California Health & Human Services Agency  
Center for Data Insights and Innovation  
Data Exchange Framework Stakeholder Advisory Group  
Meeting Summary  
Wednesday, May 18, 2022, 10:00 a.m. to 1:00 p.m.

**Attendance**


**Stakeholder Advisory Group Staff and Presenters in attendance:** Dr. Rim Cothren (Independent HIE Consultant to CDII), Jonah Frohlich (Manatt Health Strategies), Kevin McAvey (Manatt Health Strategies), Marko Mijic, (CalHHS), John Ohanian (CalHHS/CDII), Helen Pfister (Manatt Health Strategies), Elaine Scordakis (CalHHS/CDII), Khuoa Vang (CalHHS/CDII)

**Public in attendance:** approximately 128 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 Data Exchange Framework Stakeholder Advisory Group meeting. Notes may be revised to reflect public comment received in advance of the next Stakeholder Advisory Group meeting. Meeting materials, full video recording, transcription, and public comments may be found at: https://www.chhs.ca.gov/data-exchange-framework/.

**Welcome and Roll Call**

John Ohanian, Chief Data Officer, California Health & Human Services, welcomed attendees the eighth Stakeholder Advisory Group meeting.

John noted that Secretary Ghaly was would not be able to join the meeting because he his attendance was requested by the governor for a briefing and an event related to COVID-19, and Undersecretary Marko Mijic would provide opening remarks.

John reviewed the meeting agenda and reviewed the timelines for posting drafts and public comment periods of the Data Exchange Framework, Data Sharing Agreement, Policies and Procedures, and Strategy for Digital Identities (see table below).
Stakeholder Advisory Group Members were named and introduced via roll call.

**Vision and Meeting Objectives**
Marko Mijic, Undersecretary, CalHHS, thanked Stakeholder Advisory Group Members and public attendees for their continued engagement in the Data Exchange Framework development process. Marko expressed his optimism that the Data Exchange Framework will produce meaningful benefits for all Californians.

Marko reiterated CalHHS’ support for the proposals included in the Governor’s May revision that is being considered by the legislature. He emphasized the importance of data exchange to the success of CalAIM, the Master Plan on Aging, and other initiatives that are improving the health and well-being of Californians. Marko asked Stakeholder Advisory Group Members to keep individual Californians in mind as they review drafts of the Data Exchange Framework, Data Sharing Agreement, and Policies and Procedures.

**Data Sharing Agreement Policies and Procedures**
Helen Pfister, Partner, Manatt Health Strategies, provided an overview of the relationship between the Data Sharing Agreement and the Policies and Procedures. Helen reviewed the mapping between Data Sharing Agreement topics and the initial set

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1 The draft Strategy for Digital Identities was released on May 26th and comments were due end-of-day, June 9th.
of Policies and Procedures that will be released on July 1st, 2022 and Policies and
Procedures that will be released at a later date.

Helen noted that the presentation slides contain summaries of the Data Sharing
Agreement sections and Policies and Procedures, and that the full documents could be
found on CalHHS' Data Exchange Framework website.

Helen then summarized each section of the Data Sharing Agreement, which included:

1. Parties
2. Purpose and Intent
3. Definitions
4. Use of Health & Social Services Information
5. Policies & Procedures and Specifications
6. Authorizations
7. Requirement to Exchange Health & Social Services Information
8. Privacy and Security
9. Minimum Necessary
10. Individual Access Services
11. Cooperation and Non-Discrimination
12. Information Blocking
13. Legal Requirements
14. Representation and Warranties
15. Term, Suspension, and Termination
16. Participant Liability
17. Miscellaneous/General Provisions

Stakeholder Advisory Group Members feedback on the Data Sharing Agreement
included:

- **Section 7. Requirement to Exchange Health & Social Services Information**
  - Support for developing a process to qualify data exchange intermediaries through which providers can connect to satisfy Data Sharing Agreement and the Policies and Procedures requirements.
  - Consider whether other entities (e.g., Independent Practice Associations) can connect to data exchange intermediaries on behalf of individual providers to meet Data Sharing Agreement and the Policies and Procedures requirements.
  - Consider including requirements for the proactive exchange of data (e.g., Admission, Discharge, and Transfer information).

- **Section 9. Minimum Necessary**
  - Considerations regarding the exchange and use of sensitive data types (e.g., abortion and interpersonal violence).

- **Section 12. Information Blocking**
  - Request for clarification about whether California can expand upon federal information blocking rules to include other entities.
• **General**
  o Ensure that the Data Sharing Agreement is written with enforceable language to support compliance. For example, include granular detail on timelines and processes rather than leaving these details for participants to agree upon.
  o Request for clarification about how the Data Sharing Agreement may interact with existing contracts between data exchange intermediaries and providers.
  o Suggestion to hold private technology vendors to the same standards as qualified data exchange intermediaries.

Helen summarized each of the Policies and Procedures that will be released on July 1st, 2022, including:

1. Amendment of Data Sharing Agreement
2. Amendment of Policies & Procedures
3. Breach Notification
4. Permitted, Required, and Prohibited Purposes
5. Requirement to Exchange Health & Social Services Information
6. Privacy and Security Safeguards
7. Individual Access Services
8. Data Elements to Be Exchanged

Stakeholder Advisory Group Members feedback on the Policies and Procedures included:

• **1. Amendment of Data Sharing Agreement**
  o Suggestion to increase timeframe for Participants to implement and comply with amendments to the Data Sharing Agreement to 180 days.
  o Consider implementing standard processes and timelines for updating the Data Sharing Agreement.
  o Support for publicly posting revisions to the Data Sharing Agreement.

• **2. Amendment of Policies & Procedures**
  o Consider implementing standard processes and timelines for updating the Policies and Procedures.
  o Support for publicly posting revisions to the Policies and Procedures.

• **3. Breach Notification**
  o Suggestion to align breach notification timelines and procedures with those that Participants are already beholden to (e.g., Health Insurance Portability and Accountability Act, HIPAA, for covered entities) and set notification timelines and procedures for Participants that are not covered under existing requirements.
  o Clarify the types of data that would be subject to the beach notification requirements and how these requirements align with those of other State agencies and departments.
4. Permitted, Required, and Prohibited Purposes
   - Clarify why "Operations" is defined differently than it is under HIPAA.
   - Ensure that the definition of “Public Health Activities” allows data exchange to support public health officers’ powers under State law to enforce quarantine and isolation requirements and that the definition of “Research” is sufficiently broad to support public health research.
   - Requests for clarifications on the “Prohibited Purposes”, including allowing Participants to aggregate data and the definition of “Social Services Organization.”
   - The State should consider providing additional guidance on allowable sharing of 42 CFR Part 2 data.

5. Requirement to Exchange Health & Social Services Information
   - Ensure that responding to referrals is included under a Participant’s “Duty to Respond”.
   - Clarify the definition of “technologically ready and able”, and what happens if a Participant is not technologically ready and able to exchange the information that is required.
   - Clarify whether some Participants will be able to receive and access information exchanged under the Data Exchange Framework but not share information.

6. Privacy and Security Safeguards
   - Support for requiring Participants that are not covered entities under HIPAA to comply with the provisions of the HIPAA Regulations at 45 C.F.R. part 164, subparts C and E, as if it were acting in the capacity of a Business Associate.
   - Concern over the potential burden that Participants that are not HIPAA covered entities would face in complying with HIPAA.

7. Individual Access Services
   - Request to clarify whether individuals will be the “owner” of their data and be able to know and control the data that are shared after it is received from the originating entity.

8. Data Elements to be Exchanged
   - Define data “held by the entity” and consider focusing on data that is curated and structured by the entity since other data types, such as received faxes, would be difficult to exchange.
   - Clarify what happens if a Participant does not have a data element that is required to be exchanged.
   - Consider allowing Participants to use HL7 Fast Health Interoperability Resources (FHIR®) Release 4.0.1, US Core Implementation Guide 4.0.0 STU4 or a lessor standard.
Public Comment
John Ohanian opened the meeting to public comment, which included:2

- Katie Webber, advocate for older adults and people with disabilities, suggested adding a data exchange scenario focusing on older adults or individuals residing in an institutional setting.
- Lucy Johns, emphasized that there will be interest in how AB133 will influence data exchange in California, so it will be necessary for the governance entity to ensure accountability of Data Exchange Framework participants. She requested clarification if the governance entity can require reporting per Sections 11 and 13 of the Data Sharing Agreement and have enforcement authority if reporting requirements are not met. Lucy suggested that participants should report to the governance entity at least semi-annually.
- Delores Green, Executive Director, Riverside County Medical Association, emphasized Riverside County Medical Association’s commitment to the success of the Data Exchange Framework and appreciation for the funding proposals included in the Governor’s May Revision to the Proposed Budget. She requested consideration of the Data Sharing Equity Coalition’s $95 million funding request to support health information organization (HIO) infrastructure.
- John Halvey, SacValley MedShare and Data Sharing Equity Coalition, emphasized SacValley MedShare’s and the Data Sharing Equity Coalition’s support for the Data Exchange Framework and requested consideration of the Data Sharing Equity Coalition’s $95 million funding request to support HIO infrastructure.
- Tiffany Mathews, Inland Empire Health Plan and Data Sharing Equity Coalition, requested consideration of the Data Sharing Equity Coalition’s $95 million funding request to support HIO infrastructure.
- Bill Barcelona, America’s Physician Groups, requested consideration of the Data Sharing Equity Coalition’s $95 million funding request to support HIO infrastructure and noted that these funds would be needed for large physician groups to comply with the Data Sharing Agreement and its Policies and Procedures.

Data Exchange Framework Component Documents
Jonah Frohlich, Senior Managing Director, Manatt Health Strategies provided a brief overview of the draft Data Exchange Framework Component Documents, which included the:

1. Data Exchange Framework Development Process
2. Data Exchange Framework Guiding Principles
3. California Data Exchange Landscape
4. Data Exchange Scenarios
5. Data Exchange Framework Governance

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2 Name spelling approximated based on verbal statements.
6. California Data Exchange Gaps and Opportunities

Jonah noted that these documents were shared with the Stakeholder Advisory Group on May 12th and written comments would be accepted through June 1st.

Stakeholder Advisory Group Members feedback on the Data Exchange Framework Component Documents included:

- Suggestions to establish and launch the HIE Policy Board to support Data Exchange Framework Governance as soon as possible and establishing an interim stakeholder advisory committee until that occurs.

Digital Identity Strategy Update

Dr. Rim Cothren, Independent HIE Consultant to CDII, summarized the verbal and written comments received on the draft Strategy for Digital Identities that CDII presented during the April 7th Stakeholder Advisory Group meeting. Rim then described the actions taken based on the input received, and the next steps for the draft strategy for Digital Identities, including the timeframe for release and public comment and the areas where CDII is requesting additional feedback, including:

- Attributes included in digital identities.
- The use of digital identities in population health research, noting that the only restriction in the draft presently is that demographics in digital identities not be used as search criteria or to stratify populations.
- Purposes for use, considering the draft DSA and P&Ps.
- The utility of a statewide index

Governance and Budget Update

Marko Mijic reviewed two proposals in the May Revision of the Governor’s Proposed Budget that would support the implementation of the Data Exchange Framework:

- $50M grant program at CDII to provide technical assistance to small or under-resourced providers.
- $200M practice transformation grant program at DHCS for small physician practices to upgrade their clinical infrastructure.

Marko emphasized that these proposals are being considered by the legislature and that details about eligible entities and activities had not yet been finalized. He thanked Stakeholder Advisory Group Members for their input which helped to inform these proposals and asked that they continue to engage with CalHHS and the legislature as the proposals are considered.

Stakeholder Advisory Group Members feedback on the Governance Update included:

- General support for establishing Data Exchange Framework governance with the suggestion that the state seek to establish the Health Information Exchange
(HIE) Policy Board as soon as possible and establish an interim stakeholder advisory committee until it can be established.

- Some Members expressed concerns over the potential for duplicative state regulatory authorities and misalignment with federal requirements. These Members suggested requiring participation in the federal Trusted Exchange Framework and Common Agreement (TEFCA) in lieu of the state establishing Data Exchange Framework governance.

Stakeholder Advisory Group Members feedback on the Budget Update included:

- Appreciation for the proposals in May Revision of the Governor’s Proposed Budget.
- Requests for additional detail on the types of health and human service providers who would be eligible for funding under these programs.
- Suggestion to consider funding for technical assistance and upgrades to state, county, and local public health infrastructure as well as county mental health infrastructure to support participation in the Data Exchange Framework.

Closing Remarks
John Ohanian reviewed project next steps and noted that the next and final Stakeholder Advisory Group meeting is scheduled for June 23rd.
## Appendix 1. Data Exchange Framework Stakeholder Advisory Group Member - Meeting Attendance (May 18, 2022)

<table>
<thead>
<tr>
<th>Last Name</th>
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<td>Ghaly</td>
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<td>Secretary (Chair)</td>
<td>California Health and Human Services Agency</td>
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<tr>
<td>Almanza</td>
<td>Jamie</td>
<td>CEO</td>
<td>Bay Area Community Services</td>
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<td>Amarnath</td>
<td>Ashrith</td>
<td>Medical Director</td>
<td>California Health Benefit Exchange</td>
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<td>Bacchi</td>
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<td>California Association of Health Plans</td>
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<td>Beckley</td>
<td>Mark</td>
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<td>Department of Aging</td>
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<td>Bindman</td>
<td>Andrew</td>
<td>Executive Vice President; Chief Medical Officer</td>
<td>Kaiser Foundation Health Plan, Inc. and Hospitals</td>
<td>Adams</td>
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<td>Cabrera</td>
<td>Michelle Doty</td>
<td>Executive Director</td>
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<td>Christman</td>
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<td>Cowling</td>
<td>David</td>
<td>Chief, Center for Information</td>
<td>California Public Employees' Retirement System</td>
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<td>Coyle</td>
<td>Carmela</td>
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<td>Dhawan</td>
<td>Rahul</td>
<td>Associate Medical Director</td>
<td>MedPoint Management (representing America's Physician Groups)</td>
<td>Crane</td>
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<td>Diaz</td>
<td>Joe</td>
<td>Senior Policy Director and Regional Director</td>
<td>California Association of Health Facilities</td>
<td>Cornett</td>
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<td>Fisher</td>
<td>Kayte</td>
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<td>Department of Insurance</td>
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<td>Ford</td>
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<td>Gibboney</td>
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<td>Hack</td>
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<td>Hernández</td>
<td>Sandra</td>
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<td>Houser</td>
<td>Brent</td>
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<td>Department of State Hospitals</td>
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<td>Cameron</td>
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<td>County of San Diego (representing the California Conference of Local Health Officers)</td>
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<td>Kiefer</td>
<td>Andrew</td>
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<td>Blue Shield of California</td>
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<td>Koopmans</td>
<td>Linnea</td>
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<td>Larson</td>
<td>Cheryl</td>
<td>Director &amp; CIO</td>
<td>Department of Corrections and Rehabilitation</td>
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<td>Legé</td>
<td>Matt</td>
<td>Government Relations Advocate</td>
<td>SEIU California</td>
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<td>Lindeman</td>
<td>David</td>
<td>Director, CITRIS Health</td>
<td>UC Center for Information Technology Research in the Interest of Society</td>
<td>N/A</td>
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<td>Lo</td>
<td>Julie</td>
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<td>Business, Consumer Services &amp; Housing Agency</td>
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<td>McAllister-Wallner</td>
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<td>McCallin</td>
<td>DeeAnne</td>
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<td>Modaressi</td>
<td>Ali</td>
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<td>Los Angeles Network for Enhanced Services</td>
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<td>Nau</td>
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<td>Mark</td>
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<td>Savage &amp; Savage LLC</td>
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<td>York</td>
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<td>211 San Diego/Community Information Exchange</td>
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