Data Exchange Framework Stakeholder Advisory Group Meeting #5

California Health & Human Services Agency

Tuesday, January 25, 2022
10:00 a.m. to 12:30 pm

Meeting Participation Options
Written Comments

- Participants may submit comments and questions through the **Zoom Q&A box**; all comments will be recorded and reviewed by Advisory Group staff.

- Participants may also submit comments and questions – as well as requests to receive Data Exchange Framework updates – to CDII@chhs.ca.gov.

Meeting Participation Options
Spoken Comments

- *Participants and Advisory Group Members* must "raise their hand" for Zoom facilitators to unmute them to share comments; the Chair will notify participants/Members of appropriate time to volunteer feedback.

If you logged on via <u>phone-only</u>

Press "*9" on your phone to "raise your hand"

Listen for your <u>phone number</u> to be called by moderator

If selected to share your comment, please ensure you are "unmuted' on your phone by pressing "*6"

If you logged on via <u>Zoom interface</u>

Press "Raise Hand" in the "Reactions" button on the screen

If selected to share your comment, you will receive a request to "unmute;" please ensure you accept before speaking

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Public Comment Opportunities

- Public comment will be taken during the meeting at designated times.
- Public comment will be limited to the total amount of time allocated for public comment on particular issues.
- The Chair will call on individuals in the order in which their hands were raised.
- Individuals will be recognized for up to two minutes and are asked to state their name and organizational affiliation at the top of their statements.
- Participants are encouraged to use the comment box to ensure all feedback is captured or email their comments to CDII@chhs.ca.gov.

Agenda

Time	Item
10:00 AM	**Welcome and Roll Call** • *John Ohanian, Chief Data Officer, California Health and Human Services*
10:05 AM	**Vision and Meeting Objectives** • *Dr. Mark Ghaly, Secretary, California Health and Human Services*
10:15 AM	**Data Exchange Standards, Provider Identity Management, and Consumer Data Access** • *Jonah Frohlich, Managing Director, Manatt Health Strategies*
11:40 AM	<u>**Public Comment**</u>
11:55 AM	**Digital Identity Strategy Update** • *Dr. Rim Cothren, Independent HIE Consultant to CDII*
12:05 PM	**Data Sharing Agreement Subcommittee Update** • *Jennifer Schwartz, Chief Counsel, CalHHS CDII*
12:15 PM	**Data Exchange Framework Guiding Principles and HIT Capacity Gaps and Opportunities Feedback Update** • *John Ohanian*
12:25 AM	**Closing Remarks** • *Dr. Mark Ghaly*

Welcome and Roll Call

Advisory Group Members
Stakeholder Organizations (1 of 3)

Name	Title	Organization
Mark Ghaly *(Chair)*	Secretary	California Health and Human Services Agency
Jamie Almanza	CEO	Bay Area Community Services
Charles Bacchi	President and CEO	California Association of Health Plans
Andrew Bindman *designated by Greg A. Adams*	Executive Vice President; Chief Medical Officer	Kaiser Permanente
Michelle Doty Cabrera	Executive Director	County Behavioral Health Directors Association of California
Carmela Coyle	President and CEO	California Hospital Association
Rahul Dhawan *designated by Don Crane*	Associate Medical Director	MedPoint Management (representing America's Physician Groups)
Joe Diaz *designated by Craig Cornett*	Senior Policy Director and Regional Director	California Association of Health Facilities
David Ford *designated by Dustin Corcoran*	Vice President, Health Information Technology	California Medical Association
Liz Gibboney	CEO	Partnership HealthPlan of California

Note: Complete bios for each member are available in a publicly posted biography listing; updated on Sept. 30th at 5pm PT

Advisory Group Members
Stakeholder Organizations (2 of 3)

Name	Title	Organization
Michelle Gibbons *designated by Colleen Chawla*	Executive Director	County Health Executives Association of California
Lori Hack	Interim Executive Director	California Association of Health Information Exchanges
Matt Legé *delegate for Tia Orr*	Government Relations Advocate	Service Employees International Union California
Sandra Hernández	President and CEO	California Health Care Foundation
Cameron Kaiser *designated by Karen Relucio*	Deputy Public Health Officer	County of San Diego (representing the California Conference of Local Health Officers)
Andrew Kiefer *designated by Paul Markovich*	Vice President, State Government Affairs	Blue Shield of California
Linnea Koopmans	CEO	Local Health Plans of California
David Lindeman	Director, CITRIS Health	UC Center for Information Technology Research in the Interest of Society
Amanda McAllister-Wallner *designated by Anthony E. Wright*	Deputy Director	Health Access California

Advisory Group Members
Stakeholder Organizations (3 of 3)

Name	Title	Organization
DeeAnne McCallin *designated by Robert Beaudry*	Director of Health Information Technology	California Primary Care Association
Ali Modaressi	CEO	Los Angeles Network for Enhanced Services
Erica Murray	President and CEO	California Association of Public Hospitals & Health Systems
Janice O'Malley *designated by Art Pulaski*	Legislative Advocate	California Labor Federation
Mark Savage	Managing Director, Digital Health Strategy and Policy	Savage & Savage LLC
Kiran Savage-Sangwan	Executive Director	California Pan-Ethnic Health Network
Cathy Senderling-McDonald	Executive Director	County Welfare Directors Association
Claudia Williams	CEO	Manifest MedEx
William York	President and CEO	San Diego Community Information Exchange

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Advisory Group Members
State Departments (1 of 2)

Name	Title	Organization
Ashrith Amarnath	Medical Director	California Health Benefit Exchange
Nancy Bargmann	Director	Department of Developmental Services
Mark Beckley	Chief Deputy Director	Department of Aging
Scott Christman	Chief Deputy Director	Department of Health Care Access and Information
David Cowling	Chief, Center for Information	California Public Employees' Retirement System
Kayte Fisher	Attorney	Department of Insurance
Julie Lo	Executive Officer	Business, Consumer Services & Housing Agency

Advisory Group Members
State Departments (2 of 2)

Name	Title	Organization
Dana E. Moore	Acting Deputy Director	Department of Public Health
Nathan Nau	Deputy Director, Office of Plan Monitoring	Department of Managed Health Care
Linette Scott	Chief Data Officer	Department of Health Care Services
Diana Toche	Undersecretary, Health Services	Department of Corrections and Rehabilitation
Julianna Vignalats	Assistant Deputy Director	Department of Social Services
Leslie Witten-Rood	Chief, Office of Health Information Exchange	Emergency Medical Services Authority

Vision & Meeting Objectives

Vision for Data Exchange in CA

Every Californian, and the health and human service providers and organizations that care for them, will have timely and secure access to usable electronic information that is needed to address their health and social needs and enable the effective and equitable delivery of services to improve their lives and wellbeing.

Progress and Next Steps

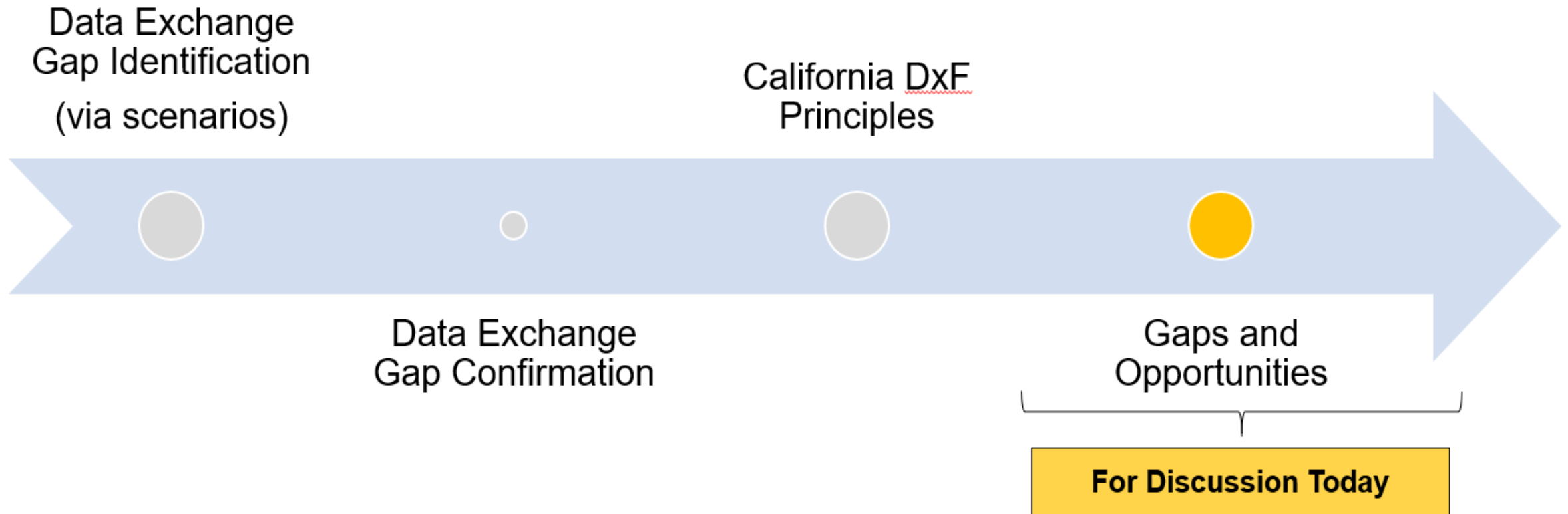| Status	Step
✔	Convene DxF Stakeholder Advisory Group (AG)
✔	Convene AG Data Sharing Agreement Subcommittee
✔	Identify key barriers to data exchange across technical infrastructure and standards, financing and business operations, and regulatory and policy domains
✔	Establish guiding principles for health and human services data exchange in California
✔	Provide feedback on options for resolving **infrastructure gaps (HIT)**
Today	Provide feedback on resolution options for **standards and consumer access gaps**
3/3	Provide feedback on options for establishing **governance**
4/7	Provide feedback on options for resolving **business operations gaps**
5/18	Provide feedback on options for resolving **regulatory and policy gaps**
6/23	Provide feedback on the **draft DxF**

Meeting #5 Objectives

1. Discuss potential opportunities to address gaps in **data exchange standards, provider identity management, and consumer data access**

2. Provide **digital identity strategy update**

3. Provide a **Data Sharing Agreement Subcommittee update**

4. Review **updates** to the **DxF Guiding Principles** and **Potential HIT Capacity Opportunities**

Potential Opportunities:
Data Exchange Standards, Provider Identity Management, and Consumer Data Access

Data Exchange Framework (DxF) Development Process

Data Exchange Gap Identification (via scenarios)

California DxF Principles

Data Exchange Gap Confirmation

Gaps and Opportunities

For Discussion Today

Potential Opportunities

Potential Opportunities

- Opportunities presented here represent areas for private and public stakeholders to address specific program, policy, and system gaps to advancing the vision of AB 133.
- Opportunities may require the blending and braiding of existing resources across various sectors to support health and human service organizations in the implementation of AB 133.
- Opportunities must consider and incorporate significant system transformation efforts underway nationally and in California – and opportunities to build from those efforts to advance the vision of AB 133.

Feedback Requested

CDII requests Stakeholder Advisory Group feedback on:

- Opportunity feasibility and effectiveness to address the specified gap
- Existing programs, incentives, and initiatives that may be built-upon and modified to address the gap
- What philanthropic, private sector, and public sector funding may be already available to support the implementation of the opportunity

Gaps: Standards and Consumer Access

1. **Human Service Data Exchange Standards and Capacity.** National and federally recognized human service data exchange standards are nascent, and the standardized collection, exchange, and use of SDOH and other human service information remains limited; national networks, HIOs, and EHRs generally have limited capabilities to exchange structured and standardized SDOH and other human service data.

2. **Demographic Data.** Race, ethnicity, languages (spoken/written), sexual orientation, gender identity and other demographic data necessary to support population health and to identify and address disparities and inequities are often missing, incomplete, or are not collected or shared, and multiple standardized terminologies exist and regulations conflict on which must be supported.

3. **Provider Identity Management.** Robust provider, care team, and social service organization directories are not available or accessible to health and human service organizations across California.

4. **Consumer Data Access.** Individuals consistently face challenges in accessing their health and human service records - directly or through selected third parties - in a manner that is convenient, timely and compliant with federal access requirements.

(Covered by Digital Identity Strategy) Person Identity Management. Robust person identity matching services are not available or accessible to health and human service organizations across California.

Gaps and Opportunities

1. **Human Service and Demographic Data Exchange Standards and Capacity***

    ➢ **Opportunity 1a:** <u>SDOH</u> data collection and use standards, requirements, and incentives

    ➢ **Opportunity 1b:** <u>Demographic</u> data collection and use standards, requirements, and incentives

    ➢ **Opportunity 1c:** Enhance cross-state agency data sharing efforts to support the exchange of program enrollment data and consumer demographic and SDOH information to support cross-program service coordination and whole person care

    ➢ **Opportunity 1d:** Advance recommendations to federal government to improve demographic data collection nationally

2. **Provider Identity Management****

    ➢ **Opportunity 2a:** Expand upon the provider directory API Requirements in CMS's Interoperability and Patient Access Final Rule.

    ➢ **Opportunity 2b:** Require qualifying HIOs to participate in a federated provider identity management service

3. **Consumer Data Access**

    ➢ **Opportunity 3a:** Adopt policies to ensure consumers have meaningful access to their longitudinal health information across all health care organizations subject to AB-133, allowing them to make informed health care decisions

    ➢ **Opportunity 3b:** Adopt policies to ensure consumers understand how their health information may be used and trust in the systems in place that govern its use

*Combines two previously identified gaps for solutioning purposes
**Previously identified "Person Identity Management" is being addressed through the Digital Identity Strategy process

Gap #1: **Human Service and Demographic Data Exchange Standards and Capacity** (1 of 2)

Gap #1a: National and federally recognized human service data exchange standards are nascent, and the standardized collection, exchange, and use of Social Determinants of Health (SDOH) and other human service information remains limited; national networks, HIOs, and EHRs generally have limited capabilities to exchange structured and standardized SDOH and other human service data.

Relevant AB 133 Provision(s): *Identify ways to incorporate data related to social determinants of health, such as housing and food insecurity, into shared health information. [§130290(c)(3)(C)]*

Key Considerations:

- SDOH data collection efforts remain largely nascent, though are developing to allow health care organizations to better understand and support individuals' whole person care needs. SDOH – the conditions in the environments where people are born, live, learn, work, play, worship, and age – are estimated to account for up to 80% of health outcomes; understanding and addressing these factors is central to improving the health and wellbeing of all Californians. DHCS' CalAIM program focuses on addressing SDOH (link).

- SDOH data may be collected:
    - **Directly** from interactions with an individual (e.g., patient screening, observed conditions noted in clinical records or on claims).
    - **Indirectly** from changes in an individual's engagement with the human service system (e.g., SNAP enrollment/food insecurity, HMIS identification/housing insecurity, jail and prison data to support care transitions).

- SDOH data **directly** collected from interactions with an individual and recorded in:
    - Screenings or in clinical records that are often not collected in alignment with federal standards and definitions, such as the USCDI v2 (released by ONC in July 2021 and available here), as health care organizations sought to collect information prior to federal or national standards being widely disseminated.
    - Claims/encounters using the ICD-10-CM codes (primarily Z55-65 under *Factors influencing health status and contact with health services*, described here) remain limited (link), as health care organizations frequently do not have financial incentives or training to accelerate use.

- SDOH data that may be **indirectly** collected from changes in an individual's engagement with human service programs may not always be accessible in a timely manner to health care organizations that could use it to inform an individual's care and/or connect individuals with needed supports due to various legal, operational, and technical barriers to data exchange.

Gap #1: **Human Service and Demographic Data Exchange Standards and Capacity** (2 of 2)

Gap #1b: Race, ethnicity, languages (spoken/written), sexual orientation, gender identity and other demographic data necessary to support population health and to identify and address disparities and inequities are often missing, incomplete, or are not collected or shared.

Relevant AB 133 Provision(s): *Identify ways to incorporate data related to underserved or underrepresented populations, including, but not limited to, data regarding sexual orientation and gender identity and racial and ethnic minorities. [§130290(c)(3)(D)]*

Key Considerations:

- Demographic data collection completeness and consistency across health and human service programs varies significantly by data type.
    - "Gender" data are almost universally collected against a consistent – though outdated – male/female classification schema.
    - "Sexual Orientation" and "Gender Identity" data are rarely collected at present, and when collected, are captured against varying local or industry standards.
    - "Race", "Ethnicity", and "Language" (preferred spoken/written) data are almost universally voluntarily solicited by programs from individuals, but frequently left blank, and collected against varying federal, state, local, and industry standards.
- Health disparities in California are pervasive, and reflective of structural racism in our society and inequities in our systems of health. For example, Black Californians are expected to live 11 years less than Asian Californians, and experience the highest death rates from breast, cervical, colorectal, lung, and prostate cancer among all racial and ethnic groups (CHCF Brief); while nationally – according to data from the Trevor Project – 42% of LGBTQ youth seriously considered attempting suicide in 2021. Understanding Californians' unique diversity and the barriers specific groups may face in accessing and receiving health care is essential for ensuring their long-term health and wellbeing.
- Demographic data are ideally collected directly from an individual against standardized definitions. However, many individuals are hesitant to volunteer such information for fear of discrimination. Health care organizations may "fill in" missing demographic data with "indirect" data matched from other data sources or through statistical imputation (i.e., approximations based on other individual information). There are no systemic operational/technical methods in the health care ecosystem to maintain a "hierarchy of truth" (i.e., member data vs. indirect data).
- Demographic data collection, curation, and use will benefit from data standards, protocols, and practices that may not presently be in place across the health care data ecosystem – or nascent in implementation. In addition, federal HRSA and UCSDI demographic data standards conflict and may cause confusion in the market.

Opportunity #1: **Improving SDOH and Demographic Data Collection and Use to Identify and Address Health Disparities** (1 of 4)

(1a): *Consider establishing SDOH data collection and use standards, requirements, and incentives.* CalHHS should adopt the US Core Data for Interoperability (USCDI) Version 2 standards to facilitate the collection of consumer SDOH data collection, in addition to consumer race, ethnicity, language, sexual orientation, gender identity, and social and behavioral risk information (see Opportunity #2a). California should also support the adoption of additional standards for the collection of disability (functional and cognitive) status and accommodation needs information to support greater and more consistent disability data collection, sharing, and use. Standards may be paired with common collection and reporting requirements (e.g., quality/performance reporting requirements) and incentives to support system change. Data collectors and users may also require technical assistance to support new data collection and use practices.

California DHCS has prioritized identifying and addressing SDOH through CalAIM, which builds upon its Whole Person Care (WPC) pilot program that promoted coordinated care – physical, behavioral, and social – for high-risk, high-utilizing Medi-Cal enrollees by increasing service integration and SDOH data sharing and use among counties, plans, and CBOs. Successful WPC pilots – including Alameda County Care Connect, LA County WPC, Marin County WPC, and San Francisco DPH WPC – each established new data sharing protocols to support the exchange of SDOH related information. More broadly, CMS has encouraged state Medicaid and CHIP programs to adopt strategies that address SDOH, including instituting new data collection and reporting requirements, investing in systems capable of exchanging SDOH data, and programs that can put such data to meaningful use. Many states already incorporate SDOH screening and/or referral requirements in their Medicaid MCO contracts; and use quality reporting requirements and incentive payments to monitor and reward SDOH progress (KFF overview).

Discussion Question(s):
- EHRs are currently certified against USCDI v1 and CMS requires plans to meet v1 only; should California embrace v2 now?
- Where federal USCDI V2.0 standards may not exist for important SDOH characteristics, are there viable federal or national standards that may be referenced? If not, should California develop them?
- What have been the most successful programs to incentivize/require SDOH data collection and use?

Opportunity #1: **Improving SDOH and Demographic Data Collection and Use to Identify and Address Health Disparities** (2 of 4)

(1b): Consider establishing demographic data collection and use standards, requirements, and incentives. Paired with Opportunity #1a, California may work with private health care organizations to establish and require demographic data collection and reporting (e.g., race, ethnicity, sexual orientation, gender identity, disability status, etc.) against federal standards (e.g., OMB, USCDI v2.0), and ensure consistent and comprehensive demographic data collection across public agencies (e.g., Connecticut SB-1). Standards may be paired with common collection and reporting requirements (e.g., MCP/provider quality/performance reporting) and incentives to <u>use</u> data to identify and reduce disparities. Data collectors/users may require technical assistance to support new data collection and use practices.

DHCS analyzes Medi-Cal MCP quality data through its External Quality Review Organization (EQRO) process to assess potential differences in health outcomes between racial and ethnic population groups and shares those analyses with MCPs to guide interventions. DHCS also emphasizes increased data collection to reduce disparities and inequities through CalAIM. Covered California, meanwhile, continues to increase its race and ethnicity data reporting and use expectations for its QHPs. CDPH has also collected demographic and SDOH data to inform the state's response to COVID-19. More broadly, CMS has prioritized its expansion of the "collection, reporting and analysis of standardized data" – including race, ethnicity, language, sexual orientation, gender identity, and disability status - in its Medicare Equity Plan, as broader federal action in this area has been encouraged.

Discussion Question(s):

- Where federal USCDI V2.0 standards may not exist for important demographic data (e.g., disability functional/cognitive status), are there viable federal or national standards that may be referenced? If not, should California develop them?

- Which federal standards should be required for implementation across departments and health care organizations?

- What have been the most successful programs to incentivize/require demographic data collection and use?

Opportunity #1: **Improving SDOH and Demographic Data Collection and Use to Identify and Address Health Disparities** (3 of 4)

(1c): *Consider enhancing cross-state agency data sharing efforts to support the exchange of program enrollment data and consumer demographic and SDOH information to support cross-program service coordination and whole person care*.

California may enhance its interagency data sharing efforts in accordance with the Framework's vision and goals to allow – in compliance with federal law – the sharing of individuals' public program information across agencies and departments, and with health and human service organizations and consumers, to support coordinated service delivery and improve the health and wellbeing of Californians. Data sharing may include program enrollment, demographic, service utilization, and/or health and human service needs information captured by agencies and departments including:

- DHCS/Medi-Cal, including enrollment and identified social needs (if captured on claims/encounters);
- DPSS/CalFresh, including enrollment and other food insecurity indicators;
- BCSH/Homeless Data Integration System (HDIS), including enrollment and other housing stability indicators;
- DOJ/Criminal Justice Statistics Center (CJSC), including justice involvement and probation events or transitions;
- DSS/Child Welfare Services/Case Management System (CWS/CMS), including intake, screening, and health/social needs data; and
- Covered CA and CalPERS, including enrollment and identified social needs (if captured on enrollment, screenings, and claims/encounters).

Under CalAIM, health care organizations will be expected to identify SDOH needs directly from individuals, if not available directly through state systems or regional community information exchanges (CIEs), such as San Diego CIE and Access Sonoma (see case examples).

DHCS could potentially leverage enhanced federal Medicaid matching funds for "state expenditures to design, develop, install, or enhance" interoperable systems capable of identifying individuals' SDOH needs and sharing that information with appropriate medical and social support services (CMS guidance).

Discussion Question(s):

- What intra-state data exchanges are most critical to support informed public program delivery?

- Should state data sharing/interoperability be focused on state-to-payer/plan exchange, state-to-CIE exchange, state-to-county or -provider exchange, or some combination thereof?

Opportunity #1: **Improving SDOH and Demographic Data Collection and Use to Identify and Address Health Disparities** (4 of 4)

(1d): Consider advancing recommendations to federal government to improve demographic data collection nationally. Race and ethnicity data collection remain uneven across the health care data ecosystem, with applications limited for its use. And multiple federal standards also exist; HRSA for example does not align with USCDI v1 or v2. As such providers in HRSA(e.g., FQHCs) programs must now support both standards. Sexual orientation and gender identity data collection are also relative nascent, with federal standards only now emerging. Demographic data should accurately reflect the truth of the individual, though the technical systems and protocols for collection that presently exist do not always reflect this value – or collect/maintain needed meta information required to preserve that testimony (i.e., systems do not identify whether demographic information was provided directly by the member or collected through other sources). As California advances a Data Exchange Framework that prioritizes health equity, it should consider highlighting misalignment of national standards and gaps in our national data collection, curation, and use efforts for national awareness – particularly to the attention of HRSA, CMS and ONC, who may design new standards for future federal/national use.

Discussion Question(s):

- What legal, technical and operational gaps to demographic data collection might benefit from national attention?

Gap #2: **Provider Identity Management**

Gap #2: Robust provider, care team, and social service organization directories are not available or accessible to health and human service organizations across California.

Relevant AB 133 Provision(s): *Identify gaps, and propose solutions to gaps, in the life cycle of health information, incl. gaps in the: Linking, sharing, exchanging, and providing access to health information. [§130290(c)(3)(B)(iv)]*

Key Considerations:

- Provider identity management can be improved to support various objectives, including, but not limited to understanding bidrectional:
    - **Individual-to-provide**r relationships (i.e., attribution) to support care coordination;
    - **Provider-to-provider** data exchange addresses to ensure the appropriate and secure routing of individual information; and
    - **Provider-to-plan** data exchange (i.e., provider directories) to ensure plans maintain up-to-date network information to share with their members.
- California has invested significant public and private resources into improving **provider-to-plan** data exchange through Integrated Healthcare Association in California's Symphony project.
    - Other national provider directories include DirectTrust and the National Plan & Provider Enumeration System (NPPES) (National Provider Standard).
    - CMS's recent Interoperability and Patient Access Final Rule and California's SB-137 stipulate more rigorous requirements for certain plans to maintain up-to-date consumer-facing provider directories.
- While provider-to-provider address directories may be tied to provider directories, less progress has generally been made in ensuring their timeliness and reliability.
- Several challenges exist to developing robust provider identity management systems, including:
    - Many widely used identifiers have shortcomings for advancing the objectives above. For example, many billing providers have an NPI, but not all treating providers do. Further, both organizations and individual providers can have NPIs, potentially causing confusion.
    - Provider clinical, system affiliation, and technical/address information can often change, requiring updates to the systems of all organizations that depend upon it.
    - Provider identity management systems are most effective when they can be used across organizations and sectors; however, this requires transparent governance.
    - Social service providers often lack robust identity management processes that are compatible with identifiers and processes used in the health care sector. Some private sector organizations (such as kno2) offer solutions that facilitate data sharing between health and social service providers.

Opportunity #2: **Enhance Provider Directory Requirements to Incorporate Provider Address Information** (1 of 2)

(2a): Consider expanding upon the provider directory API Requirements in CMS's Interoperability and Patient Access Final Rule. California could require all signatories of the DxF DSA to maintain and update identity credentials. The requirement in CMS's Interoperability and Patient Access Final Rule (CMS-9115-F) that specified payers offer a public facing Provider Directory API using a FHIR-based API, specifically, the PDEX Payer Network Implementation Guide, could be expanded to include:

- All payers licensed in California, including Qualified Health Plans (QHPs); and
- DxF DSA signatories, such that all parties provide updated credentials to payers and to any qualifying health information exchange intermediaries with which they share data.

Discussion Questions:

- Should digital identity credential and contact information include Direct Addresses? FHIR API endpoints? Other information?
- Are there other national or state provider directory initiatives (e.g., DirectTrust, CTEN) that may be leveraged or aligned with?
- Should the DxF consider adopting national guidelines promulgated by NIST regarding identity proofing providers, authentication and requirements when using federated identity architectures?

Opportunity #2: **Enhance Provider Directory Requirements to Incorporate Provider Address Information** (2 of 2)

(2b): Consider requiring qualifying HIOs to participate in a federated provider identity management service. There is significant value in implementing identity and master data management as a shared service to reduce individual organizational burden. The DxF can establish a set of requirements for qualifying HIOs that they deploy master data management approaches to identity management that include technical systems, processes, governance, policies, and standards to establish a consistent reference identity for individuals, the data attributed to them, the identity of providers, provider membership in organizations, and patients attributed to them. (ONC's State Health IT Modular Functions for Value-based Payment Strategic Implementation Guide)

Discussion Question*:*

- Do national networks have similar requirements, and if so, can California adopt a similar process for qualifying CA-based data sharing intermediaries?

Gap #3: **Consumer Data Access**

Gap #3: Individuals consistently face challenges in accessing their health and human service records - directly or through selected third parties - in a manner that is convenient, timely and compliant with federal access requirements.

Relevant AB 133 Provision(s):
- *Identify gaps, and propose solutions to gaps, in the life cycle of health information, incl. gaps in the:*
    - *Linking, sharing, exchanging, and providing access to health information. [§130290(c)(3)(B)(iv)]*
- *Identify how all payers will be required to provide enrollees with electronic access to their health information, consistent with rules applicable to federal payer programs. [§130290(c)(3)(I)]*

Key Considerations:

- **Consumer Data Access and HIPAA.** Under, HIPAA, patients have a legal, enforceable right to access their health records maintained by a covered entity such as a provider or health plan. In reality, numerous barriers exist to accessing one's own health data including complex access requirements, consumer portals that are difficult to navigate, fragmented data, financial costs (e.g., printing fees), and often health care organization non-compliance.

- **Recent Regulations and Frameworks**. ONC's Cures Act Final Rule includes provisions that support consumer data access, including efforts to curtail information blocking. CMS's Interoperability and Patient Access Final Rule requires CMS-regulated payers to make patient data, including claims and encounter data, available to patients via a secure, standards-based API. TEFCA counts easy access to electronic health information for individuals and their authorized caregivers as one of its principles for trusted exchange.

- **Potential Opportunities.** Improving consumer data access will require an industry-wide effort with participation from both the public and private sectors.

Opportunity #3: **Ensure Consumer Access to their Health Information** (1 of 2)

(3a): Consider adopting policies to ensure consumers have meaningful access to their longitudinal health information across all health care organizations subject to AB-133, allowing them to make informed health care decisions. Potential policies and requirements to advance this objective may include:

- Expand federal information blocking and patient access API rules to <u>all</u> health care organizations subject to the DxF including:
    - All California licensed health plans and health care organizations listed in AB 133 subdivision (f)(1-6).
    - Requiring all health care organizations listed in AB 133 subdivision (f)(1-6) to implement and maintain a secure, standards-based (HL7 FHIR Release 4.0.1) API that allows patients to easily access their health information through third-party applications of their choice and made available electronically by the request of the individual.
- Provide consumers with bi-directional access to their health information maintained by health care organizations – including to add self-reported health information and correct inaccurate information to the extent allowed by law – in a manner that accommodates their preferred language, readability, disability access, and support access for those Californians who have limited access to technology or broadband and consider consumer health and IT literacy.
- Consumers should be provided with education and support by health care organizations on how to: access their health information; use their health information to inform their decision-making; and update their health information if inaccurate.

Discussion Questions:

- Where are the biggest consumer data access gaps beyond existing federal and state requirements? Should California seek to fill these gaps through the DxF process? If so, should consumer data access and educational responsibilities differ by type of health care organization?
- Consumer access APIs would require identity proofing, authentication and authorization. Should the state consider a centralized service coupled with digital identities?

Opportunity #3: **Ensure Consumer Access to their Health Information** (2 of 2)

(3b): Consider adopting policies to ensure consumers understand how their health information may be used and trust in the systems in place that govern its use. Potential policies and requirements to advance this objective may include:

- California should review its current Fair Information Practices, consider updates and develop stronger guidelines that can be linked with the state's Data Sharing Agreement and future State Policy Guidance. Guidelines may include transparency about data policies; limitations on health information collection, use, and disclosure; consent; data quality, integrity, and security protections; and ensuring accountability through appropriate audit trails and enforcement. Guidelines should be clear to consumers around how their health information will be shared and where they have the ability to provide consent or not prior for its exchange and use, in alignment with state and federal laws

- California should develop practices and policies to hold DSA participants accountable for participation in the appropriate exchange and use of consumer health information, including:
    - Monitoring and evaluating participation and adherence to policies regarding data sharing, safeguarding and use of health information;
    - Integrate explicit protections against misuse of health data;
    - Supporting health care organization training on consumer access to health information; and
    - Supporting consumer feedback mechanisms to improve data access.

Discussion Questions:

- What have been the most successful programs to educate consumers on how their health information may/may not be used to support informed consent?

- How can health care organizations most effectively be held accountable for appropriate consumer data exchange and use to support their health and wellbeing?

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Public Comment Period

Digital Identity Strategy Update

Digital Identities Strategy

AB133 requires that, by July 31, 2022, CalHHS in consultation with the Stakeholder Advisory Group, develop:

"a strategy for unique, secure digital identities capable of supporting master patient indices to be implemented by both private and public organizations in California."

Digital Identities Strategy
Development Plan: Approach and Timeline

Jan Assess DxF participant needs; explore overarching approaches

Feb Refine needs and explore strategy components

Mar Refine strategy components with emphasis on privacy, security

Apr Complete a draft strategy

May Refine strategy with AG; align potential requirements with DxF, DSA

Jun/Jul Finalize strategy for delivery to legislature (June, July 2022)

CalHHS will:

1) Keep the Advisory Group apprised of progress at each meeting
2) Bring key issues raised by focus groups to the Advisory Group for discussion

Focus Group - Goals

Goal of Each Focus Group

To gain input from specific stakeholder perspective on a strategy for digital identities for the Data Exchange Framework

First Meeting Objectives

1) Potential components of a strategy for digital identities
2) How each stakeholder would contribute to and use digital identities in the Data Exchange Framework

Digital Identities Focus Groups

CalHHS is convening expert focus groups across a number of stakeholder constituencies

HIOs
First Meeting Scheduled for Friday, 1/28

Health Plans
Scheduling TBD

Consumers
Scheduling TBD

Social Service Organizations
Scheduling TBD

Providers
Scheduling TBD

State Health and Human Service Departments
Scheduling TBD

Example Focus Group Questions

Strategy Components

1. Must the strategy include a statewide MPI?

2. What data elements comprise a digital identity?

3. Is there a need for a consensus "golden record" of the most accurate data elements?

Engagement

1. How might participants contribute data elements to a digital identity?

2. How might participants enhance accuracy to data elements?

3. How might participants use a common, shared digital identity?

Status Update

HIOs

Suggested members of **HIO focus group** to be convened **January 28**:

- Aadli Abdul-Kareem, OCPH HIE
- Bill Beighe, Santa Cruz HIO
- Jamie Franklin, Central Valley HIE
- John Helvey, SacValley MedShare
- Lori Hack, CAHIE
- Kate Horle, formerly CORHIO

- Alex Horowitz, Intrepid Ascent
- Tim Pletcher, MiHIN
- James Kirkwood, SHIN-NY
- Leo Pak, LANES
- Claudia William, Manifest MedEx

Consumer

Provider

Plan

Social Services

Please submit any suggestions for the consumer, provider, plan, or social services focus groups to Rim Cothren (robert.cothren@chhs.ca.gov).

CalHHS DxF staff will also continue to meet with CalHHS departments to obtain additional input

Digital Identities Strategy - Next Steps

Advisory Group members will:

Send CDII any final thoughts on focus group members

CalHHS will:

Report at the next Advisory Group meeting on progress of initial focus group sessions:

- Members of each focus group
- Schedule for meetings
- Initial discussions and findings

Bring any high-level issues that may arise in focus group meetings

Data Sharing Agreement (DSA) Subcommittee Update

DSA Subcommittee Status Update

Purpose

Support the CalHHS's Data Exchange Framework Stakeholder Advisory Group's development of recommendations for the creation of California's Data Sharing Agreement ("DxF DSA") as required by AB133.

Status Update

The DxF DSA Subcommittee met on Dec 22nd and Jan 18th. At the January 18th meeting, the DSA Subcommittee discussed: (1) threshold questions for data exchange, (2) the draft DxF DSA outline, and (3) draft versions of the first set of DxF DSA topics.

To date, DSA Subcommittee members and the public provided feedback on:

- **Threshold questions** regarding: (1) DSA signatories; (2) differing levels of technical readiness; (3) requirements for individual and proxy access to data; and (4) considerations for entities that are not Business Associates.
- **DSA topics** including: (1) breach, privacy, and security; (2) technology agnostic; (3) exchange purposes; and (4) requirement to respond

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DSA Subcommittee Meeting #4 (Feb 23rd)

Tentative Agenda

1. Welcome & Roll Call

2. Meeting Objectives

3. DxF DSA Content: Second Set of Topics

4. Closing Remarks

DxF Principles and HIT Capacity Gaps & Opportunities Feedback Update

Updated DxF Principles

> **Stakeholder feedback on the updated DxF Guiding Principles was congruous in some areas and divergent in others.**

Key updates to the <u>DxF Guiding Principles</u> (v5) based on stakeholder input included:

➢ *Principle 4: Promote Individual Data Access:*

  ➢ Acknowledged the need to address the digital divide to support equal access to health and human service information.

  ➢ Noted that consumers should have bidirectional access to their longitudinal health and human service information to correct possible errors, to the extent allowed by state and federal law.

➢ *Principle 5: Reinforce Individual Data Privacy & Security:*

  ➢ *Added subprinciple to establish procedures for sharing electronic consent between entities exchanging health and human services data in compliance with state and federal data sharing rules.*

Stakeholder comments as well as the revised data exchange principles that incorporate stakeholder feedback are available on the DxF website.

Updated HIT Capacity Opportunities

Stakeholder comments broadly supported the potential opportunities to address gaps in HIT capacity discussed during AG4 and provided thoughtful suggestions.

Key clarifications and revisions to the updated HIT Capacity Opportunities (discussed during AG Meeting #4) based on stakeholder input included, but were not limited to:

➤ **Opportunity #1:** Multi-Payer EHR Incentive Program
  - ➤ Potential EHR incentive program funding <u>could be directed towards adoption of CEHRT for HIPAA covered entities and other electronic documentation technologies for non-HIPAA covered</u> entities as long as those technologies are capable of and implemented to support California's DxF goals and objectives and DSA requirements.
  - ➤ Public and private payers <u>may choose to allow EHR incentive program funding to be used to upgrade providers' existing EHRs</u> as long as providers meet specified DxF goals and objectives and DSA requirements.
  - ➤ Guidance should be developed to support provider selection of technology and services that meet state data sharing requirements.

➤ **Opportunity #2:** HIE On-Boarding Program, Qualified Networks and State Data Sharing Requirements
  - ➤ A potential HIE onboarding program should support onboarding <u>to any network/data sharing intermediary</u> that meets the state's qualification requirements
  - ➤ HIE onboarding program funding should be used to <u>support onboarding</u>, not to defray ongoing costs associated with maintaining connections to qualifying information exchange intermediaries.

➤ **Opportunity #3:** Expand California Alert Notification Requirements
  - ➤ <u>Expand event notification requirements</u> described in <u>CMS-9115-F</u> to: require notifications to be sent to a beneficiary's health plan/payer; and, establish a goal to expand alert notification requirements to additional entities to alert care team members to changes in a client's incarceration, housing and other statuses.

Stakeholder comments as well as the revised HIT capacity opportunities that incorporate stakeholder feedback are available on the <u>DxF website</u>.

Closing Remarks

Next Steps

CalHHS will:

- Summarize and post meeting notes in advance of next meeting.

- Develop materials to support our next recommendation working session focused on establishing governance for the DxF.

Members will:

- Provide additional feedback on opportunities to address gaps related to data exchange standards, provider identity management, and consumer data access.

Advisory Group Workplan & Meeting Schedule

#	Date	Proposed Topics
6	March 3, 2022	*Opportunities*: Governance
7	April 7, 2022	*Opportunities*: Business Operations
8	May 18, 2022	*Opportunities*: Regulatory & Policy
9	June 23, 2022	Framework review

For more information or questions on Stakeholder Advisory Group meeting scheduling and logistics, please email Kevin McAvey (Kmcavey@manatt.com).