Data Exchange Framework Stakeholder Advisory Group Meeting #3

California Health & Human Services Agency

Wednesday, November 10, 2021
10:00 a.m. to 12:30 pm

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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.

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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

10:00 AM	**Welcome and Roll Call** • *John Ohanian, Chief Data Officer, California Health and Human Services*
10:10 AM	**Vision and Meeting Objectives** • *Dr. Mark Ghaly, Secretary, California Health and Human Services*
10:20 AM	**Principles of Data Exchange in California** • *John Ohanian*
10:55 AM	**Public Comment**
11:10 AM	**Barriers to Data Exchange in California** • *Jonah Frohlich, Managing Director, Manatt Health Strategies*
12:05 AM	**Data Exchange Framework Workplan** • *John Ohanian*
12:15 PM	**Data Sharing Agreement Subcommittee Update** • *Courtney Hansen, Assistant Chief Counsel, CalHHS CDII* • *Jennifer Schwartz, Chief Counsel, CalHHS CDII*
12:25 PM	**Closing Remarks** • *Dr. Mark Ghaly*

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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

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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

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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

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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

CalHHS GUIDING PRINCIPLES AND STRATEGIC PRIORITIES

Our Guiding Principles

Focus on equity

Actively listen

Use data to drive action

See the whole person

Put the person back in person-centered

Cultivate a culture of innovation

Deliver on outcomes

Our Strategic Priorities

Create an equitable pandemic recovery

Build a healthy California for all

Integrate health and human services

Improve the lives of the most vulnerable

Advance the well-being of children & youth

Build an age-friendly state for all

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SCENARIO: SERVING INDIVIDUALS WITH COMPLEX NEEDS

WHO

A 40-year-old Latino male with a diagnosis of schizophrenia and diabetes who is also experiencing housing instability. He is admitted to a mental health facility following an acute episode of schizophrenia.

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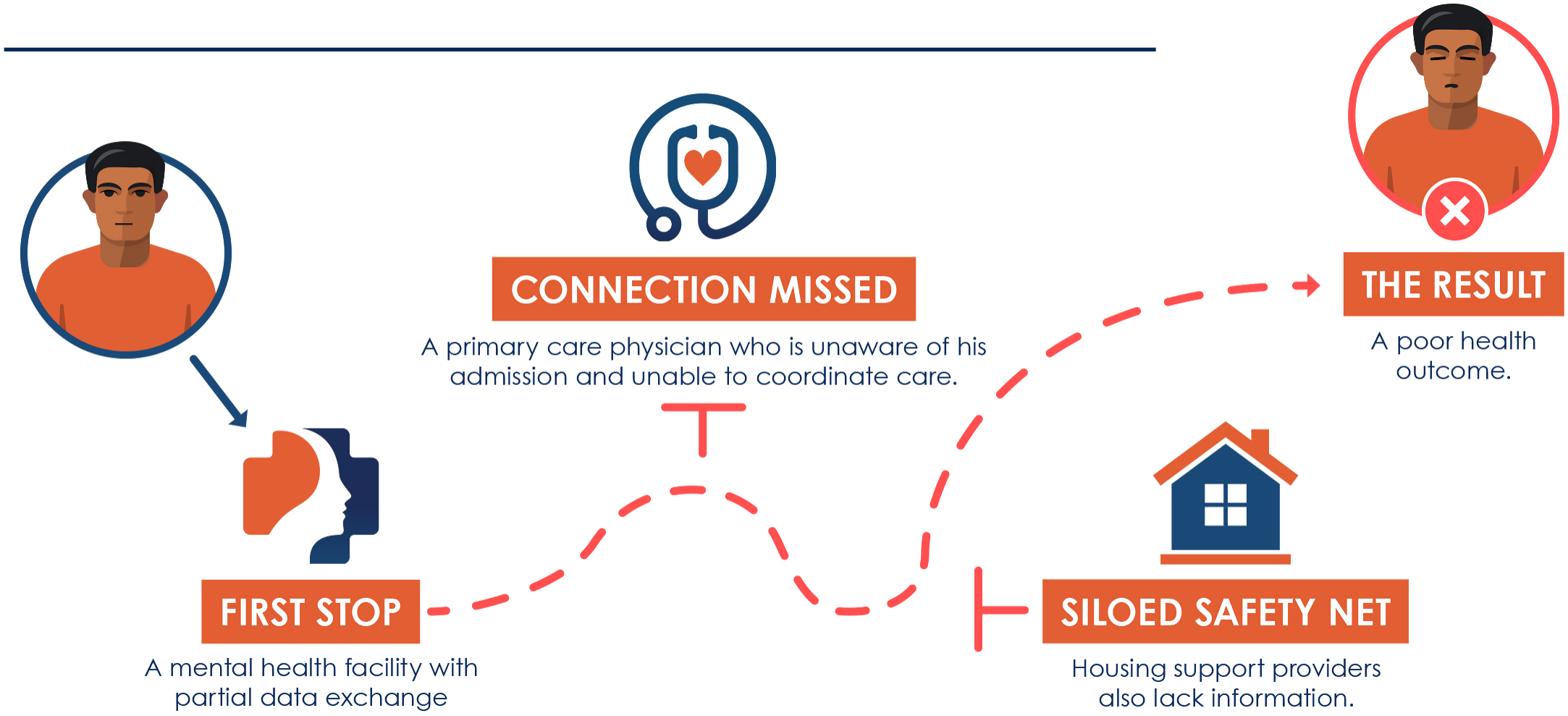
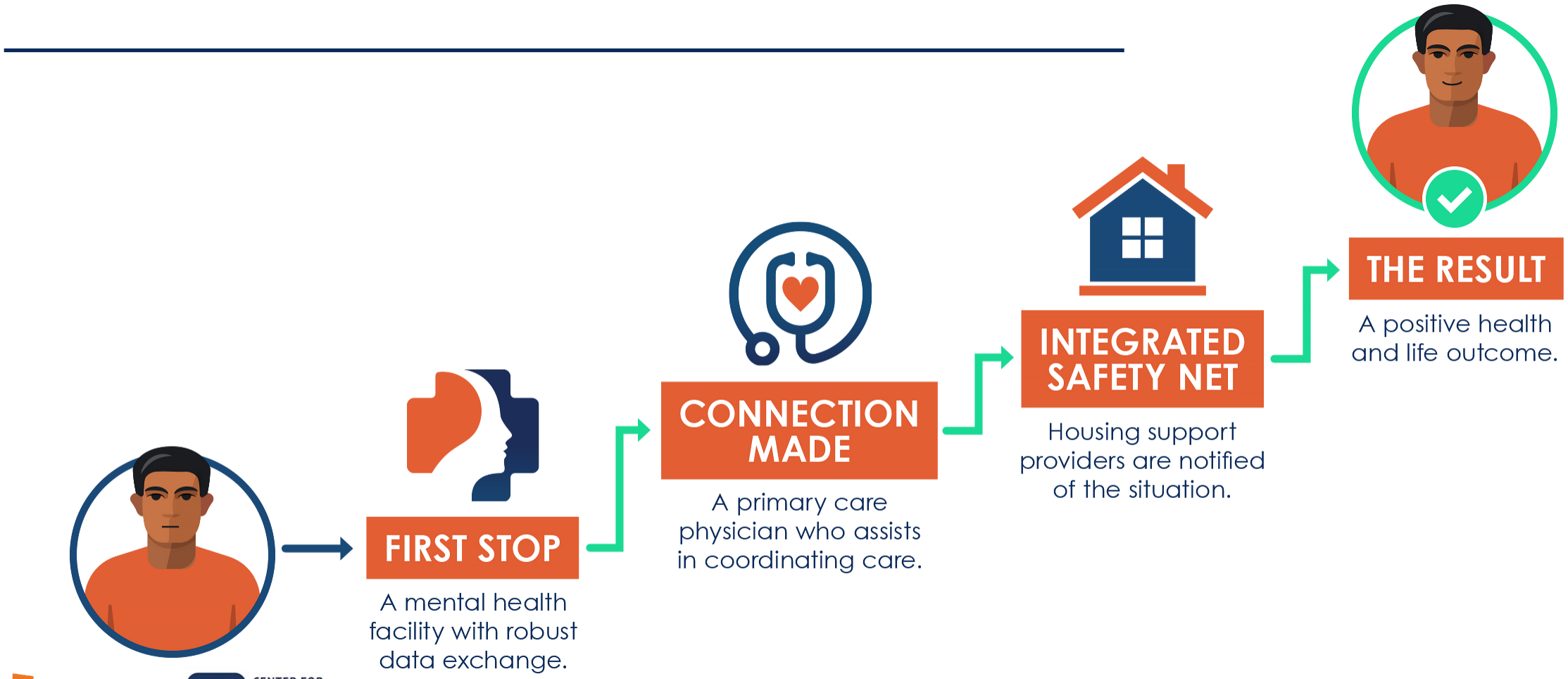
BEFORE... CALIFORNIA HAS ALL THE DATA EXCHANGE WE NEED



AFTER... CALIFORNIA HAS ALL THE DATA EXCHANGE WE NEED



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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.

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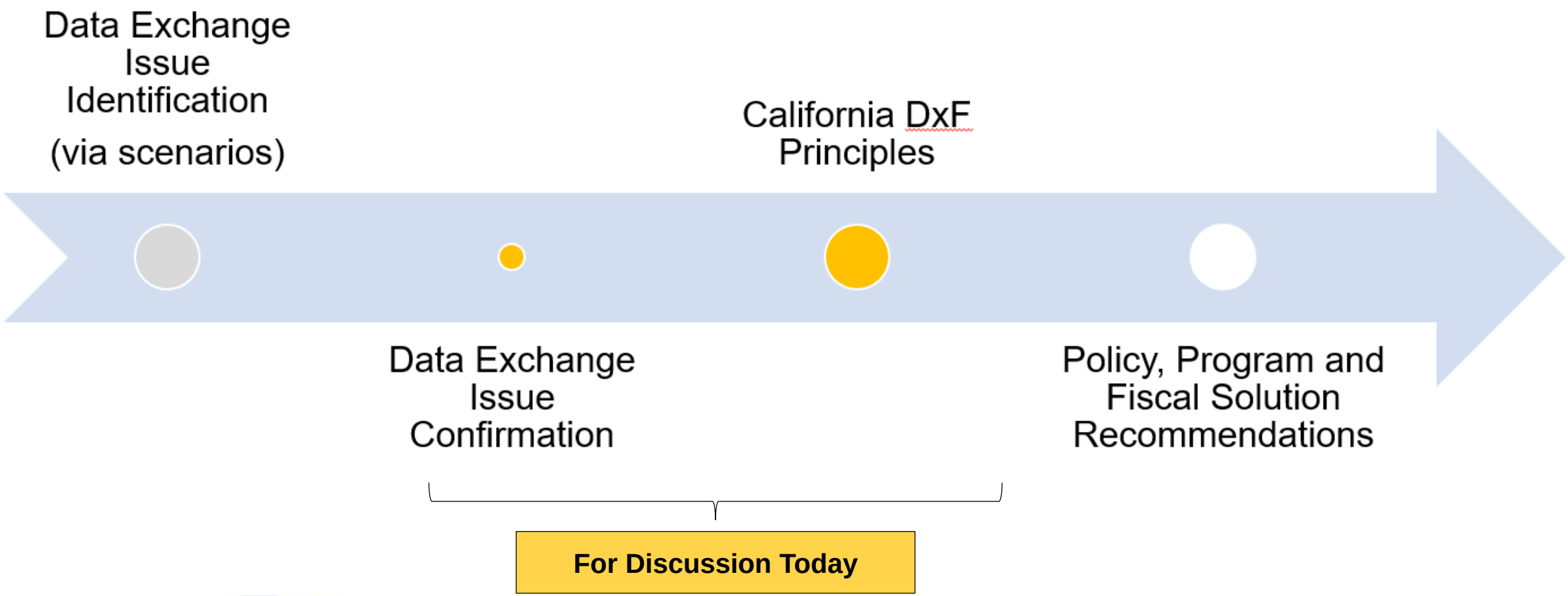
Meeting #3 Objectives

1. Discuss **draft DxF principles** that will guide state HIE policies, priorities and programs.
2. Discuss the **cross-cutting health information exchange barriers** we identified through our scenario exercise.
3. Review our **workplan** to address these barriers within our Data Exchange Framework through the months ahead.
4. Provide a **Data Sharing Agreement Subcommittee update**.

Principles of Data Exchange in California

Data Exchange Framework (DxF) Development Process



DxF Guiding Principles: Purpose

The CalHHS Data Exchange Framework (DxF) principles will be core expectations or "rules of the road" that establish minimum criteria to guide and govern the design and implementation of the DxF and electronic health information exchange in California.

How Principles Will be Used

- Guide the design and implementation of the DxF
- Support the deliberations and formulation of Advisory Group and its subcommittees' DxF and DxF Data Sharing Agreement recommendations
- Build trust among data exchange partners

DxF Guiding Principles: Development

How the Principles Were Developed

The DxF Guiding Principles were informed by the CalHHS Guiding Principles[1], Consumer and Patient Protection Principles for Electronic HIE in CA[2], and the ONC's TEFCA Principles for Trusted Exchange[3] in alignment with the requirements of AB 133.

1. CalHHS Guiding Principles. https://www.chhs.ca.gov/guiding-principles-strategic-priorities/
2. Consumer and Patient Protection Principles for Electronic HIE in CA. https://advocacy.consumerreports.org/wp-content/uploads/2013/02/HIE-Principles-6-10.pdf
3. ONC's TEFCA Principles for Trusted Exchange. https://www.healthit.gov/sites/default/files/page/2019-04/FINALTEFCAQTF41719508version.pdf

DxF Guiding Principles Overview & Feedback

Six guiding principles have been developed for discussion today

1. **Advance Health Equity**
2. **Make Data Available to Drive Decisions and Outcomes**
3. **Support Whole Person Care**
4. **Reinforce Patient Access, Privacy & Security**
5. **Adhere to Data Exchange Standards**
6. **Establish Clear & Transparent Data Use**

We are seeking Stakeholder Advisory Group feedback in the following areas

1. Are these the right principles to guide development and implementation of the California Data Exchange Framework?
2. Are the principles fully and appropriately described?
3. Are there other principles that should be included to guide the Advisory Group's work?
4. Should these be prioritized and listed in order of priority?

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Principle 1: Advance Health Equity

We must develop and implement data exchange policies, processes and programs to better understand and address inequity and disparities.

CalHHS	Consumer & Patient	TEFCA
Equity: We must be a leader in the fight for equity and strive to create programs that address persistent and systemic inequities. The COVID-19 pandemic showed us how so many people are far behind and that the distance to make up to achieve equity is driven by historical, deep seated structural factors of racism, sexism and other forms of discrimination. In order to create a state where all of us can have a chance to thrive based on our efforts and hard work, we cannot allow certain groups and individuals to be disadvantaged because of the color of their skin, gender identity, sexual orientation, age or disability. We will seek to lift all boats, but some boats need to be lifted more.	**Inclusivity & Equality**: All Californians should have full and equal use of electronic health information exchange and technology and their benefits, including California's underserved low-income communities, communities of color, people speaking primary languages other than English, people with disabilities, seniors and youth, immigrant residents, and rural and inner-city communities.	None

Principle 2: Make Data Available to Drive Decisions and Outcomes

We must share actionable and real-time information within and across sectors to better understand conditions at the level of the individual, within our communities, and across populations, and the impact of our programs so that we may identify opportunities and implement solutions that improve service delivery and outcomes.

CalHHS	Consumer & Patient	TEFCA
Use Data to Drive Action: We must better leverage our data to understand the current conditions in our communities, the impact of our existing programs and the opportunities to improve service delivery. While we have built good systems to amass data, we find ourselves data rich but information poor. Actionable and timely data will help us advance social and economic mobility and improve the health and well-being of children, families and individuals. **Deliver on Outcomes:** We must ensure that the delivery of our programs and services yield concrete and meaningful results. We will focus our attention and energy on work which will directly improve the lives of all Californians. We will continuously evaluate and adapt our programs to better address our clients' unmet needs while furthering our goal of delivering positive outcomes.	**Important Benefits for Population Health:** EHI exchange and technology should also be designed and used to improve health for the public and communities at large, such as promoting healthy environments and preventing unhealthy environments; reducing and preventing chronic disease, epidemic and health disparities; promoting patient safety and preventing medical errors; measuring and reporting the quality and performance of providers and facilities, and the comparative effectiveness of treatments; and reducing the cost of health care.	**Cooperation and Non-Discrimination**: Collaborate with stakeholders across the continuum of care to exchange EHI, even when a stakeholder may be a business competitor. **Population Level Data:** Exchange multiple records for a cohort of individuals at one time in accordance with applicable law to enable identification and trending of data to lower the cost of care and improve the health of the population.

Principle 3: Support Whole Person Care

We must promote and improve data collection, exchange, and linkages across health and human services organizations so that we may gain greater insight into the needs of the people we serve and can better meet individuals' whole person care needs.

CalHHS	Consumer & Patient	TEFCA
See the Whole Person: We must always think about what each person needs to thrive, always considering the cultural, economic and social factors that impact people's lives. We will integrate shared opportunities to meet individual needs across departments – both within government and across our community partners. Our focus will be on the needs of the people we serve, not on the siloed structures of government and its programs.	None	None

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Principle 4: Reinforce Patient Access, Privacy & Security

We must share health and human service information in a secure manner that is accessible to individuals and caregivers, ensures data integrity, and adheres to federal and state privacy law and policy.

CalHHS	Consumer & Patient	TEFCA
Put the Person back in Person-Centered: We must re-engage individuals and their communities so that programs are informed and structured to meet the diverse and unique needs of each community and person. Too often, "person-centered" programs stopped being about people and became focused on satisfying a specific funding source or administrative process. We will refocus our programs on the people being served.	**Important Benefits for Individual Health**: Electronic health information exchange and technology should be designed and used to improve individual health care and its quality, safety, and efficiency. Patients should have ready and complete electronic access to their health data as well as relevant tools and educational resources, in their primary or preferred languages, to make meaningful use of that information. The technology should facilitate active engagement of patients in their health care, and engagement of family members and others as the patient chooses or law provides. It should enable full coordination of the patient's care among diverse providers and systems. It should enhance the privacy and security of the patient's health information, and reduce costs. **Privacy and Security**: Health information exchange and technology must promote trust and protect the privacy, security, confidentiality, and integrity of health data. Strong privacy and security policies should be established to accomplish these ends, which are then supported by the technology necessary to implement and enforce them…	**Access**: Ensure that individuals and their authorized caregivers have seamless access to their EHI. **Privacy, Security and Patient Safety**: Exchange EHI securely and in a manner that promotes patient safety, ensures data integrity, and adheres to privacy policies.

Principle 5: Adhere to Data Exchange Standards

We must adhere to federal, state and industry recognized standards, policies, best practices, and procedures.

CalHHS	Consumer & Patient	TEFCA
None	None	**Standardization:** Adhere to industry and federally recognized standards, policies, best practices, and procedures.

Principle 6: Establish Clear & Transparent Data Use

We must adopt and communicate clear policies and procedures so that all Californians can understand both the purpose of data exchange and how data that are shared are to be used.

CalHHS	Consumer & Patient	TEFCA
None	**Openness and Transparency**: All data stewards should make their policies and practices regarding health information open and transparent to patients and to the public generally. Data stewards should inform individuals about what personal health information exists about them, for what purpose or purposes it may be used, who can access and use it, and who retains it. Data stewards should also maintain and provide individuals with corresponding audit trails. **Purpose Specification and Minimization**: The purposes for which personal health data are collected should be specified at the time of collection, and only the information reasonably necessary for those purposes should be collected.	**Transparency:** Conduct all exchange and operations openly and transparently.

Public Comment Period

Barriers to Data Exchange in California

Barriers Identification & Categorization

Scenario Discussion

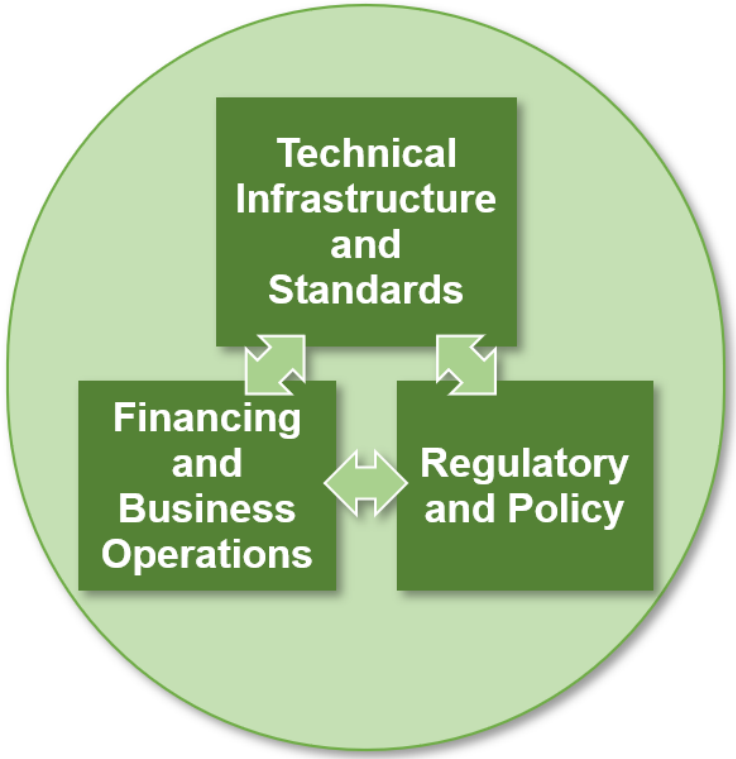
1. Coordinating Care for Individuals with Acute or Chronic Health Needs
2. Serving Individuals with Complex Health and Social Needs
3. Population Health & Value-Based Care
4. Supporting Emergency Responses
5. Supporting Public Health Responses
6. Coordinating Reentry Health Services

Barrier Identification

Cross-cutting barriers: issues that prevent data exchange across multiple scenario-examples where information would be beneficial to the health and wellbeing of the individual.

Barriers for critical exchanges: issues that prevent data exchange within specific, scenario-examples, where exchange would be beneficial to the health and wellbeing of the individual.

Barrier Categorization



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Barrier Categories

- ***Technical Infrastructure and Standards:*** barriers to health and human services organizations adopting health information technology, standards, and protocols that are required for efficient and secure sharing, access, and use of health and social information.

- ***Financing and Business Operations:*** financing, incentives and business operations barriers that present themselves to health and human service organization as they implement health information exchange.

- ***Regulatory and Policy:*** federal and state regulatory and policy barriers that health and human service organizations face when sharing, collecting, and using health information with and from external organizations.

Major Barriers: Technical Infrastructure & Standards (1/2)

1. **EHR Adoption.** EHR adoption is limited among some health care organizations, particularly those without access HITECH and other federal and state modernization funding opportunities (e.g., behavioral health, long term care facilities, correctional facility health providers); not all EHRs are certified or have capacity to share data using national standards.
2. **Technological Capacity at Human Service Organizations.** Many human service organizations have limited technological capacity to store, electronically share, and use health and human service information.
3. **Event Alerts**. Alerts and notifications today are mostly limited to transitions from acute care facilities and are not widespread for housing, incarceration status and other important events.
4. **Provider and Person Identity Management.** Robust provider, care team, and social service organization directories and person identity matching services are not available or accessible to health and human service organizations across California.

Major Barriers: Technical Infrastructure & Standards (2/2)

5. **Consent Management.** Robust consent management services that would indicate a person's authorization to disclosure sensitive information to other institutions aren't available to health and human services organizations in California.
6. **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.
7. **Cross-Sector Data Exchange.** Some state, county and other local government public health and human service organization information systems have limited capabilities to electronically exchange usable health information with health care organizations in real-time.
8. **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.

Major Barriers: Financing and Business Operations

1. **Education & Technical Assistance.** Many health and human service organizations will likely require implementation guidance and technical assistance to adopt processes and technology to comply with the state Data Exchange Framework and Data Sharing Agreement requirements.
2. **Privacy and Security Policies.** Many health and human service organizations need to better understand data collection, exchange, and use policies to allow information to be consistently exchanged – with appropriate patient consent – in a secure, timely and usable manner.
3. **Financial Incentives and Business Rationale.** Most health and human service organizations are not funded or incentivized to - and do not have a business imperative to - exchange information with other organizations within and across sectors.
4. **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.

Major Barriers: Regulatory & Policy

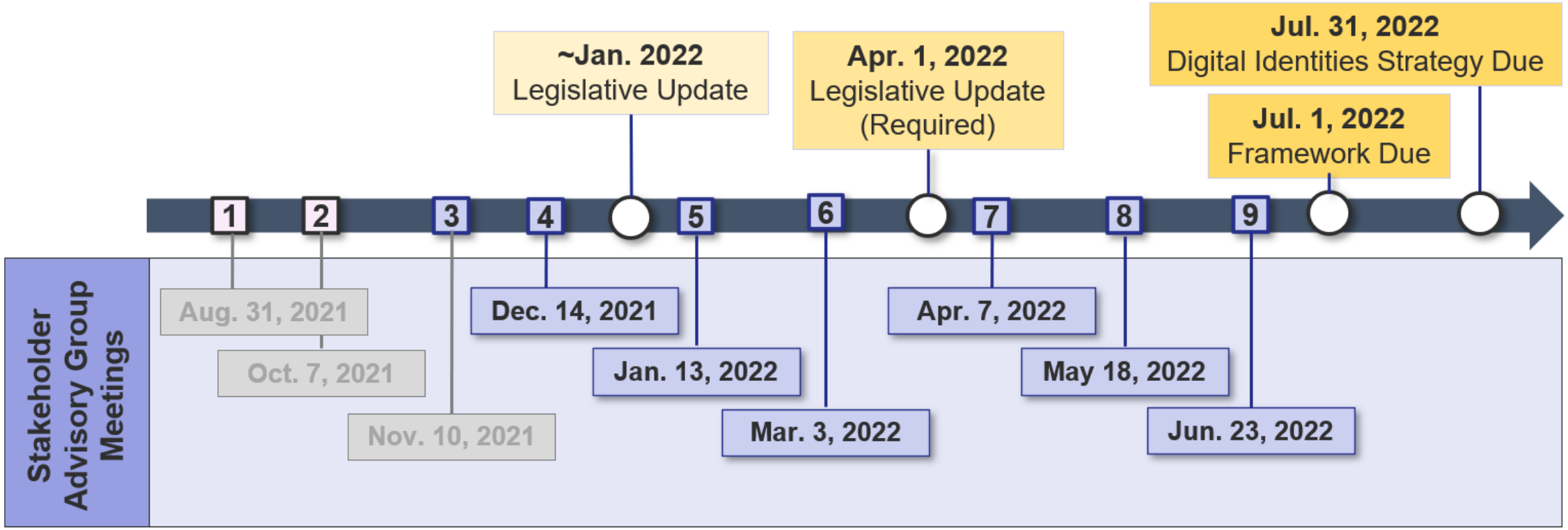
1. **Data Exchange Policies.** Numerous federal and state laws, regulations and policies that govern the exchange of physical, behavioral health, social and human services data create real or perceived barriers to sharing information that is necessary to inform whole person care and population health needs.
    - i. **Physical and Behavioral Health.** Certain data types, including behavioral health (e.g., mental health, substance use disorder), HIV/AIDS test results, some sexual health information, and information pertaining to minors, are governed by specific federal and state rules and regulations that require patient authorization to disclose information for data sharing purposes.
    - ii. **Social and Human Services.** Federal and state rules and regulations may prohibit the exchange of certain types of social and human service data (including housing, food security/support), without patient authorization.
    - iii. **Criminal History.** Unlike federal law, California law does not permit the disclosure of some criminal record identifiers for purposes of coordinating care.
    - iv. **Public Health Data**. Some public health data may be collected and used only for specified purposes.

   These federal and state policies result in a lack of understanding and confusion about what is and is not permissible to exchange with - or without - signed patient data sharing authorization.

Data Exchange Framework Workplan

Data Exchange Framework: Timeline

CDII will provide a project status update to the legislature in January, before delivering a more formal and comprehensive legislative update by April 1st.



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Data Exchange Framework: Workplan

The Advisory Group will focus on developing specific and actionable recommendations to address barriers through the remainder of our sessions.

#	Date	Proposed Topics
4	December 14, 2021	*Recommendations*: Technical and Digital Identity
5	January 13, 2022	*Recommendations*: Data Standards (SDOH, Health Equity)
6	March 3, 2022	*Recommendations*: Business Operations
7	April 7, 2022	*Recommendations*: Regulatory & Policy
8	May 18, 2022	*Recommendations*: Governance
9	June 23, 2022	Framework review

Stakeholder Advisory Group recommendations will inform Data Sharing Agreement Subcommittee (DSA) activities; the Advisory Group will receive regular updates on DSA progress from CDII leadership.

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Data Sharing Agreement (DSA) Subcommittee Update

DSA Subcommittee Purpose, Role, and Meeting Agenda

Purpose

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

Role

The DSA Subcommittee will:

- **Inform the development of a data sharing agreement**
- **Review drafts** of the data sharing agreement and related public comments
- **Advance recommendations** to the Stakeholder Advisory Group on the following topics:
  - **Technical and operational issues** related to the development of a single statewide data sharing agreement.
  - **Supporting alignment** with existing federal and state data sharing laws, policies, and frameworks.
  - **Questions** raised by the Stakeholder Advisory Group.

DSA Subcommittee Meeting #1 (Nov. 8th)

I. Welcome and Introductions
II. Vision and Meeting Objectives
III. AB133 and DSA Requirements
IV. DSA Subcommittee Charge, Charter, & Workplan
V. Overview of Existing Data Sharing Agreements
VI. CA DSA: Basis for the Agreement and Core Content (Survey Results)
VII. Closing Remarks

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Closing Remarks

Next Steps

CHHS will:

- Summarize meeting notes and circulate for review over email in advance of next meeting.
- Develop pre-read and presentation materials to support our first recommendation development working session

Members will:

- Provide additional feedback on major barriers and gaps in health information exchange that should be addressed (or acknowledged) in the DxF
- Review meeting notes and provide feedback to CHHS staff

Advisory Group Meeting Schedule

Meeting	Date
Advisory Group Meeting #4	**December 14, 2021, 10:00 AM to 12:30 PM**
Advisory Group Meeting #5	January 13, 2022, 10:00 AM to 12:30 PM
Advisory Group Meeting #6	March 3, 2022, 10:00 AM to 12:30 PM
Advisory Group Meeting #7	April 7, 2022, 10:00 AM to 12:30 PM
Advisory Group Meeting #8	May 18, 2022, 10:00 AM to 12:30 PM
Advisory Group Meeting #9	June 23, 2022, 10:00 AM to 12:30 PM

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

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Appendix

DSA Subcommittee Roster (1 of 2)

Name	Title	Organization
John Ohanian *(Chair)*	Chief Data Officer	California Health & Human Services Agency
Ashish Atreja	CIO and Chief Digital Health Officer	UC Davis Health
William (Bill) Barcellona	Executive Vice President for Government Affairs	America's Physician Groups (APG)
Jenn Behrens	Chief Information Security Officer	LANES
Michelle (Shelly) Brown	Attorney	Private Practice
Louis Cretaro	California Welfare Directors Association of California	Lead County Consultant
Elizabeth Killingsworth	General Counsel & Chief Privacy Officer	Manifest Medex
Helen Kim	Senior Counsel	Kaiser Permanente
Patrick Kurlej	Director, Electronic Medical Records & Health Information Exchange	Health Net
Carrie M. Kurtural	Attorney & Privacy Officer	CA Dept. of Developmental Services

DSA Subcommittee Roster (2 of 2)

Name	Title	Organization
Steven Lane	Clinical Informatics Director | Family Physician	Sutter Health | Palo Alto Medical Foundation
Lisa Matsubara	General Counsel & VP of Policy	Planned Parenthood Affiliates of California
Deven McGraw	Lead, Data Stewardship and Data Sharing, Ciitizen Platform	Invitae
Eric Raffin	Chief Information Officer	San Francisco Department of Health
Morgan Staines	Privacy Officer & Asst. Chief Counsel	CA Dept. of Health Care Services
Ryan Stewart	System VP, Data Interoperability and Compliance	CommonSpirit Health
Lee Tien	Legislative Director and Adams Chair for Internet Rights	Electronic Frontier Foundation
Belinda Waltman	Acting Director, Whole Person Care LA	Los Angeles County Department of Health Services
Terry Wilcox	Director of Health Information Technology/Privacy & Security Officer	Health Center Partners