

## CalHHS Data Exchange Framework

### *Data Exchange Scenarios*

July 1, 2022

### Introduction

This section introduces six scenarios: potential events, combinations of events, or sets of activities that would require the exchange of health and/or human services information between actors in support of Californians' health and well-being. Examining scenarios through the Data Exchange Framework (DxF) development process allowed the DxF Stakeholder Advisory Group to:

- Identify shortcomings of California's current system of electronic information exchange; and
- Develop policy, program, and fiscal recommendations and actions that can be incorporated into the Data Exchange Framework to overcome barriers.

The six scenarios include:

1. **Acute or Chronic Health Needs:** Addressing the health and social needs of individuals with acute or chronic health conditions.
2. **Complex Health and Social Needs:** Addressing the health and social needs of individuals with complex medical and behavioral health conditions and social needs.
3. **Population Health and Value-Based Care:** Addressing the health and social needs of individuals and populations across the continuum of care using data-driven risk stratification, predictive analytics, and standardized assessments.
4. **Emergency Responses:** Addressing the health and social needs of individuals and populations by ensuring that emergency response providers and disaster health care volunteers have access to individuals' clinical records and other relevant information during emergencies.
5. **Public Health Responses:** Addressing the health and social needs of Californians by strengthening public health surveillance, research, preparedness, and response to emergencies.
6. **Coordinating Reentry Health Services:** Addressing the health and social needs of individuals as they transition from incarceration back into the community.

Each scenario has been illustrated with an example of how it might unfold, including:

1. An illustration or "story," from an individual's perspective, as he/she/they confront(s) a triggering adverse event and engage(s) with health and human service organizations that are required to exchange information to address the individual's needs; and

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2. A summary of the key data exchange challenges health and human services organizations confront when striving to meet the individual's needs.

Scenarios are intended to surface the most pressing data exchange needs, highlight existing gaps, and guide the development of policy and program DxF recommendations (“opportunities”). The scenarios are simplified illustrations and are not intended to be a comprehensive inventory of all possible health and human service organizations, data exchanges, and challenges that may exist within a given scenario.

## A. Coordinating Care for Individuals with Acute or Chronic Health Needs

### Description

Addressing the health and social needs of individuals with acute or chronic care needs.

### Current State and Illustrative Example

Many individuals receive health care from multiple unaffiliated providers, resulting in care coordination challenges. Despite widespread adoption of electronic health records (EHRs), there remain significant barriers to seamless exchange of data to effectively coordinate care.<sup>1</sup>

#### *Illustrative Example*

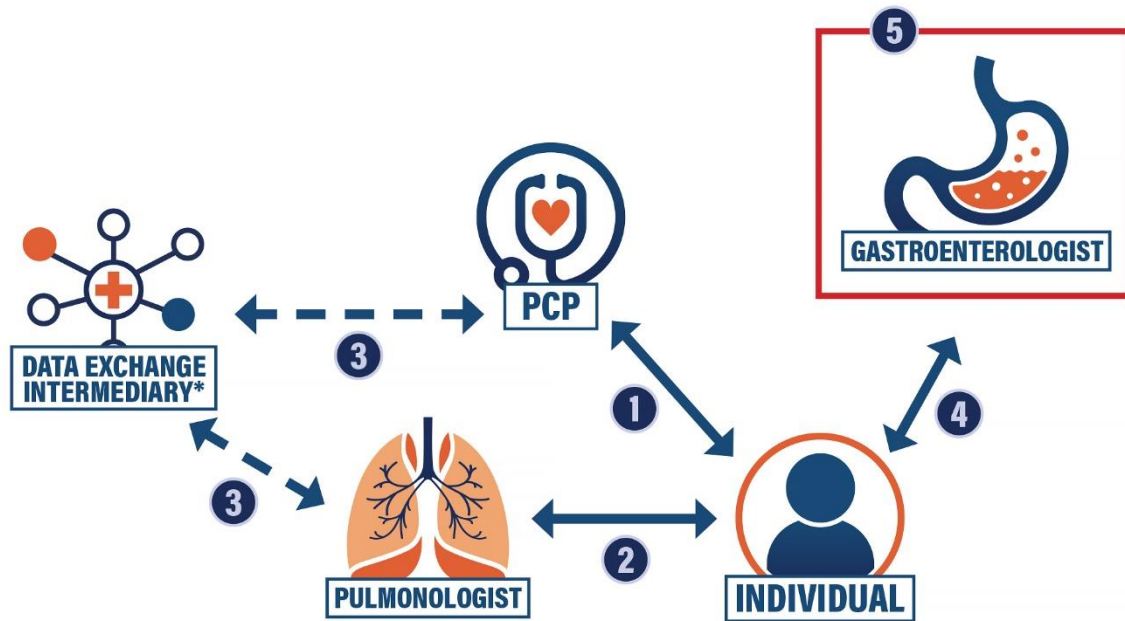
A 70-year-old woman is undergoing treatment for hypertension and chronic obstructive pulmonary disease (COPD). Her primary care provider (PCP) refers her to a specialist, a gastroenterologist, after she presents with persistent gastrointestinal distress. The gastroenterologist diagnoses her with inflammatory bowel disease (IBD), and she begins to receive treatment for the condition in addition to the care she receives from her PCP and pulmonologist. None of the three providers work for or within the same health system or participate in a common provider network.

The PCP and the pulmonologist use a common EHR system that allows for data exchange. Shared participation in the EHR vendor network allows the two providers to access the individual's progress notes and medication information across both practices to inform care plans and avoid contraindicated care. However, the gastroenterologist is a solo practitioner and does not participate in the EHR vendor network or in any data exchange intermediary. Instead, the gastroenterologist shares information with other providers primarily through telephone discussions and use of a fax machine. The gastroenterologist's data access and exchange limitations result in her having incomplete information and being unable to share complete patient records with the individual's PCP and pulmonologist; these limitations also necessitate the individual spending large portions of provider visit time relaying information about treatment received in other settings. However, the individual has trouble recalling her treatment plan, prescribed medications, and other important details, putting her at greater risk of misdirected or delayed care. If the individual's providers could electronically exchange this individual's health record, or if a health plan were able to furnish her complete

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<sup>1</sup> Fewer than half of U.S. primary care providers reported being able to receive information from specialists about changes to patients' medications or care plans, according to one international survey. "2019 Commonwealth Fund International Health Policy Survey of Primary Care Physicians," Commonwealth Fund (Commonwealth Fund, December 10, 2019), <https://www.commonwealthfund.org/publications/surveys/2019/dec/2019-commonwealth-fund-international-health-policy-survey-primary>.

health record from both clinical and administrative data sources (as intended by CMS' [Interoperability and Patient Access Rule](#)), the individual would be much better supported in her ability to both inform and participate in her treatment plan.



\*Data exchange intermediary may include a health information organization (HIO), national network, EHR vendor network, or another intermediary

### Data Exchange & Process Steps

1. Individual engages primary care provider (PCP) for treatment of hypertension and general health needs.
2. Individual engages pulmonologist (specialist) for treatment of COPD.
3. PCP and pulmonologist are engaged in data sharing with a data exchange intermediary.
4. Individual engages gastroenterologist (specialist) for treatment of newly diagnosed IBD.
5. Gastroenterologist is not engaged in data sharing with a data exchange intermediary.

## Key Challenges<sup>2</sup>

The following challenges were identified in this scenario.

**Gaps in Data Infrastructure:** While overall adoption of electronic data infrastructure has grown significantly over the past two decades, technological gaps persist for some sectors and actors. For example, there has been substantial growth in EHR adoption among California's acute care hospitals (increasing from 46% in 2012 to 83% in 2019<sup>3</sup>), and approximately 80% of physician practices have adopted an EHR as of 2017.<sup>4</sup> However, some smaller hospitals and physician practices, behavioral health, long-term and post-acute care, and safety-net providers face particular challenges – primarily financial and technical – when adopting technical infrastructure to share data with other entities that provide care for the same individuals. Additionally, less than half of surveyed California skilled nursing facilities (SNFs) reported being fully electronic for many critical care functions, e.g., documenting clinical notes (39%), viewing lab results (28%), viewing image reports (22%), and clinical decision support for medication (33%).<sup>5</sup>

**Barriers to Data Exchange:** Availability of base data infrastructure does not guarantee the ability to exchange usable data. In California, gaps in infrastructure extend to the availability of data exchange intermediaries: not all EHR vendors offer inter- and intra-provider information exchange, and up to 19 of California's 58 counties have limited access to an HIO to support data exchange.<sup>6</sup> Nationally, in 2018, such barriers resulted in fewer than half of non-federal acute care hospitals reporting being able to find patient health information and send, receive, and integrate patient summary-of-care records from sources outside their health system.<sup>7</sup> Barriers to effective data exchange include lack of interoperability between EHRs (particularly among providers using non-certified EHR technologies), challenges with individual and provider identity matching, and absence of key data types.

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<sup>2</sup> For more detailed discussions of current state health information technology and exchange gaps and opportunities to address them, see the DxF Landscape and Gaps and Opportunities sections posted on the [CalHHS DxF website](#).

<sup>3</sup> The American Hospital Association (AHA) Annual Survey – IT Supplement changed response options in 2019, which likely accounts for the decrease in EHR adoption rates from 97% in 2018 to 83% in 2019.

<sup>4</sup> Julia Adler-Milstein et al., "California Health IT Landscape Assessment" (San Francisco, CA: University of California, San Francisco, 2022).

<sup>5</sup> Ibid.

<sup>6</sup> Mark Elson, "Issue Brief Overview of Network Types and Characteristics: Overview of Network Types and Characteristics," chcf.org (California Health Care Foundation, August 2021), <https://www.chcf.org/wp-content/uploads/2021/02/HIECAOverviewNetworkTypesCharacteristics082021.pdf>.

<sup>7</sup> Yuriy Pylypchuk et al., "State of Interoperability among U.S. Non-federal Acute Care Hospitals in 2018," The Office of the National Coordinator for Health Information Technology, March 2020, <https://www.healthit.gov/sites/default/files/page/2020-03/State-of-Interoperability-among-US-Non-federal-Acute-Care-Hospitals-in-2018.pdf>.

## B. Serving Individuals with Complex Health and Social Needs

### Description

Addressing the health and social needs of individuals with complex medical and behavioral health conditions and social needs.

### Current State and Illustrative Example

Individuals with complex health and social needs may receive care from a spectrum of unaffiliated primary care, specialty care, behavioral health, and human services providers, each providing services to address specific needs of an individual – and all potentially benefitting from stronger information sharing and service coordination.

#### *Illustrative Example<sup>8</sup>*

A 40-year-old Latino male with schizophrenia and diabetes who is experiencing housing instability is admitted to a mental health facility following an acute episode of schizophrenia. He is covered by Medi-Cal. The mental health facility does not send or receive event notification alerts,<sup>9</sup> have a certified EHR, or connect to an HIO, national network, EHR vendor network, or any other data exchange intermediary. As a result, clinicians at the mental health facility are unable to digitally access the individual's medical record without identifying and contacting his previous providers and, as a result, remain unaware of his diabetes. The individual's PCP has a certified EHR that is connected to an HIO, but she is unaware of the individual's admission to a mental health facility and thus is unable to coordinate care and support the development of a treatment plan. Similarly, the individual's Medi-Cal plan does not receive a notification that the individual has been admitted, preventing the health plan from quickly coordinating supportive services.

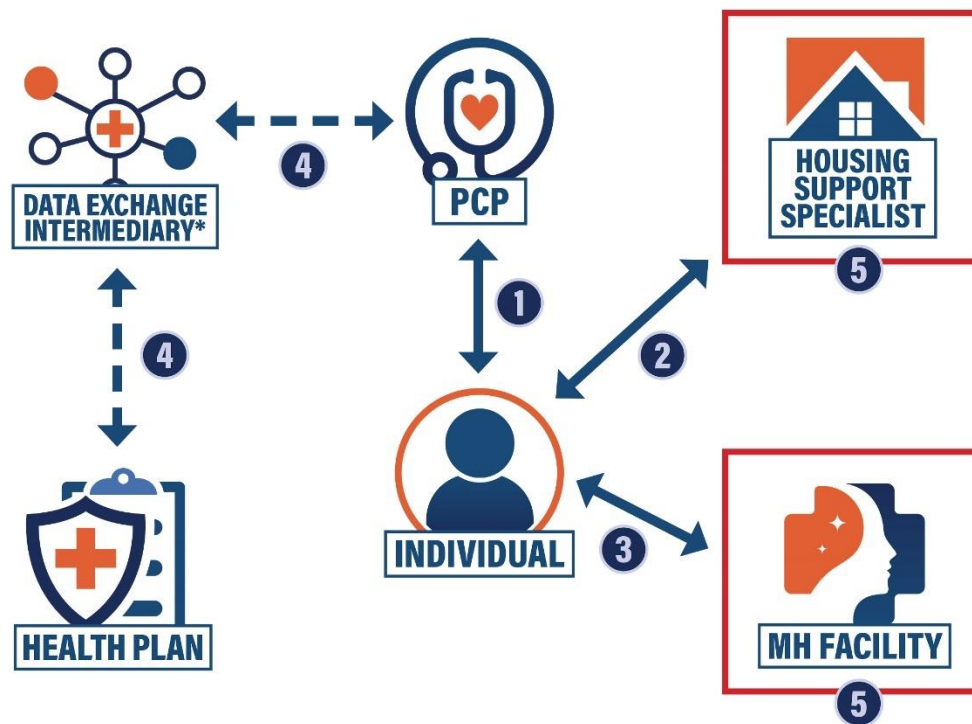
The housing support specialist at the community-based organization (CBO) who supported the individual in finding temporary housing also remains unaware of the individual's hospitalization. After several failed attempts to contact the individual to renew his housing placement, the housing support specialist suspends further outreach efforts and the individual loses his source of housing. Since the providers at the mental health facility do not have access to the individual's housing information, both they and the individual are unaware that the individual no longer has a place to live, and they discharge the individual once he is stabilized.

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<sup>8</sup> Scenario based on a scenario originally developed for a California Health Care Foundation Issue Brief: [Why California Needs Better Data Exchange: Challenges, Impacts, and Policy Options for a 21st Century Health System](#).

<sup>9</sup> The scenario occurred before the effective date of the CMS Patient Access and Interoperability final rule, which requires hospitals that bill Medicare or Medicaid to provide admission, discharge, and transfer (ADT) data.

The individual is forced to reside at a homeless shelter while he attempts to reengage with the housing support specialist to renew his housing placement. The shelter does not have a refrigerator for the individual to store his insulin, putting him at greater risk of acute and long-term complications from diabetes.



\*Data exchange intermediary may include a HIO, national network, EHR vendor network, or another intermediary.

Data Exchange & Process Steps
<ol style="list-style-type: none"> <li>1. Individual engages PCP for treatment of diabetes.</li> <li>2. Individual engages housing support specialist to secure safe, affordable housing</li> <li>3. Individual is admitted to a mental health (MH) facility to receive treatment for psychiatric symptoms.</li> <li>4. PCP and health plan are engaged in data sharing with a data exchange intermediary.</li> <li>5. MH facility and housing support specialist are not engaged in data sharing with a data exchange intermediary.</li> </ol>

### Key Challenges<sup>10</sup>

The following challenges were identified in this scenario.

<sup>10</sup> For more detailed discussions of current state health information technology and exchange gaps and opportunities to address them, see the DxF Landscape and Gaps and Opportunities sections posted on the [CalHHS DxF website](#).

**Gaps in Data Infrastructure:** Behavioral health providers and many small and under-resourced safety-net providers often lack technical infrastructure – including certified EHR technology – capable of exchanging clinical and behavioral health data with other providers to support care management and coordination.<sup>11</sup> Further, not all providers with certified EHR technology are connected or have access to a data exchange intermediary, or actively engage in cross-sector data sharing. CBOs that provide housing support and other services often do not have technologies or platforms to share and receive social or health information with or from other providers.

**Absence of Key Data Types:** National networks, HIOs, and EHRs often have limited capabilities to exchange social determinant of health (SDOH) data, including housing data. Closed-loop referral networks and emerging community information exchanges (CIEs) (e.g., Alameda County Care Connect, CIE San Diego) can share some SDOH data but are still not present across much of California. And health plans often do not have ready access to information needed for accurate and timely assessment of medical necessity. This means, for example, health plans cannot develop an automated or artificial intelligence (AI)-driven process to pre-authorize prescriptions and services based on the individual's historical diagnoses.

**Complex Data Exchange Rules and Regulations:** Many federal and state laws, regulations, and policies that govern the exchange of physical, behavioral health, and human services data can create real or perceived barriers to sharing information that is necessary to inform the care of individuals with complex health and social needs. These regulations can create challenges for consent management by imposing a variety of consent processes and time frames on sharing an individual's data.<sup>12</sup> For example, certain behavioral health and substance use data is protected by 42 C.F.R. Part 2, which requires the individual's written authorization to share data; however, the lack of universal consent management systems and processes hampers data sharing.

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<sup>11</sup> Twenty Whole Person Care (WPC) pilots (80%) reported difficulty implementing planned data sharing systems or integrating health and human services data, and 12 pilots (48%) identified data sharing as one of the biggest barriers to implementing WPC. Emmeline Chuang et al., "Integrating Health And Human Services In California's Whole Person Care Medicaid 1115 Waiver Demonstration: An overview of a California demonstration program focused on improving the integrated delivery of health, behavioral health, and social services for certain Medicaid beneficiaries," *Health Affairs*, April 2020, 639–648.

<sup>12</sup> Sixteen WPC pilots (64%) identified patient privacy and confidentiality regulations as a major root cause of these barriers, and nine pilots explicitly referred to Title 42 of the Code of Federal Regulations, Part 2, as complicating efforts to share data on substance use treatment. *Ibid.*



## C. Promoting Population Health and Value-Based Care

### Description

Addressing the health and social needs of individuals and populations across the continuum of care using data-driven risk stratification, predictive analytics, and standardized assessments.

### Current State and Illustrative Example

Health care organizations are increasingly being held accountable for managing the health of their broad and diverse populations, a responsibility reflected in their contracting, payment arrangements, and workforce and health information technology and exchange needs.

#### *Illustrative Example*

An African American non-binary teenager has been experiencing respiratory distress and visits their assigned PCP for diagnosis and treatment. The PCP performs a new patient screening, collecting information on their health history, and an examination, where they are diagnosed with asthma. The PCP prescribes a temporary inhaler and provides a referral to a specialist for a follow-up evaluation. The teenager, however, leaves the visit feeling uncomfortable with the interaction and does not pick up the inhaler from the pharmacy.

The PCP files a claim with the health plan for the new patient visit and examination, noting the asthma diagnosis. The health plan's population health management system uses the claims-based information to classify the teenager in a higher-risk asthmatic clinical condition cohort. The PCP's recorded demographic information is not transmitted to the health plan, as such information is not recorded in a standard claims-based transaction, and neither is the alert the PCP receives regarding the unfilled prescription.

During the following weeks, the teenager visits the school-based clinic on several occasions, reporting tightness in their chest. The nurse – with a limited, paper-based health history and no access to clinical information through a data exchange intermediary – re-diagnoses the symptoms as allergies. Neither the teenager's health plan nor their PCP are notified of the visits.

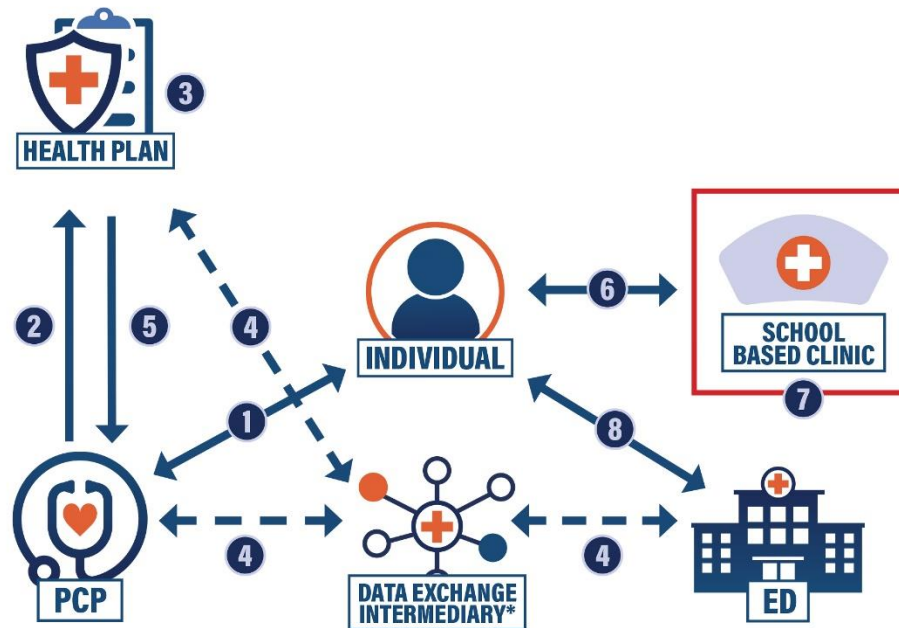
When a wildfire breaks out in a neighboring county, and prevailing winds direct smoke into the teenager's community, the health plan alerts area PCPs – including the teenager's PCP – of increased risk for asthmatics through a data exchange

intermediary's secure messaging service.<sup>13</sup> However, as with the prescription alert, the PCP does not see the health plan's message among the hundreds it receives daily. The health plan also makes direct, targeted outreach to high-risk members with asthma, but the teenager is not recorded as "high-risk" as the health plan does not know of the unfilled prescription; there is no claims-based record of specialist care, and – while the health plan is piloting dedicated support for LGBTQIA individuals – it does not yet have this information on record for existing members. While the PCP may have access to this important demographic and clinical information, it does not have the analytic systems to generate these alerts for its small practice or the capacity and training to meaningfully implement them. Neither the health plan nor the provider has a record of the teenager's worsening condition as observed at the school-based clinic.

When the teenager begins to experience respiratory distress, they choose not to notify their parents or PCP until the point where conditions warrant a hospital emergency department visit. The hospital is able to access the individual's medical history through the regional HIO, the individual is provided with an inhaler, and their condition stabilizes; the teenager's family and health plan face significant costs associated with an avoidable hospital visit. Neither the health plan nor the PCP had access to the required, immediately actionable information that would result in such preventive action, despite their connections to a data exchange intermediary.

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<sup>13</sup> "Asthma and African Americans," Asthma and African Americans § (2021), <https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=15>.



\*Data exchange intermediary may include a HIO, national network, EHR vendor network, or another intermediary.

### Data Exchange & Process Steps

1. Teenager engages PCP; PCP performs screening, diagnoses asthma, and prescribes inhaler.
2. PCP files claim with health plan, noting asthma diagnosis, but does not transmit teenager’s demographic information or alert of unfilled inhaler prescription.
3. Health plan’s population health management system classifies the teenager in a higher-risk asthmatic clinical condition cohort.
4. Health plan, PCP, and ED are engaged in data sharing with a data exchange intermediary.
5. After wildfire, health plan alerts teenager’s PCP of increased risk for asthmatics, but does not directly contact teenager or their guardians because the teenager is not classified as “high-risk”
6. Teenager engages school nurse at school-based clinic due to tightness in their chest.
7. School-based clinic is not engaged in data sharing with a data exchange intermediary.
8. Teenager is admitted to local ED after symptoms worsen; ED accesses patient history and sends alert to health plan and PCP through the data exchange intermediary.

## Key Challenges<sup>14</sup>

Uneven progress toward health data interoperability and use hinders health care organizations' ability to support the care of individuals as well as broader population health management activities, including risk stratification, quality and performance measurement for subpopulations, value-based purchasing, and targeted, population-specific interventions. A survey conducted by the American Hospital Association found that adoption of population management tools has been hampered by data acquisition, aggregation, and interoperability challenges.<sup>15</sup>

The following challenges were identified in this scenario.<sup>16</sup>

**Gaps in Data Infrastructure and Exchange Capabilities:** Persistent gaps in EHR infrastructure in a variety of health care settings, including at school-based health providers, limit information digitization and exchange among health care providers.

**Absence of Key Data Types:** The collection and use of demographic data – including data on race, ethnicity, language, sexual orientation, and gender identity – by health and human services providers to identify and address health disparities remains nascent.<sup>17</sup> Recent reports found that one out of every three commercial health plans had race data missing for over 50% of their members, and half of Medicaid health plans had similar data gaps.<sup>18</sup>

Further, health plans and providers may not always have the data or systems in place to derive clinically important insights about their populations. Health plans often lack access to clinical data, which may be available at the provider level. This can, for example, have implications for Healthcare Effectiveness Data and Information Set (HEDIS) measurement and review processes because it requires health plans to conduct onsite medical record audits, which can be time-consuming for the health plan and disruptive for the provider. Providers may lack the system capacity, staff capacity, or training to analyze the claims and clinical data they may have available and to connect this data to clinical workflows. Without access to timely physical, behavioral health, and SDOH information, health plans' and providers' efforts at care management and population health management may be delayed or limited.

<sup>14</sup> For more detailed discussions of current state health information technology and exchange gaps and opportunities to address them, see the DxF Landscape and Gaps and Opportunities sections posted on the [CalHHS DxF website](#).

<sup>15</sup> Jennifer Bresnick, "Data Exchange, Integration Shortfalls Stymie Population Health," *Health IT Analytics*, November 1, 2018, <https://healthitanalytics.com/news/data-exchange-integration-shortfalls-stymie-population-health>.

<sup>16</sup> Jonah Frohlich, Eric Barthelet, and Jonathan DiBello, "Why California Needs Better Data Exchange: Challenges, Impacts, and Policy Options for a 21st Century Health System" (California Health Care Foundation, March 2021), <https://www.chcf.org/wp-content/uploads/2021/02/WhyCaliforniaNeedsBetterDataExchange.pdf>.

<sup>17</sup> Kevin McAvey and Alisha Reginal, "Unlocking Race and Ethnicity Data to Promote Health Equity in California: Proposals for State Action," *Manatt*, April 2021, <https://www.manatt.com/insights/white-papers/2021/unlocking-race-and-ethnicity-data-to-promote-health>.

<sup>18</sup> Kelsey Waddill, "How to Overcome Challenges in Gathering Racial, Ethnicity Data," *HealthPayerIntelligence*, April 2021, <https://healthpayerintelligence.com/news/how-to-overcome-challenges-in-gathering-racial-ethnicity-data>.

## D. Supporting Emergency Responses

### Description

Addressing the health and social needs of individuals and populations by ensuring that emergency response providers and disaster health care volunteers have access to patients' clinical records and other relevant information during emergencies.

### Current State and Illustrative Example

During emergencies and disasters, emergency response providers and other first responders, disaster health care volunteers, and emergency departments seek access to health and human service information that is needed to support care for individuals who are impacted by the emergency.

During disasters, California's Patient Unified Lookup System for Emergencies (PULSE) allows certain types of registered disaster health care volunteers to view clinical summaries that include patient records for allergies, problem lists, and medications to inform clinical decision-making.<sup>19</sup>

During emergencies, California's Search, Alert, File, and Reconcile (SAFR) process enables emergency response providers to electronically query participating HIOs or hospitals for an individual's health information, alert the receiving emergency department of the individual and their condition prior to arrival, deliver a record of the treatment provided to the receiving hospital's EHR, and (following discharge or transfer of the individual) receive key information on patient outcomes from the hospital.<sup>20,21</sup>

Health plans also have a [statutory obligation](#) that is overseen and enforced by the California Department of Managed Health Care (DMHC) to prepare and execute response plans for ensuring that displaced members have access to medically necessary services during emergency evacuations.<sup>22</sup>

### *Illustrative Example*<sup>23</sup>

A 50-year-old adult male with chronic heart disease who receives Supplemental Nutrition Assistance Program (SNAP) benefits through CalFresh and is eligible for medically tailored meals through his managed care plan is evacuated from a wildfire.

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<sup>19</sup> "Health Information Exchange," ca.gov, California Emergency Medical Services Authority, accessed April 2022, <https://emsa.ca.gov/hie/>.

<sup>20</sup> "Use of Electronic Health Records (EHRs) and Connections to Other Systems," California Emergency Medical Services Authority, April 2021, <https://hieinemsinca.files.wordpress.com/2021/04/emsa-dhcs-workshop-2-a-april-20-2021-lwr-final-4-19-1.pdf>.

<sup>21</sup> "Health Information Technology for EMS Project," California Emergency Medical Services Authority, October 2018, <https://emsa.ca.gov/wp-content/uploads/sites/71/2018/10/California-HIE-for-EMS-CAHIE-Webinar-10-2018.pdf>.

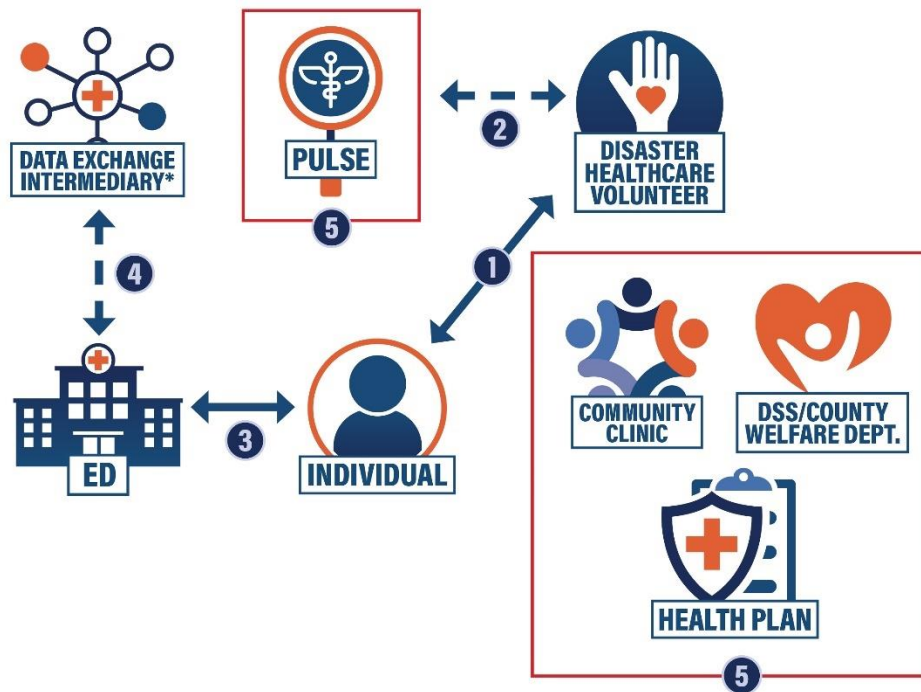
<sup>22</sup> AB2941 Health care coverage: state of emergency, [https://leginfo.ca.gov/faces/billCompareClient.xhtml?bill\\_id=201720180AB2941&showamends=false](https://leginfo.ca.gov/faces/billCompareClient.xhtml?bill_id=201720180AB2941&showamends=false).

<sup>23</sup> Scenario based on a scenario originally developed for a California Health Care Foundation Issue Brief: [Why California Needs Better Data Exchange: Challenges, Impacts, and Policy Options for a 21st Century Health System](#).

The man is disoriented and seeks care from a disaster health care volunteer at an alternative care facility near the evacuation center.

In his haste to evacuate, he was unable to bring his medications, CalFresh benefit card, or medical insurance card. Since the local clinic where he receives most of his care is closed and the disaster health care volunteer does not have access to his medical record, responders must rely on the individual to explain his conditions and medications.

The individual notes that he takes medication for chronic heart disease, but does not remember the medication's name, the dosage, or the time of his last dose, or what health plan he has or the name of the last physician he visited. He does not mention that he receives medically tailored meals to help manage his condition. Without immediate access to the individual's medical or medication history, the disaster health care volunteer queries PULSE for information, but no records are found: the individual received medication from a clinic that was not connected to a hospital or an HIO. Unsure of the individual's health condition or risks, the disaster health care volunteer orders his transport to an overwhelmed local emergency department (ED) as a precaution. After a day under observation, the man is diagnosed at the ED – which is able to access some historical information about the individual through its data exchange intermediary – and his medication is restarted and steps are taken to readjust his diet.



\*Data exchange intermediary may include a HIO, national network, EHR vendor network, or another intermediary.

### Data Exchange & Process Steps

1. Individual is disoriented and seeks care from disaster healthcare volunteer.
2. Disaster healthcare volunteer queries PULSE to view individual's available clinical summaries, but no records are found.
3. Individual is transferred to a hospital emergency department (ED) for further assessment and treatment.
4. Emergency department are engaged in data sharing with a data exchange intermediary.
5. Some health and human service organizations are potentially disconnected from information exchange.

### Key Challenges<sup>24</sup>

While PULSE and SAFR provide important data exchange functions for emergency response providers and disaster health care volunteers during disasters and personal health emergencies in California, several challenges remain.

<sup>24</sup> For more detailed discussions of current state health information technology and exchange gaps and opportunities to address them, see the DxF Landscape and Gaps and Opportunities sections posted on the [CalHHS DxF website](#).

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The following challenges were identified in this scenario.

**Gaps in Data Infrastructure:** Gaps in PULSE and SAFR information access persist, leaving emergency response and disaster health care providers with limited access to critical physical health records that may be used to direct care as soon as individuals are engaged. While PULSE is operational across all of California’s counties, and all of California’s HIOs participate, some hospitals do not connect to PULSE directly or indirectly, leaving major regional information gaps. SAFR, as of April 2021, was only active in 29 of California’s 58 counties but connected with eight HIOs, 70 emergency response organizations, and 50 receiving hospitals (specifically for the search and reconcile functions).<sup>25</sup>

**Absence of Key Data Types:** Neither PULSE nor SAFR currently collect or exchange non-clinical SDOH data, potentially creating challenges in ensuring continuity in coordination of human services for individuals who are impacted by a disaster or other personal health emergency.

**Complex Data Exchange Rules and Regulations:** Federal and state laws may prohibit the exchange of SDOH data. Medically tailored meal providers that are subject to United States Department of Agriculture (USDA) rules may not disclose member information to entities other than those directly connected with the administration of the applicable USDA program or public agencies operating under contract with the state’s SNAP or Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) agency, for example. Such rules can create consent management challenges, particularly during a time-sensitive emergency.

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<sup>25</sup> “Use of Electronic Health Records (EHRs) and Connections to Other Systems,” California Emergency Medical Services Authority, April 2021, <https://hieinemsinca.files.wordpress.com/2021/04/emsa-dhcs-workshop-2-a-april-20-2021-lwr-final-4-19-1.pdf>.



## E. Supporting Public Health Responses

### Description

Addressing the health and social needs of Californians by strengthening public health surveillance, research, preparedness, and response to public health emergencies.

### Current State and Illustrative Example

In support of public health, information exchange plays a critical role for, among other activities:

- Disease surveillance;
- Reporting, tracking, and response (e.g., lab result reporting and case reporting);
- Resource availability and utilization (e.g., personal protective equipment, hospital bed availability);
- Epidemiological investigation (e.g., contact tracing);
- Vaccine and immunization management (e.g., distribution and tracking of administration);
- Outbreak management of infectious and chemical exposures; and
- Laboratory, medical, nursing, and other clinical consultation and direct clinical management for pathogens that are new (e.g., COVID-19) or drug resistant (e.g., multi-drug-resistant TB), or that pose a threat to a broader community (e.g., chemical toxicity in public pools).

With timely access to testing information from laboratories, providers, and hospitals, public health concerns (e.g., disease clusters) can be quickly identified and used to inform decisions on allocation of critical resources (e.g., intensive care unit [ICU] beds, ventilators) and to rapidly manage outbreaks and toxic exposures. Reliable and timely information regarding statewide testing, contact tracing, isolation support, clinical consultation and management, and vaccination administration programs supports the ability of the state, counties, cities, and health systems to organize and coordinate public health efforts.

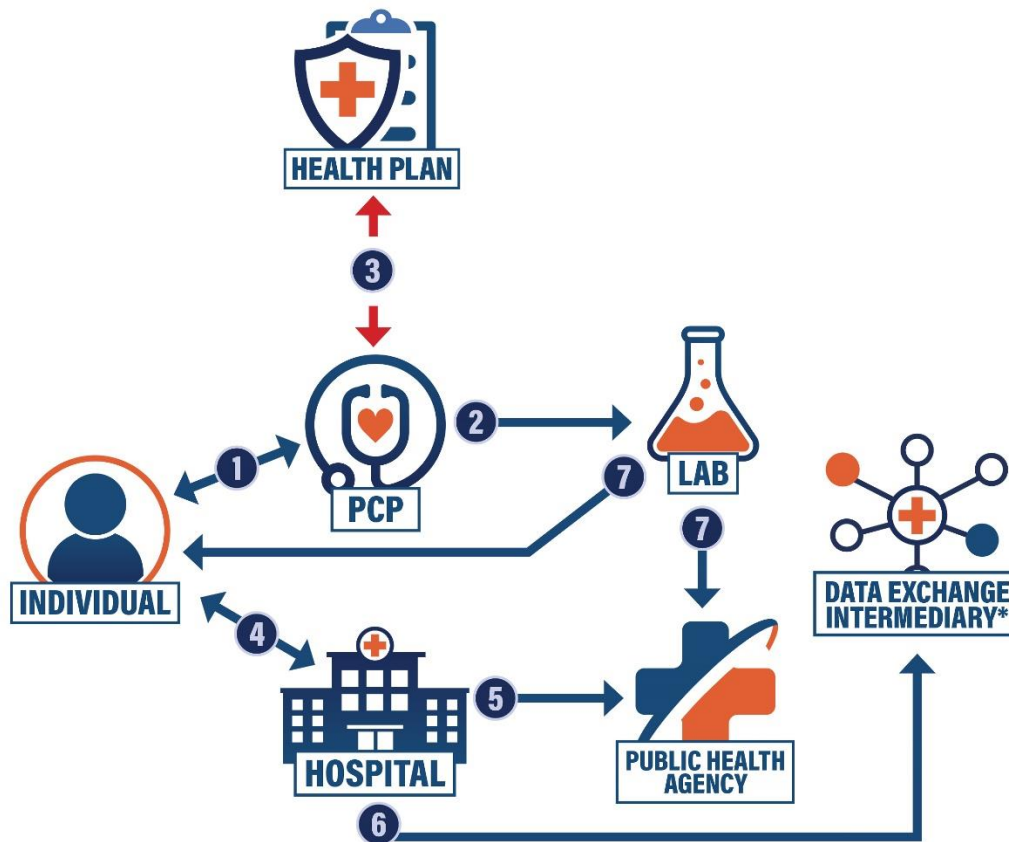
### *Illustrative Example*

A 45-year-old Asian American woman works as a housecleaner and lives in a multi-generational setting with her husband, three children, and parents. She begins to exhibit symptoms associated with the onset of COVID-19, including a fever, fatigue, and body aches. She contacts her PCP, who directs her to a COVID-19 test site – which she visits to receive a 24-hour PCR test – and who recommends that she self-quarantine and monitor her condition. Her PCP and health plan do not have the means to rapidly exchange clinical information. The individual restricts her activities but, without the supportive care that could have been arranged, must leave her home to purchase food and otherwise support her family.

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While she is awaiting test results, her condition declines. At the advice of her PCP, she is transported to the nearest hospital, which has no ICU capacity. A rapid test at the hospital indicates that she has COVID-19, and she is kept in a temporary isolated waiting area for an extended period. The hospital notifies the public health agency of the test results after several days, as does the original testing site once the positive result is established. Treatment is delayed until an ICU bed and a ventilator are available, after which her condition stabilizes, though she requires an extended hospital stay to recover. Her PCP remains unaware of her condition and test results.

Once the individual is stabilized, a public health investigator contacts her and tries to reconstruct where she had been and to identify the individuals with whom she has been in proximity during her contagious period. However, due to delays in processing test results through the California Reportable Disease Information Exchange (CalREDIE), over a week has passed since she first exhibited symptoms, so attempts to trace her interactions are unsuccessful.



\*Data exchange intermediary may include a HIO, national network, EHR vendor network, or another intermediary.

### Data Exchange & Process Steps

1. Individual engages primary care provider (PCP) for diagnosis and COVID-19 testing.
2. PCP directs individual to get tested at a local testing site/lab.
3. PCP and health plan do not have the means to rapidly exchange clinical information, so support services are not activated.
4. While the individual is awaiting test results, her condition worsens, and she is brought to the nearest hospital, admitted, and diagnosed with COVID-19.
5. Hospital transmits test results to applicable public health agencies; public health agency to follow up with contact tracing.
6. Individual's admission data is transmitted to the data exchange intermediary (PCP may not be connected)
7. Lab transmits results to the individual and the applicable public provider, but the PCP remains unaware of the individual's condition and test results.

## Key Challenges<sup>26</sup>

The COVID-19 pandemic and response revealed the fragmentation of California's health data infrastructure in supporting public health responses. The speed, scale, and impact of COVID-19 illuminated weaknesses in California's ability to scale and adapt systems to identify, monitor, contain, and respond to a rapidly emerging infectious disease.

The following challenges were identified in this scenario.<sup>27,28</sup>

**Gaps in Data Infrastructure and Exchange Capabilities:** Many types of public health data are collected and transmitted via paper-based, phone, fax, or other non-machine-readable formats. Information may be re-keyed or manually reported, which results in errors and transmission delays of critical information.<sup>29</sup> In addition, challenges remain in connecting and linking information. For example, vital records in part due to the multiple state statutes that govern the sharing of, and the funding<sup>30</sup> for the sharing of, vital records, are not completely linked to laboratory data, clinical data, medical examiner/coroner data systems, or case reporting systems.<sup>31</sup> CalREDIE and the California Immunization Registry (CAIR) systems were not conceived in statute or technically designed to connect, consume, and incorporate health information from HIOs or directly from EHRs at the scale needed to tackle a global pandemic.<sup>32</sup> Reported public health information may also lack basic demographic information critical to addressing health equity concerns as they arise.

**Absence of Key Data Types:** Basic clinical data (e.g., symptom, progress notes, vital signs); hospital/ED alerts; capacity of emergency departments, acute care beds, and ICUs; personal protective equipment; demographic information (race, ethnicity, sexual orientation, and gender identity); and social information

<sup>26</sup> For more detailed discussions of current state health information technology and exchange gaps and opportunities to address them, see the DxF Landscape and Gaps and Opportunities sections posted on the [CalHHS DxF website](#).

<sup>27</sup> Jonah Frohlich, Eric Barthelet, and Jonathan DiBello, "Why California Needs Better Data Exchange: Challenges, Impacts, and Policy Options for a 21st Century Health System" (California Health Care Foundation, March 2021), <https://www.chcf.org/wp-content/uploads/2021/02/WhyCaliforniaNeedsBetterDataExchange.pdf>.

<sup>28</sup> Association of Public Health Laboratories (APHL), Association of State and Territorial Health Officials (ASTHO), Council of State and Territorial Epidemiologists (CSTE), Healthcare Information and Management Systems Society (HIMSS), National Association of County and City Health Officials (NACCHO), and National Association for Public Health Statistics and Information Systems (NAPHSIS), "\$450M Data Modernization Initiative Letter to Congress," July 2020, <https://astho.org/Federal-Government-Relations/Correspondence/PH-Orgs-Request-450-Million-for-CDC-Data-Modernization-Initiative/>.

<sup>29</sup> Ibid.

<sup>30</sup> Per California Health and Safety Code §102230(f) and §102231(d), vital records services are funded in part by fees charged for responses to data requests, so sharing vital records for free without a new revenue stream may create funding challenges for the California Department of Public Health's Center for Health Statistics which administers vital records in the state.

<sup>31</sup> California Health and Safety Code §102230 and §102231 (Confidentiality and Release Restriction); §102680 and §102705 (Adoptions); §102725 and §102730 (Adjudication of Fact of Parentage); §102750 and §102760 (Acknowledgement of Paternity); §102766, §102767, and §102768 (Voluntary Declaration of Parentage and Rescission of Declaration); §103360 and §103365 (Amendment to Delete Racial Slurs); §103440 (Amendment to Change Gender and Sex Identifier); §103447.5 and §103448 (Amendment to Correct Gender Errors by Hospital or Local Registrar); §102425(b)&(e); §102426(b); §102455; §102460, §102465; §102475; and §103025.

<sup>32</sup> California Civil Code §1798.24 (CalREDIE Data Disclosures) and California Health and Safety Code §120440 (CAIR Data Disclosures).

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(occupation, living conditions, etc.) are stored in a variety of systems that are not easily electronically shared with public health departments and other stakeholders.

**Complex Data Exchange Rules and Regulations:** Navigation of complex data exchange regulations and patient consent requirements can be difficult to manage, particularly during public health emergencies, which necessitate rapid responses to contain and manage outbreaks or toxic exposures.

## F. Coordinating Reentry Health Services

### Description

Addressing the health and social needs of individuals as they transition from incarceration back into the community.

### Current State and Illustrative Example

The transition (or “reentry”) from incarceration to the community can be challenging. Individuals released from an incarceration setting must reintegrate themselves with their families and communities while addressing a range of issues, including potentially securing housing, coordinating care, navigating access to health services, and finding employment. Incarcerated individuals have significantly higher rates of disease than the general non-incarcerated population and tend to suffer in greater numbers from infectious disease, mental health problems, substance use, and addiction.<sup>33,34</sup> Upon reentry, prompt and continuous coordination and management of health and social needs are complicated by health insurance coverage gaps, finding primary care physicians and specialty providers (particularly for behavioral health services), making health care appointments, locating and securing needed human service supports, and refilling prescriptions.<sup>35</sup>

Through CalAIM, Medi-Cal eligible individuals transitioning from jails, state prisons, and youth correctional facilities will have access to coordinated physical health, behavioral health, and community services upon release (and in some instances, while still incarcerated) to support their successful transition to the community. Successful reentry depends upon the ability of health care organizations to collect, store, and share information in a timely fashion among incarceration facilities, providers, and human service agencies to support:

- (1) Accurate and timely screening, assessment, and support processes that begin prior to release;
- (2) Development of multi-sector community-based collaborations; and
- (3) Integrated and coordinated care models that link individuals to the full range of physical and behavioral health and human services they need as they transition back into their communities.

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<sup>33</sup> David H. Cloud, Jim Parsons, and Ayesha Delany-Brumsey, “Addressing Mass Incarceration: A Clarion Call for Public Health,” *American Journal of Public Health*, 2014, 389–391.

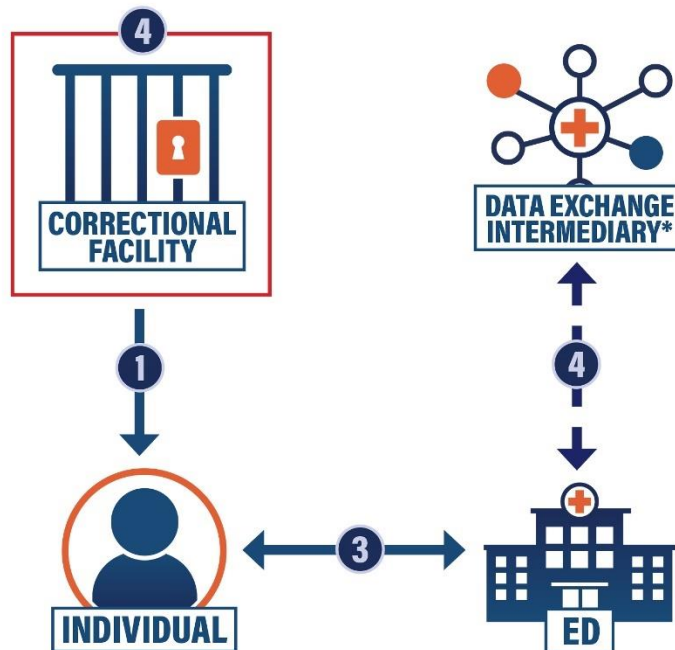
<sup>34</sup> American Academy of Family Physicians, “Incarceration and Health: A Family Medicine Perspective,” April 2017, <https://www.aafp.org/about/policies/all/incarceration.html>.

<sup>35</sup> Ibid.

### ***Illustrative Example***

A 55-year-old white male in a county jail prepares for release and transition back into the community. Prior to incarceration, he was diagnosed with hypertension and mild depression. Upon his release, he is provided with a temporary supply of medication to address these conditions, but otherwise lacks health coverage; he seeks access to Medi-Cal in order to schedule an appointment with his PCP to address his clinical and behavioral health conditions and medication needs. Before he has an opportunity to finish his Medi-Cal application, he begins to experience chest pain and is taken to the emergency department. While he is being admitted, the hospital is able to locate old medical records from its data exchange intermediary, but does not have access to his medical history, diagnosis, and treatment from the period he was incarcerated: the jail's EHR is not connected to any data exchange intermediary. The man is eventually re-diagnosed, treated, and released with a new set of medications.

The stress of his recent hospitalization and medication change exacerbates his depression, for which he has limited support – and only makes the process of seeking program support more difficult.



\*Data exchange intermediary may include a HIO, national network, EHR vendor network, or another intermediary.

Data Exchange & Process Steps
<ol style="list-style-type: none"> <li>1. Individual is released from the correctional facility.</li> <li>2. Upon release, individual seeks access to Medi-Cal for PCP appointment (not shown).</li> <li>3. Individual is taken to emergency department (ED) for treatment.</li> <li>4. Hospital ED queries data exchange intermediary for available health data (correctional facility’s health information is not available).</li> </ol>

### Key Challenges<sup>36</sup>

The following challenges were identified in this scenario.

**Limited Data Exchange:** Data on justice-involved individuals is highly siloed across settings, which creates barriers to collaboration and effective care coordination. Some justice settings do not store and manage clinical and human services data in certified EHR technology, and this data often is not shared with other county agencies and community health and human services provider partners. In some cases, limited information is shared with consent from the individual, though this is not consistently obtained. In many cases where

<sup>36</sup> For more detailed discussions of current state health information technology and exchange gaps and opportunities to address them, see the DxF Landscape and Gaps and Opportunities sections posted on the [CalHHS DxF website](#).



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referrals have been shared from state prisons, very limited information is shared, often limited to demographic and release date.

**Absence of Key Data Types:** National networks, HIOs, and EHRs generally have limited capabilities to exchange mental health and SDOH data. This information, if securely accessed and properly applied, could help individuals reentering their communities to identify, obtain, and utilize mental health and SDOH-related services. Closed-loop referral networks and emerging CIEs (e.g., Alameda County Care Connect and CIE San Diego), which support the sharing of non-clinical SDOH data, are showing promising results. For example, Alameda County Care Connect reported having over 660,000 client records available in 2020, and CIE San Diego reports exchanging data with 115 partner organizations.<sup>37,38</sup> However, CIEs currently operate in only a few communities in California, and are not widely available to support pre-release and reentry planning and coordination efforts.

**Complex Data Exchange Rules and Regulations:** Criminal history privacy laws typically assume that such information will be used for criminal justice purposes and for background checks – not to help a person find services such as housing.<sup>39</sup> Unlike federal law, California law does not permit the disclosure of criminal record data for purposes of coordinating care.<sup>40,41</sup> While federal law is ambiguous on this point, California law is clearer in that disclosures for treatment purposes may be sent only to “providers of health care, health care service plans, contractors [generally independent practice associations or pharmacy benefit managers], or other health care professionals or facilities.”<sup>42</sup>

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<sup>37</sup> “Alameda County Care Connect Outcomes Snapshot,” Alameda County Care Connect Performance Measures, accessed April 29, 2022, <https://accareconnect.org/news-updates/#news-updates>.

<sup>38</sup> “CIE Partners,” CIE San Diego, accessed April 2022.

<sup>39</sup> Alex Dworkowitz and Cindy Mann, “Data Sharing and The Law: Overcoming Healthcare Sector Barriers to Sharing Data on Social Determinants,” Manatt Health, July 2020, [https://sirenetwork.ucsf.edu/sites/default/files/2021-02/Data%2520Sharing%2520and%2520the%2520Law\\_July%25202020\\_.pdf](https://sirenetwork.ucsf.edu/sites/default/files/2021-02/Data%2520Sharing%2520and%2520the%2520Law_July%25202020_.pdf).

<sup>40</sup> Cal. Penal Code §§11105, 13300.

<sup>41</sup> Release dates and booking data are among the more important data points for the provision of health services and may be subject to different data sharing requirements.

<sup>42</sup> Cal. Civ. Code §56.10(c)(1).