

**California Health & Human Services Agency  
Center for Data Insights and Innovation  
Joint Implementation Advisory Committee and Data Sharing Agreement (DSA)  
Policies and Procedures Subcommittee Meeting  
Data Exchange Framework Roadmap Workshop Summary  
Tuesday, September 17, 2024, 2:15 PM – 3:30 PM PT**

### **Attendance**

*CDII:* John Ohanian, DeeAnne McCallin, Han Bai, John Fajardo, Julia Gallardo, Courtney Hansen, Michelle Land, Jacob Parkinson, Jaykob Zaleski,

*Independent Consultants to CDII:* Sophia Chang, Rim Cothren

*Mannat Health Strategies:* Cindy Bero, Jonah Frohlich, Amanda Goorin, Christine Irlbeck, Kate Motley, Lili Muskal, Lauren Sears, Ryan Vu, Justin Yoo, Justine Yu

*DxF Committee Members:* Bill Barcelona, Shelley Brown, Jason Buckner, Louis Cretaro, Joe Diaz, Matthew Eisenberg, David Ford, Aaron Goodale, John Helvey, Sanjay Jain, Diana Kaempfer-Tong, Troy Kaji, Andrew Kiefer, Mark Knee, Steven Lande, Matt Lege, Carol Leveroni, Kelby Lind, Sunny Lowell, Belinda Luu, Deven McGraw, Amie Miller, Ali Modaressi, Jackie Nordhoff, Margaret Porto, Mark Savage, Tom Schwaninger, Becky Shoemaker, Felix Su, Lee Tien, Belinda Waltman, Jim Willis

### **Meeting Notes**

*Notes aim to elevate major points made by attendees and may not be a comprehensive accounting of all points made.*

### **Opening Remarks**

John Ohanian, Director, Center for Data Insights and Innovation (CDII), welcomed Implementation Advisory Committee (IAC) and DSA and Policies and Procedures (P&Ps) Subcommittee Members to the DxF Roadmap Workshop meeting. John introduced the Roadmap's priority areas, referred to as "pillars", and opened Zoom breakout rooms for smaller group discussions.

## DxF Roadmap Priority Area Breakout Sessions

### Event Notifications

Rim Cothren, Independent Consultant to CDII, introduced priority area content and reviewed discussion questions. Comments from workshop participants included:

- **What important use cases for event notification exist beyond admissions and discharges to acute and post-acute care facilities as now required by DxF? What priorities should DxF consider?**
  - Prioritize notifications for basic admissions to and discharges from acute care facilities.
  - Require skilled nursing facilities to provide notifications of admissions and discharges.
  - Expand notifications from acute and post-acute care settings to include behavioral health and ambulatory care encounters.
  - Begin notifications for social services, focused on abuse and protective services, supported by a flexible data model to allow for expansion of use cases.
  - Ensure the DxF includes notifications from out-of-state entities.
  - Focus on support and management of chronic health conditions.
  - Address concerns over alert-fatigue.
- **What other barriers exist to sharing notification of important health-related events?**
  - Fragmented solutions and incomplete geographic coverage by Qualified Health Information Organizations (QHIOs).
  - Process barriers exist in addition to technical barriers, particularly as it relates to responses by notification recipients.
    - Integration into workflows of provider and care team workflows.
    - Delegation to appropriate entities or individuals for follow-up.
    - Determining responsibility for consuming, responding to, and acting upon notifications.
    - Ensuring notifications are actionable and the data can be consumed by the intended recipient.
    - Including contact information to make notifications more actionable.
  - Matching events to identities on rosters to ensure appropriate recipient notification.
    - Lack of a centralized statewide master person index to support consistent identity for notification subjects.
- **Do you agree with focusing on rosters to request event notifications in alignment with the first tenet?**
  - Rosters support transparency and accountability.

- Rosters are preferred over the other proposed methods for requesting notifications.
- **Would Participants voluntarily use statewide services to consolidate rosters and/or distribute notifications? What would be required to encourage adoption?**
  - Support was split on whether Participants would use a voluntary statewide roster service.
    - Providers may not use a voluntary shared service.
  - Focus on the cost of matching events to individuals on a roster rather than managing rosters.
  - Create a statewide (or federated) master person index to address matching challenges.
  - Shared service that includes person matching would support QHIOs and increase social services participation.

### Social Services Data

Lauren Sears, Manatt Health Strategies, introduced priority area content and reviewed discussion questions. Comments from workshop participants included:

- **Do you agree with the outlined tenets for social services data exchange?**
  - Expand upon the tenet “integrate the consumer voice into strategy development” to incorporate “health equity by design” concepts.
  - Create visual representations of social services data flow to identify gaps and challenges in local health and social data exchanges.
- **What are the most important types of social services data to prioritize to further advance the connection of individuals to available benefits?**
  - Demographic data is necessary for matching records.
  - Eligibility data should be included to determine service access.
  - Self-reported conditions may bypass regulatory concerns and challenges in managing substance use data.
  - Household composition data, particularly within the child welfare system, requires careful tracking of representatives, guardians, and caregivers.
  - Social services data should remain flexible, capturing both what can be and is recorded, including data provenance.
  - Social Determinants of Health data elements from US Core Data for Interoperability (UCSDI) v2 and beyond should be included to assess health needs and interventions.
- **Where might the DxF have an opportunity to build on existing community information exchange systems to support broader social service data sharing?**
  - Create a directory of social services data to better integrate community information exchange (CIE) data into broader health data flows.
  - Create additional funding opportunities to support increased CIE usage as Medi-Cal programs expand.
  - Develop requirements for a minimum set of data elements to support standardized exchange across systems.
  - Require QHIOs to handle social services data available from existing CIEs.
- **What key actions do you believe CDII can take to enable the exchange of social service data across stakeholders? Are there specific stakeholders that should be prioritized?**
  - Include community-based organizations (CBOs), faith-based organizations, counties, and public health entities in stakeholder engagement efforts.

- Address the varying social services data flows between traditional providers, CBOs, social service organizations, and individuals.
- Provide guidance to address the varying consent and privacy issues across Health Insurance Portability and Accountability Act (HIPAA) and non-HIPAA environments.

## Consent Management

Jonah Frohlich, Manatt Health Strategies, introduced priority area content and reviewed discussion questions. Comments from workshop participants included:

- **What gaps, barriers or challenges do we need to consider in the design and implementation of a statewide consent management service?**
  - Manage consent at a statewide level, ensuring accessibility for health and social service entities with varying technological capabilities, while leveraging QHIOs to support consent management at the regional level.
  - Start with a pilot in technologically advanced areas before scaling.
  - Incorporate insights from other states (e.g., Washington) and state initiatives (e.g., Authorization to Share Confidential Medi-Cal Information, or ASCMI, Pilot).
  - Support data sharing through standardized formats (HL7v2, CDA, FHIR) and nonstandard formats (PDF, CSV).
  - Ensure existing consent formats can be imported into the state system.
  - Prioritize secure identity management, patient privacy, and interoperable consent documentation.
  - Empower consumers and providers by ensuring simplified consent language, multi-language support, and education on consent processes, including what is being consented to and with whom.
  - Ensure consumers can review, modify, and revoke consents.
  - Address digital consent barriers, especially among small organizations and non-covered entities, to prevent low participation and data exchange issues.
  - Managing granular consent (e.g., specific data, providers) adds complexity and may not be guaranteed.
- **How can the DxF support statewide consent management services - specifically are there policies, guidance, standards and financing strategies that should be considered?**
  - Develop use cases for Part 2 substance use data, reentry services, minors, housing, and supplemental nutrition programs.
  - Develop standardized policies and procedures for consent management, with clear guidelines on who can update consent and how.
  - Leverage federal matching funds to support Medi-Cal implementation.
  - Offer incentives linked to technical standards and implementation guidance before enforcing requirements.
  - Make consent management a prerequisite for CBO involvement in the DxF, with standardized legal language.

## Public Health Data

Cindy Bero, Manatt Health Strategies, introduced priority area content and reviewed discussion questions. Comments from workshop participants included:

- **How do you view the current state of public health data reporting in California?**
  - Reporting often requires manual reporting and duplicate data submissions.
  - Sharing is often one-way, not bidirectional.
  - Reporting varies by county with a lack of clarity on what each county supports and wide variation in the laws that govern the hundreds of different programs.
- **What other public health data challenges do you believe the DxF could effectively address?**
  - Limited technology support and funding for public health reporting.
  - Privacy and security of public health data.
  - The DxF is limited because it is technology agnostic and doesn't have electronic case reporting standards.
- **Are there emerging opportunities or risks CDII should consider integrating into its strategic planning?**
  - Drive standardization and consistency in the standards for sending and receiving data; one specific area discussed was the lack of a single state-wide registry in California prior to 2023.
  - Invest in public health infrastructure including investments in technology to make it more stable and scalable.
  - Support public health data queries by supporting/incentivizing CDPH to utilize Trusted Exchange Framework and Common Agreement (TEFCA) to query providers for needed clinical information to support case investigation and follow-up.
  - Carefully consider the privacy and security of data (including reproductive and gender-affirming care)
  - Other proposed public health use cases include:
    - Syndromic surveillance
    - Electronic case reporting
    - Prescription Drug Monitoring Program
    - Immunization registry
    - Identifying homelessness and connecting individuals to housing
    - Use cases derived from the data in DxF event notifications, in accordance with legislative/regulatory guidance

- New use cases via best practice collaboratives to help catalyze adoption



### Impact Measurement

Justin Yoo, Manatt Health Strategies, introduced priority area content and reviewed discussion questions. Comments from workshop participants included:

- **As we consider how the DxF impacts service delivery and quality in future phases, which domains should be our focus for measurement?**
  - It may be challenging to establish causality between the DxF and changes in health outcomes due to numerous confounding factors, including other local and national data exchange efforts concurrently being pursued.
  - Track transaction volumes being supported by the DxF, such as the number of data exchange queries and the volume of transitions of care documents being exchanged.
- **As we think ahead toward the outcomes associated with better data exchange, what areas should be explored?**
  - Assess the extent to which data is being exchanged according to DxF requirements (e.g., for all required purposes of use) as an intermediate step before moving to assess impact on health outcomes.
  - Consider sustained data partnerships to obtain actionable data to understand exchange occurring between healthcare providers and CBOs.
  - Obtain data through public health repositories or by requiring participants to report data directly.
  - Address the differences in resources and technological capabilities between urban and rural counties which may affect entities' ability to contribute impact data if such data will be obtained via new reporting requirements.
  - Include robust privacy and security protocols to protect data exchanged under the DxF as well as data used for impact measurement.
- **What are other data sources or metrics the DxF could use to better understand its impact?**
  - Collect data on participant satisfaction through surveys and focus groups to understand individual trust and perceptions of the DxF.
  - Select specific use cases to benchmark (e.g., prevalence of data exchange to support automated prior authorization procedures).

### DxF Signatory Campaign Strategy

DeeAnne McCallin, CDII, introduced priority area content and reviewed discussion questions. Comments from workshop participants included:

- **What stakeholder communication and engagement strategies should CDII employ to reach 100% of required organizations signing the DSA?**
  - Incorporate DxF education and communications into recertification and license renewal processes to gain exposure to 100% of mandatory signatories.
  - Collaborate with state departments and major organizations where possible to collectively communicate the DxF requirements.
  - Clarify definitions and denominators for provider organizations and medical groups (POMGs), potentially through a DxF governing board or legislative action, to eliminate ambiguity in DxF requirements.
  - Impose consequences for not complying with the requirement to sign the DSA.
  - Organize the DSA and DxF to have phased implementation to make adoption less daunting.
  - Align with national programs (e.g., TEFCA and CMS Interoperability).
  - Tailor engagement strategies to different stakeholder groups and target the most influential organizations in the hopes of achieving a domino effect.
  - Provide additional education and clarification of the DxF components such as the DSA and Participant Directory and the requirements for each.
- **What stakeholder communication and engagement strategies should CDII employ to reach 100% of required organizations meeting their Participant Directory P&P obligation of indicating their methods of exchange?**
  - Communicate the requirement to make selections in the Participant Directory.
  - Create training videos on how to complete the Participant Directory with examples for different types of entries.
  - Update types of exchange choices to make them more inclusive of all possible scenarios.
  - Continue creating job aids to address marketplace confusion.
  - Offer stakeholders different avenues for communication and questions, such as a call-in line or AMA (ask-me-anything) events.
  - Clarify the definition of what “Information Delivery” entails and how it works at scale in an automated fashion, since it is not supported by national networks.

## Next Steps and Closing Remarks

Jonah reviewed next steps to close the meeting. Jonah noted that CDII will discuss the developing Roadmap in additional detail at the next IAC meeting on November 7, 2024.