnerable communities. Federally qualified health centers (FQHCs) and safety net outpatient clinics are less likely to have connections to their main hospital, which exacerbates missed opportunities for coordinated care.

Alice Chen

> *"The data initially showed the case rates were lower in communities of color. We knew immediately that was because of disparities and access to testing. As the pandemic progressed, it became very clear that COVID-19 was going to be defined by disparities."*

Dr. Alice Chen, Chief Medical Officer for Covered California, reflected on how a statewide HIE could have been leveraged during the COVID-19 pandemic to address the needs of vulnerable populations. Dr. Chen was previously the Deputy Secretary for Policy and Planning at the California Health and Human Services Agency, and helped lead the state's response to the pandemic. For the first six months, data was very sparse and getting timely and accurate data on testing volume, cases, and hospitalizations became the focus. Despite mandates to collect race and ethnicity data, most tests and cases did not have this information associated. Instead, the state leveraged zip code data and the Healthy Places Index (HPI) to develop the COVID-19 health equity metric. Under California's Blueprint for a Safer Economy, this marker for equity informs whether a county can move to a less restrictive tier. Specifically, the positivity rate in certain neighborhoods must not be substantively different from the county. In order to progress to a less restrictive tier, counties must target and dedicate a proportion of funding to interrupt disease transmission among disproportionately impacted populations. Dr. Chen called for a statewide initiative to improve the quality, completeness, and accuracy of race and ethnicity data in order to address equity through policy.

Rhonda Smith

> *"Decreasing health disparities really takes a village. It takes payers, patients, providers, policy, the public, and partners in this process – to begin to dismantle the barriers and all the issues that create the complex system of health disparities. We all have a role to play in advancing health equity for every California community, and there's no time like the present to get started."*

Rhonda Smith, Executive Director of the California Black Health Network (CBHN), spoke about The Campaign for Black Health Equity, a multi-year effort to mitigate the inequities that significantly impacts the lives and well-being of African Americans and Black Immigrants in California. Having access to patient data through a statewide HIE would advance the campaign's goals of decreasing health disparities and improving life expectancy among Black Californians, which has been exacerbated by the COVID-19 pandemic. Rhonda referenced a testimonial provided by Dr. Hakeem Adeniyi, a family and community medicine physician in Sacramento who repeatedly requested records for a patient with a recent stroke. The process took 3-4 months, which unnecessarily delayed patient care and caused the patient to endure additional pain. Rhonda emphasized that data exchange is a critical component for breaking down barriers to achieve more equitable and timely care, especially among underserved communities and communities of color.

Julia Adler-Milstein

> *"Health Information Exchange is moving data to where it needs to be, and aggregating it in ways that are useful to different types of decision makers. We now understand with excruciating detail not just the type of data we need—but how the data needs to be connected to provide insights into the equity challenges."*

Dr. Julia Adler-Milstein, Professor at UCSF and leading researcher in health IT policy, discussed how identifying which problem the HIE intends to solve is equally important to the development of the HIE itself. By starting with clear use cases and determining what data is relevant and necessary to solve the identified problem, HIE can then serve as the mechanism to solve the identified problem. The challenge is figuring out where the data exists, and then making sure the information is securely shared to relevant decision makers at the appropriate time. From there, decision makers can allocate resources accordingly and make informed decisions to improve access and equity. Dr. Adler-Milstein highlighted the uneven implementation of interoperability exacerbated the existing differences in capability among better resourced systems and less resourced systems. The COVID-19 pandemic demonstrated the need for interoperability and presents a rare and important policy window to leverage existing HIE infrastructure and advance health equity. Dr. Adler-Milstein noted the ONC's STAR HIE Program, an initiative to improve HIE capabilities among public health agencies in five participating states. These may serve as important examples for California to understand the learnings and model success stories. Dr. Adler-Milstein closed by emphasizing the starting point should be identifying the broad problem needing to be solved, followed by determining what data is needed to inform these decisions, and then considering how a statewide HIE can solve the identified problem.

POLICY RECOMMENDATIONS

The panel discussion offered policy recommendations for California in its pursuit of building a statewide health information exchange network.

- **Offer strong incentives conditional on the adherence of data standards.**
  Provide organizations with incentives for implementing and sustaining day-to-day integration of data exchange. Incentives should be tied to data standards to ensure data exchanged is clean and machine-readable for seamless interoperability.
- **Collect, locate, and aggregate data.**
  Race, ethnicity, and language data can provide valuable insights on equity challenges. Collect race, ethnicity, and language data that is standardized yet tailored to California's diversity without losing granularity and specificity. Aggregate data in ways that are useful to different types of decision makers.
- **Establish state leadership.**
  A strong governance structure can adjudicate potential conflicts and challenges among competitors. States with robust data exchange networks have strong leadership and direction from the state.

QUESTION AND ANSWER

How might the pathway look for building a statewide HIE to advance health equity?

Dr. Alice Chen: We need to build on what we have and learn from regional successes. The digital divide exists among health systems, in addition to the individual level, and targeted investment in the safety net would improve capabilities to share data and care for the most vulnerable communities.

Dr. Julia Adler-Milstein: After figuring out which problem to solve first, stakeholders need to come together and agree to collaborate. Strong incentives are necessary for engaging organizations, especially when dollars are left on the table due to inaction.

How might we build and improve patient trust in data sharing?

Dr. Julia Adler-Milstein: By demonstrating how data sharing provides value, patients can better understand the benefits and be more willing to share data. Ensuring the privacy and security of data is also important for gaining trust.

How might we improve federal and state alignment for HIE?

Dr. Julia Adler-Milstein: While it is important to coordinate and align at federal level, there's opportunity for the state to move above the common floor by aligning momentum to address particular use cases. Looking to the STAR HIE Program and learning about additional use cases, in addition to public health needs, can inform California's prioritized use cases.

What is our call to action in improving California race and ethnicity data collection and reporting?

Dr. Alice Chen: Race and ethnicity data should be collected in a way that is standardized yet tailored to California's diversity without losing granularity and specificity.

Rhonda Smith: It is important to build awareness among communities to promote trust for sharing information and demonstrate how this data is being used.

Dr. Julia Adler-Milstein: Trust, standards, incentives—and making sure incentives adhere to the standards for sustainable day-to-day integration.

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