

**California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework Stakeholder Advisory Group**

**Meeting Summary (v1)
Tuesday, August 31, 2021, 9:30 a.m. to 12:00 p.m.**

Attendance

Stakeholder Advisory Group Members¹ in attendance: Chair Mark Ghaly, Jamie Almanza, Ashrith Amarnath, Palav Babaria, Charles Bacchi, William Barcellona, Nancy Bargmann, Mark Beckley, Joseph Bick, Andrew Bindman, Michelle Doty Cabrera, Carla Castaneda, Scott Christman, Craig Cornett, David Cowling, Carmela Coyle, Kayte Fisher, David Ford, Scott Fujimoto, Liz Gibboney, Michelle Gibbons, Lori Hack, Alma Hernández, Sandra Hernández, Linnea Koopmans, David Lindeman, Julia Logan, Carolyn Kubish, Cheryl Larson, Paul Markovich, DeeAnne McCallin, Dana E. Moore, Erica Murray, Nathan Nau, Heather Readhead, Daniel Rodda, Cary Sanders, Mark Savage, Linette Scott, Cathy Senderling-McDonald, Dan Southard, Diana Toche, Michael Valle, Claudia Williams, Leslie Witten-Rood, Anthony E. Wright, William York.

Stakeholder Advisory Group Staff and Presenters in attendance: Rim Cothren (Independent HIE Consultant to CDII), Jared Goldman (CHHS), Jonah Frohlich (Manatt Health Strategies), Kevin McAvey (Manatt Health Strategies), John Ohanian (CHHS/CDII), Elaine Scordakis (CHHS/CalOHII).

Public in attendance: approximately 242 public attendees joined this meeting via Zoom video conference or through call-in functionality.

Meeting Notes

Meeting notes elevate points made by presenters, Stakeholder Advisory Group Members, and public commenters during the August convening of the Data Exchange Framework (DxF) Stakeholder Advisory Group meeting. Notes may be revised to reflect public comment received in advance of the second Stakeholder Advisory Group meeting. Meeting materials and a full video recording and transcription of the meeting and its public comments may be found at: <https://www.chhs.ca.gov/data-exchange-framework/>.

Welcome and Introductions

John Ohanian, Chief Data Officer, California Health and Human Services welcomed attendees to the inaugural meeting of the CHHS Stakeholder Advisory Group. Stakeholder Advisory Group Members were named and introduced via a roll call. CHHS government departments participating as part of the Advisory Group were also named.

¹ May include interim delegates. Final Advisory Group roster, including permanent delegates will be finalized by the second Stakeholder Advisory Group.

Public Comment

John Ohanian opened the meeting to receive public comment, which included:²

- Marty Omoto, Executive Director of California Disability Community Action Network (CDCAN) voiced support for the establishment of the Stakeholder Advisory Group and appreciation for the represented voices and perspectives.
- Hector Ramirez, a resident of Los Angeles County, noted the importance of learning from the past in order to move toward more equitable health services for diverse populations.
- Troy Kaji, a physician practicing in Contra Costa County, asked the Stakeholder Advisory Group to consider data access issues for those working in the field of corrections, particularly access issues related to immunization data.
- Jon Goldfinger, CEO of Didi Hirsch Mental Health Services, recommended inclusion of more provider perspectives in the Stakeholder Advisory Group, particularly in the areas of specialty mental health and crisis care.
- Jennifer Inden, Health IT Program Manager of Redwood Community Health Coalition, expressed appreciation for the establishment of the Stakeholder Advisory Group and recommended the inclusion of more voices representing direct service providers and health information exchanges.
- Jonathan Feit, representing the California Fire Chief's Association – EMS Section, recommended that the Stakeholder Advisory Group consider data exchange issues in the pre-hospital environment including fire departments and emergency medical services.
- John Helvey of SacValley MedShare recommended that the Stakeholder Advisory Group build upon existing HIE infrastructure and strengthen data sharing between the state and clinical providers.
- Amanda McAllister-Wallner of the California LGBTQ Health and Human Services Network recommended more LGBTQ representation in the Stakeholder Advisory Group and strong consideration of issues pertaining to the LGBTQ population such as more consistent collection of sexual orientation and gender identity data.
- Lisa Chan-Sawin of Transform Health asked whether the scope of the Data Exchange Framework included data exchange related to social needs and social determinants of health and, if so, recommended that the Stakeholder Advisory Group consider the perspectives of individuals working within social services organizations at the county level.

Broadly, common themes from verbal and written public comment throughout the meeting included:

- Appreciation for the Stakeholder Advisory Group's representation of a variety of voices and perspectives, and encouragement to ensure additional, diverse perspectives are heard from across California, including:

² Name spelling approximated based on verbal statements.

- Health and human service providers, such as correctional facilities; direct service providers; emergency medical services and crisis providers; and county behavioral health organizations.
- Population of varied backgrounds, experiences, and needs, including those who can speak to behavioral health and substance use disorder conditions and data exchange needs; structural barriers confronted by individuals of various races, ethnicities, sexual orientations, and gender identities.
- Requests that the Stakeholder Advisory Group, in advising on the Data Exchange Framework:
 - Build upon existing health data exchange infrastructure.
 - Remain technology agnostic.
 - Align with national interoperability networks and frameworks.
 - Strengthen open exchange of data between the state, county, and private health care providers.
 - Advise on resource investments required to support data exchange.
 - Prioritize and advance opportunities to address health equity.
 - Protect patient privacy and security.
- Requests for more information on:
 - The topics the Stakeholder Advisory Group will cover and in what order.
 - How to serve on one of the anticipated Stakeholder Advisory Group Subcommittees or otherwise engage in the development of the Data Exchange Framework.

The Vision for Data Exchange in California

Dr. Mark Ghaly, Secretary, California Health and Human Services, welcomed Stakeholder Advisory Group Members and the public to the first CHHS Data Exchange Framework meeting. Dr. Ghaly shared the importance of developing a health and human services data exchange framework, a prerequisite to promoting the exchange of electronic information across health and social service systems. Dr. Ghaly noted that developing a health and human services data exchange framework was:

- A pillar of the state’s commitment to whole person care, with its need has only grown my apparent and urgent through the pandemic.
- Critical as the state moves forward with efforts to expand integrated care through CalAIM, major new homelessness initiatives, and other programs aimed at connecting health and social services—from Cradle-to-Career to the Master Plan for Aging.

Dr. Ghaly emphasized the importance of this Framework to help individuals across California, including:

- When a patient with a combination of physical and mental conditions seeks care, their providers are able to seamlessly access their medical information to provide the best possible treatment.
- Connecting public health information with medical, behavioral and social services data to better connect Californians to the care they need during public health

responses, and identify and address health inequities and disparities early – lessons learned from the COVID-19 pandemic.

Dr. Ghaly also noted several key points about what the CHHS Data Exchange Framework would and would not set out to address, including that:

- The Framework will remain “agnostic” about the type of technology system(s) adopted in California;
- The Framework will be mindful of health equity, and advance efforts of stakeholders to use data to reduce health disparities and improve health equity; and
- The Framework will create a common set of standards that work and advance opportunities for health and human services systems to participate in data exchange.

Dr. Ghaly added that CHHS aims not to be an enforcer, but rather provide the incentives stakeholders need and the technical assistance required to derive value from and advance data exchange.

Dr. Ghaly introduced a formal vision statement for the Data Exchange Framework for discussion: “Every Californian, and the health and human service providers and organizations that care for them, will have timely and secure access to electronic information that is needed to address their health and social needs and enable the effective delivery of services to improve their lives and wellbeing.”

Advisory Group Member Expectations

John Ohanian introduced two Advisory Group Members to share their thoughts on the Data Exchange Framework development process:

- Sandra Hernandez, President and CEO of California Health Care Foundation, emphasized the importance of the Group not losing sight of why this work is being undertaken – to improve the lives of Californians and create a more equitable system of health – and seize the opportunity to reduce barriers to data exchange across health, public health, and social systems.
- Liz Gibboney, CEO Partnership HealthPlan of California, similarly encouraged Group collaboration, stepping beyond individual organizational priorities to focus on developing a health system that serves all of California.

John Ohanian opened up discussion to other Stakeholder Advisory Group Members, who offered additional thoughts on the vision statement and their hopes for the Data Exchange Framework and data exchange in California, including:

- Potentially modifying the Vision Statement to:
 - Reference data usability;
 - More explicitly call out behavioral health;
 - Recognize potential federal and state data sharing restrictions and limitations; and

- Speak to health equity, which extends beyond racial and ethnic equity to include sexual orientation and gender identity.
- The development of the Data Exchange Framework presents opportunities to:
 - Improve data exchange in California;
 - Connect diverse sectors and better address social determinants of health; and,
 - Improve data collection and exchange to address health inequities (e.g., demographic data).
- However, improving data exchange is likely to be difficult and will require:
 - The Stakeholder Advisory Group to foster trust and a collaborative spirit; and
 - Maintain focus on the overall vision for data exchange and not get caught in technical details.
- Data Exchange Framework development would be supported by:
 - Establishing guiding principles;
 - Maintaining a strong focus on the high-level vision;
 - Setting scope of the types of data to be discussed;
 - Considering the cross-sector data exchange needs of those actively participating in school-based health, public health, and with justice-involved populations, among others; and
 - Considering how education, training, and resources providers and other participants in exchange would need to realize the vision.

Overview of Assembly Bill 133

Jared Goldman, General Counsel, California Health and Human Services provided an overview of the provisions relevant to the Data Exchange Framework, as enacted in Assembly Bill 133 (AB 133), Health and Safety Code § 130290.

Stakeholder Advisory Group Purpose and Charter

John Ohanian reviewed the Stakeholder Advisory Group purpose, Member expectations and the roles of CHHS, the Chair, and Subcommittees, as previously shared in the more detailed Stakeholder Advisory Group Charter: https://www.chhs.ca.gov/wp-content/uploads/2021/08/CHHS-Data-Exchange-Framework_Stakeholder-Advisory-Group_-Charter_Draft.pdf.

Stakeholder Advisory Group members shared the following Charter revision suggestions and comments on the Data Exchange Framework development process:

- The Charter would benefit from:
 - Stronger alignment between its Vision and policies and procedures (e.g., adding language in the Purpose to further emphasize data exchange to meet social and public health needs).
 - Expanding the list of topics the Stakeholder Advisory Group may provide recommendations on to include:
 - The technical and resource assistance implementation needs of particularly small and safety net providers;

- Consumer experience and consent;
- Implementation phasing; and
- Incentives to increase compliance with data exchange requirements and participation.
- Rephrasing “minority” language to better reflect changing demographics in California.
- Acknowledgement that the Stakeholder Advisory Group’s data exchange recommendations will align with federal and state law, regulations and standards.
- The Data Exchange Framework Stakeholder Advisory Group membership should be flexible to allow for new members to join under certain circumstances (e.g., as new subject matter expertise is needed).

Jonah Frohlich, Managing Director, Manatt Health Strategies, requested that Stakeholder Advisory Group Members indicate whether they recommend approval of the Charter with the amendments discussed above. There was general consensus from the Stakeholder Advisory Group that the Charter covered the main objectives of the Group as outlined in AB 133 with the discussed amendments. Several Members requested the opportunity to review the Charter again with amendments. Jonah Frohlich noted that a revised Charter would be shared in advance of the next meeting.

Break

Jonah Frohlich suggested cutting the break and moving on to the next agenda item to no objection by Stakeholder Advisory Group Members.

Data Exchange History and Context in California

Dr. Rim Cothren, HIE Consultant to CDII on Data Exchange Framework, reviewed the types of data exchange, the history of data exchange in California, and provided an overview of the California Trusted Exchange Network (CTEN). Rim Cothren noted an error on the slide that “2-1-1 San Diego” should read “CIE San Diego,” which was launched in 2014.

Jonah Frohlich invited Stakeholder Advisory Group Members to share their perspectives on how their experiences with health information exchange should guide the Advisory Group’s work. Members emphasized the importance of:

- Building upon California’s successes in advancing data exchange (e.g., advancing use of Electronic Health Records (EHRs) among healthcare providers).
- Including how data is used, and not just how data is transferred, in a definition of “data exchange.”

Stakeholder Advisory Group Workplan and Issue Prioritization

Jonah Frohlich reviewed feedback that Stakeholder Advisory Group members shared through a pre-meeting survey,

Stakeholder Advisory Group goals were discussed and the Stakeholder Advisory Group supported the advancement of the following goals:

- Develop standard statewide HIE objectives and priority use cases;
- Develop policies to improve access to information that is needed to drive quality of care and health outcome improvements across the population;
- Identify and close gaps in data exchange for sectors that are not extensively participating in HIE networks;
- Address disparities and health equity by developing clear state guidance on how demographic and other related data should be collected and shared;
- Develop strategies to leverage and expand existing data exchange capabilities, infrastructure and networks at the local, state & national level;
- Develop policies to protect patient privacy and confidentiality;
- (Added) Develop policies and recommendations to support the provision of technical assistance and resources for organizations investing in HIE, particularly those that are small and/or face resource challenges; and,
- (Added) Develop a governance structure to enable standard, seamless, and sustainable exchange of data across sectors.

Stakeholder Advisory Group Members also commented that:

- A lack of resources can be a significant barrier to HIE participation, especially among safety net providers which serve individuals who often require coordination across several healthcare and social service providers.
- Safety net providers will likely require additional resources to participate in robust data exchange and there is an opportunity to learn from the successes achieved by California's large health systems.
- California should consider establishing a statewide mandatory provider registry.
- Patient privacy, security, and trust are important components for any initiative that consolidates and manages patient data, echoing public comments in the meeting's chat feature.
- It would be helpful to have meeting materials at least five days in advance of each meeting date to review and provide comment.
- The Stakeholder Advisory Group should align on priority use cases to inform development of the Data Exchange Framework.

Barriers to data exchange in California were outlined as:

- Fragmentation of data sources limits the availability a comprehensive health record for all patients.
- Reliance on EHRs and national networks limits the comprehensiveness of data exchange with limited connections with payers, behavioral health and social service providers, and public health & social service agencies.
- Antiquated and insufficient HIE infrastructure among stakeholders, particularly smaller providers.
- Misaligned - and often confusing - laws, policies, and standards around medical and health-determining data sharing and access.
- Business practices that restrict the availability of data.

- Financial and technical “barriers to entry” for certain types of providers

Jonah Frohlich outlined the proposed approach for triaging Data Exchange Framework topics between the Stakeholder Advisory Group and a Data Sharing Agreement Subcommittee and asked Members for recommendation to form a Data Sharing Agreement Subcommittee. The majority of Members approved a recommendation to form the Subcommittee; several requested additional information on the Subcommittee’s charge and clarity on its relation to the broader Stakeholder Advisory Group. Jonah Frohlich acknowledged the recommendation to establish a Data Sharing Agreement Subcommittee, and the need to clarify scope of the Subcommittee during the next meeting.

Closing Remarks

Dr. Ghaly thanked everyone from the Stakeholder Advisory Group and public for their participation.

John Ohanian noted that the next Data Exchange Framework Stakeholder Advisory Group meeting will occur on October 7, 2021, 10:00 AM to 12:30 PM PST, and that additional meeting dates and times will soon be shared.