

California Data Exchange Landscape

Section Draft

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I. Why Is Data Exchange Important?

The efficient, effective, and equitable delivery of health and human services is vital to the well-being of all Californians and is necessary for a strong and vibrant economy. To achieve this state, information must be easily exchanged among medical, behavioral, human services, and public health professionals to allow them to make informed decisions that impact the lives of every Californian.¹ Research shows that effective health and human services data exchange can improve care coordination and delivery while reducing costs.^{2,3,4,5,6,7,8} However, despite strong evidence and agreement among stakeholders on the promise of effective health and human services data exchange and use, federal, state, and local governments as well as private-sector organizations continue to wrestle with challenges in realizing the full potential of data exchange.

The history and current state of data exchange in California are no different – a story of successes and shortcomings. Health and human services professionals in California today have limited and uneven access to medical, behavioral, and human services histories, restraining the effectiveness of their support.⁹ Where health and human services data exchange is occurring, it is often:

- *Limited to select regional health systems and large clinics with federally certified electronic health records (EHRs) and previously established patient and data sharing relationships;*¹⁰

¹ “Expanding Payer and Provider Participation in Data Exchange: Options for California” (California Health Care Foundation, November 2019), <https://www.chcf.org/wp-content/uploads/2019/11/ExpandingPayerProviderParticipationDataExchange.pdf>.

² William R Hersh et al., “Outcomes from Health Information Exchange: Systematic Review and Future Research Needs,” *JMIR Medical Informatics* 3, no. 4 (2015), <https://doi.org/10.2196/medinform.5215>.

³ Robert S. Rudin et al., “Usage and Effect of Health Information Exchange,” *Annals of Internal Medicine* 161, no. 11 (February 2014): p. 803, <https://doi.org/10.7326/m14-0877>.

⁴ Lipika Samal et al., “Health Information Technology to Improve Care for People with Multiple Chronic Conditions,” *Health Services Research* 56, no. S1 (2021): pp. 1006-1036, <https://doi.org/10.1111/1475-6773.13860>.

⁵ Idris Adjerid, Julia Adler-Milstein, and Corey M. Angst, “Reducing Medicare Spending through Electronic Information Exchange: The Role of Incentives and Exchange Maturity,” *SSRN Electronic Journal*, April 16, 2016, <https://doi.org/10.2139/ssrn.2765098>.

⁶ “Analysis Estimates Value Associated with Use of the Statewide Health Information Network for New York,” *nyehhealth.org* (New York eHealth Collaborative, November 2019), https://www.nyehhealth.org/wp-content/uploads/2022/02/White-Paper_Analysis-Estimates-SHIN-NY-Value_11.12.19_final.pdf.

⁷ Fecher, K., McCarthy, L., Porreca, D. E., et al., “Assessing the Benefits of Integrating Health Information Exchange Services into the Medical Practices’ Workflow,” *Inf Syst Front* 23, 599–605 (2021). <https://doi.org/10.1007/s10796-019-09979-x>.

⁸ Nir Menachemi, Saurabh Rahurkar, Christopher A. Harle, and Joshua R. Vest, “The benefits of health information exchange: an updated systematic review,” *Journal of the American Medical Informatics Association*, Volume 25, Issue 9, September 2018, 1259–1265, <https://doi.org/10.1093/jamia/ocy035>.

⁹ Jonah Frohlich, Eric Bartholet, 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>.

¹⁰ Exchange is often geographically uneven, where providers in rural and underserved communities may not have access to the base health information technology or networks to engage in data exchange.

- *Incomplete and confined to a subset of traditional health care data* (e.g., clinical information and claims/encounter data), with most organizations lacking the capacity – including the systems, standards, and processes – to share or receive critical cross-sector human services data;¹¹
- *Shared through varied mechanisms*, including direct and private provider-to-provider exchanges, national networks, or one of over 15 regional health information organizations (HIOs); and
- *Limited by diverging interpretations of data sharing rules*, with entities navigating complex, confusing, and occasionally conflicting federal and state data sharing laws and regulations.¹²

Fragmented data exchange can inhibit the data-driven efforts to better coordinate human and social supports with the medical and health care sectors and provide opportunities to deliver services that are more client centered, efficient, effective, and tailored.¹³ In California’s data exchange landscape today, individuals face barriers to accessing and acting upon their health and human services information to improve their health and well-being. The current system can also impose a burden on individuals to become the intermediaries of exchange, tracking down and carrying their records from appointment to appointment.

To advance health and human services data exchange in California, it is important to understand the many federal and state efforts to advance health information exchange (HIE) and adoption of health information technology (HIT) stretching over the past two decades. This landscape assessment will also detail, to the extent information is available, HIT adoption and data exchange among several types of health, human service, public health, and data exchange organizations in California today.

II. Federal Initiatives to Advance Data Exchange

Federal initiatives to advance data exchange have included numerous laws, regulations, policies, and programs that have expended tens of billions of dollars over the past 15 years. Enacted in 2009, the Health Information Technology for Economic and Clinical Health Act (HITECH Act), part of the American Recovery and Reinvestment Act (ARRA), committed more than \$47 billion nationwide in grants, loans, and incentives to accelerate the implementation of HIT and HIE, with a focus on certain types of Medicare

¹¹ Social determinants of health (SDOH) – the conditions in which we are born, live, learn, work, play, worship, and age – are estimated to account for up to 80% of our health outcomes. Ensuring health care practitioners have access to systems to document, understand, and respond to the social needs of their patients is crucial for improving the health of Californians, reducing health care costs, and addressing long-standing and systemic health inequities and disparities. “Social Determinants of Health,” U.S. Office of Disease Prevention and Health Promotion. Available [here](#). “Addressing Patients’ Social Needs: An Emerging Case for Provider Investment,” TCF/Manatt, May 29, 2014. Available [here](#).

¹² Many federal and state rules were also not drafted with broad multi-sectoral or electronic health data exchange use cases in mind.

¹³ Jonah Frohlich, Eric Bartholet, 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>.

and Medicaid providers.¹⁴ The HITECH Act also created the State HIE Cooperative Agreement Program of the Office of the National Coordinator for Health Information Technology (ONC), which provided almost \$550 million to 56 states and territories to build capacity for exchanging health information across the health care system.¹⁵

The HITECH Act is credited with spurring widespread adoption of EHRs among provider segments eligible for incentive funding; however, EHR adoption continued to lag among providers that were not eligible for HITECH incentive funds, particularly behavioral health and human services providers.¹⁶ The HITECH Act also did little, especially in the first few years after implementation, to ensure that EHRs were interoperable and could easily exchange information with providers using different EHRs. The result was that electronic health information exchange was often siloed among providers or health systems that happened to have the same EHR.

As HITECH incentive programs and opportunities wound down in 2020, the federal government released two sets of regulations aimed at advancing HIE: the Interoperability and Patient Access final rule from the Centers for Medicare & Medicaid Services (CMS) and the 21st Century Cures Act final rule from the ONC. CMS' Interoperability and Patient Access final rule required certain payers to make beneficiary information available via standards-based application programming interfaces (APIs) and to expand payer-to-payer exchange of information. It also required Medicare and Medicaid providers to transmit electronic ADT notifications, and states to increase the frequency of data exchanges for Medicare-Medicaid dually eligible beneficiaries.¹⁷ ONC's 21st Century Cures Act final rule adopted the Health Level 7 (HL7®) Fast Healthcare Interoperability Resources (FHIR®), Release 4, as the foundational standard for application-based exchange of health information. It also specified the minimum or default set of data categories¹⁸ that certain kinds of HIT will be expected to be capable of exchanging.¹⁹ Another central focus of the rule is preventing information blocking, which is the unreasonable withholding of certain categories of health information, specifically by HIT vendors, health care providers, and health information exchanges and networks. The rule outlines eight "exceptions" to the information blocking ban that allow "common sense" flexibility in certain instances, such as considerations related to

¹⁴ "A Timeline of Health Data Exchange in California," chcf.org (California Health Care Foundation, July 2021), <https://www.chcf.org/wp-content/uploads/2021/07/TimelineHealthDataExchangeCA.pdf>.

¹⁵ *Ibid.*

¹⁶ "Health Information Exchange After 10 Years: Time For A More Assertive, National Approach," *Health Affairs Blog*, August 14, 2019. DOI: 10.1377/hblog20190807.475758.

¹⁷ Interoperability and Patient Access final rule, 85 Fed. Reg. 25510 (May 1, 2020).

¹⁸ Specifically, as a condition of certification, applicable HIT will be required to conform to United States Core Data for Interoperability (USCDI) version 1 by the end of December 2022. The USCDI defines a minimum or default set of data categories that health IT users should expect to be able to exchange between systems. The USCDI will be updated by ONC going forward on a regular schedule through a formal stakeholder engagement process. USCDI version 2 has been released, and version 3 is expected in July 2022. <https://www.healthit.gov/isa/united-states-core-data-interoperability-uscdi#draft-uscdi-v3>.

¹⁹ 21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program, 85 Fed. Reg. 25642 (May 1, 2020).

data security and acknowledgement of specific situations where moving data may be technically infeasible.

In 2021, the federal American Rescue Plan Act was signed into law and provided billions of dollars in federal funds to states for public health, behavioral health, telehealth, broadband, and other programs potentially related to HIT and HIE; however, at the time of writing, there is not a comprehensive inventory of how states are devoting funding to HIT and HIE.²⁰

Most recently, in January 2022, ONC – via the Sequoia Project²¹ – took another step in advancing HIE when it released the Trusted Exchange Framework and Common Agreement (TEFCA).²² The overall goal of the TEFCA is to establish a universal floor of interoperability across the country. The Trusted Exchange Framework describes a common set of non-binding, foundational principles²³ for trusted policies and practices that can help facilitate information exchange and use. The Common Agreement establishes the infrastructure model and governing approach for users in different networks to securely share basic clinical information with each other – all under commonly agreed-upon expectations and rules, and regardless of which network they happen to be in.

Foundational Federal Health Data Privacy Laws and Regulations

- For most health care providers, the Health Insurance Portability and Accountability Act (HIPAA) is the foundational regulation governing data sharing, access, and use. Broadly, HIPAA safeguards patient privacy by limiting the sharing of protected health information (PHI) by health plans and providers (covered entities)²⁴ and their contractors (business associates)²⁵ to only treatment, payment and operations, and a limited number of other specific purposes, such as public health.²⁶
- The federal substance use disorder (SUD) confidentiality regulation, 42 C.F.R. Part 2, applies to some, but not all, categories of SUD information. When it applies, 42 C.F.R. Part 2 is often stricter than HIPAA, in part because the

²⁰ “A Timeline of Health Data Exchange in California,” chcf.org (California Health Care Foundation, July 2021), <https://www.chcf.org/wp-content/uploads/2021/07/TimelineHealthDataExchangeCA.pdf>.

²¹ The Sequoia Project serves as the Recognized Coordinating Entity (RCE) to develop, update, implement, and maintain the Common Agreement.

²² “Trusted Exchange Framework and Common Agreement (TEFCA),” HealthIT.gov (Office of the National Coordinator for HIT, March 11, 2022), <https://www.healthit.gov/topic/interoperability/trusted-exchange-framework-and-common-agreement-tefca>.

²³ Principles: Standardization; openness and transparency; cooperation and nondiscrimination; privacy, security, and safety; access; equity; and public health.

²⁴ A health plan, a health care clearinghouse, or a health care provider that electronically transmits PHI to a health plan in a manner regulated by HIPAA.

²⁵ A person or entity that performs certain functions or activities that involve the use or disclosure of HIPAA PHI on behalf of, or that provides services to, a covered entity.

²⁶ “Health Insurance Portability and Accountability Act of 1996 (HIPAA),” Centers for Disease Control and Prevention (Centers for Disease Control and Prevention, September 14, 2018), <https://www.cdc.gov/php/publications/topic/hipaa.html#:~:text=The%20Health%20Insurance%20Portability%20and,the%20patient's%20consent%20or%20knowledge>.

regulation does not permit disclosures of information for treatment or care coordination purposes without individual consent.²⁷

III. California Initiatives to Advance Data Exchange

California's efforts to advance HIT and HIE have both intersected with and been independent of federal initiatives, and a history of starts and stops has produced the landscape we have today. California's path began in 1998, when the Santa Barbara County Care Data Exchange, a regional HIO, established an HIE program among hospitals, physicians, and other providers in the county.²⁸ Stemming from the federal HITECH Act of 2009, California created several programs that would galvanize stakeholder collaboration and commitment to HIE. The State HIE Cooperative Agreement Program, which awarded \$38.8 million in federal funds to California; the Medi-Cal EHR Incentive Program (subsequently renamed the Medi-Cal Promoting Interoperability Program); and the Regional Extension Center Program supported widespread adoption of EHRs in hospitals and ambulatory practices and clinics that are certified to electronically exchange information using national standards.²⁹ The state also appointed the first Deputy Secretary of HIT within the California Health and Human Services Agency (CalHHS) to convene and facilitate statewide HIE efforts and established a state-designated entity, Cal eConnect, for HIE to provide a set of core data exchange and identity management services to its stakeholders.³⁰

In 2014, a group of community and enterprise HIO leaders used HIE Cooperative Agreement Program funds to form the California Association of Health Information Exchanges (CAHIE). CAHIE established the California Trusted Exchange Network (CTEN), a self-governance trust framework with common standards and voluntary compliance.³¹

In 2015, the California Technical Assistance Program (CTAP) was launched with \$37.5 million in federal and state funds. CTAP continued the work of the Regional Extension Center Program in providing technical assistance to professionals, with a special emphasis on solo practitioners and specialists, in adopting, implementing, upgrading, and meaningfully using certified EHR technology.³²

California's next major action to advance HIE occurred in 2019, when the California Department of Health Care Services (DHCS) established the California HIE Onboarding Program (Cal-HOP), providing \$50 million in combined state and federal funds to

²⁷ 42 C.F.R. Part 2. <https://www.govinfo.gov/content/pkg/CFR-2010-title42-vol1/xml/CFR-2010-title42-vol1-part2.xml>.

²⁸ "Expanding Payer and Provider Participation in Data Exchange: Options for California" (California Health Care Foundation, November 2019), <https://www.chcf.org/wp-content/uploads/2019/11/ExpandingPayerProviderParticipationDataExchange.pdf>.

²⁹ Ibid.

³⁰ "A Timeline of Health Data Exchange in California," chcf.org (California Health Care Foundation, July 2021), <https://www.chcf.org/wp-content/uploads/2021/07/TimelineHealthDataExchangeCA.pdf>.

³¹ Ibid.

³² "California Technical Assistance Program," California Technical Assistance Program (California Department of Health Care Services), accessed April 2022, https://www.dhcs.ca.gov/provgovpart/Pages/California_Technical_Assistance_Program.aspx.

support Medi-Cal providers' onboarding to qualified HIOs and access to the Controlled Substance Utilization Review and Evaluation System (CURES).³³

Many of the initiatives that stemmed from HITECH have since been shuttered or have expired with the end of HITECH funding in 2021. Cal eConnect shut down in 2012; the Cooperative Agreement Program ended the following year, and with it went the funding for California's Deputy Secretary of HIT position. The Medi-Cal Promoting Interoperability Program and Cal-HOP ended in September 2021, and CTAP has also ended. One notable exception is CAHIE and CTEN, which still exist and support data exchange today.

In July 2021, California embarked on the next phase in its journey to advance health and human services data exchange when Governor Newsom signed AB133. AB133 put California on the path to building its first-ever statewide Health and Human Services Data Exchange Framework – a single data sharing agreement and common set of Policies and Procedures that will govern the exchange of health information among health care entities and government agencies beginning in January 2024. Before delving into the gaps being addressed by the Data Exchange Framework and the Data Sharing Agreement, it is important to take stock of the wide variety and enormous amount of data exchange that is happening in California today.

IV. Data Exchange in California Today

Health and human services data exchange in California today varies greatly depending on the type of organization and the type of data being exchanged. Incentive funding from HITECH, the Medi-Cal EHR Incentive Program, Cal-HOP, and other programs led to significant advancements in the adoption of health information technology and the exchange of health data. However, EHR adoption and health data exchange capabilities have lagged for smaller providers and other health care providers who were not eligible for HITECH (e.g., behavioral health providers and skilled nursing facilities).

Public health and human service organizations have not historically had access to incentive funding to develop modernized data exchange infrastructure that enables electronic data capture and interoperability. And while data exchange intermediaries, such as HIOs and national data exchange networks, and tools, such as EHRs, have developed sophisticated capabilities to exchange clinical data, these data exchange intermediaries and tools are often in the nascent stages of developing the capability to exchange human services data, which often lacks widely recognized human standards.

Below, we will take a deeper look at data exchange capabilities and the data that is being exchanged by health, public health, human service, and data exchange organizations in California, with a focus on the organizations subject to AB133.

³³ "Cal-HOP," Cal-HOP (California Department of Health Care Services), accessed April 2022, <https://www.dhcs.ca.gov/provgovpart/Pages/Cal-HOP.aspx>.

A. Health Care Organizations

i. Hospitals

California is home to 426 general acute care hospitals, which range from small critical-access hospitals in rural settings to world-leading tertiary care and teaching hospitals, and 125 acute psychiatric hospitals.³⁴ Hospitals need data to inform patient care, discharge planning, and other functions. They play many crucial roles in data exchange, such as sending alerts to an individual's care team when the individual is hospitalized and incorporating summaries of care provided into an individual's health record.

There has been substantial growth in California acute care hospitals' adoption of HIT and health data exchange capabilities over the past decade. EHR adoption among acute care hospitals, for example, has increased from 46% in 2012 to 83% in 2019.^{35,36} The proportion of acute care hospitals participating in an HIO has also steadily increased from 25% in 2012 to almost 80% in 2019, exceeding the national average of 67%.³⁷ Further, there has been substantial growth in the percentage of hospitals reporting engagement in all four of ONC's technology-agnostic domains of interoperability³⁸ from 2014 (7%) to 2020 (59%).

However, the gains in HIT adoption and data exchange capacity have not been universal among all types of hospitals, particularly for smaller, psychiatric, and long-term care hospitals. EHR adoption among smaller hospitals (approximately 70%) remains lower than among medium-size and large hospitals (approximately 90%).³⁹ There is also evidence from national surveys that critical-access hospitals' EHRs tend to have fewer advanced functions than those of non-critical-access hospitals, and EHR adoption at psychiatric hospitals and long-term care facilities has trailed that of acute care hospitals.^{40,41,42} Additionally, the proportion of smaller hospitals that connect to an HIO (68%) is approximately 10 percentage points lower than the proportion of medium-size (81%) or large (79%) hospitals.⁴³ Although hospital engagement in all four of ONC's

³⁴ "Licensed and Certified Healthcare Facility Listing – Counts Dashboard-Licensed and Certified Healthcare Facility," California Health and Human Services Open Data Portal, CalHHS, March 24, 2022, https://data.chhs.ca.gov/dataset/healthcare-facility-locations/resource/e0e6729d-47a9-4923-bbf-b793bcfc8106?inner_span=True.

³⁵ 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.

³⁶ Julia Adler-Milstein et al., "California Health IT Landscape Assessment" (San Francisco, CA: University of California, San Francisco, 2022).

³⁷ Ibid.

³⁸ ONC's four interoperability domains are (1) finding/querying for data; (2) sending data electronically; (3) receiving data electronically; and (4) integrating data into the EHR without manual intervention.

³⁹ Julia Adler-Milstein et al., "California Health IT Landscape Assessment" (San Francisco, CA: University of California, San Francisco, 2022).

⁴⁰ Nate C Apathy, A Jay Holmgren, and Julia Adler-Milstein, "A Decade Post-HITECH: Critical Access Hospitals Have Electronic Health Records but Struggle to Keep up with Other Advanced Functions," *Journal of the American Medical Informatics Association* 28, no. 9 (January 2021): pp. 1947-1954, <https://doi.org/10.1093/jamia/ocab102>.

⁴¹ Xuejun Hu et al., "Hospital Characteristics Associated with Certified EHR Adoption among US Psychiatric Hospitals," *Risk Management and Healthcare Policy* Volume 13 (2020): pp. 295-301, <https://doi.org/10.2147/rmhp.s241553>.

⁴² Office of the National Coordinator for Health Information Technology, "Percent of Specialty Hospitals that Possess Certified Health IT," Health IT Quick-Stat #59, August 2019, dashboard.healthit.gov/quickstats/pages/specialty-hospital-ehr-adoption.php.

⁴³ Julia Adler-Milstein et al., "California Health IT Landscape Assessment" (San Francisco, CA: University of California, San Francisco, 2022).

domains of interoperability has increased, findings from the same survey indicate that sizable percentages of California hospitals are still relying upon manual or paper-based processes in each of the four domains.⁴⁴ Finally, the proportion of small hospitals engaging in all four domains (37%) in 2019 was lower than the proportions of medium-size (50%) and large hospitals (51%), and urban hospitals were more likely to engage in all four domains (48%) than rural hospitals (27%).⁴⁵

ii. Physician Organizations

It is estimated that there are approximately 150,000 licensed physicians in California, with half actively delivering patient care in California.⁴⁶ Physician organizations comprise a wide variety of practice sizes, structures, and specialties, from independent solo practices to multi-specialty practices affiliated with large health systems. Indeed, California has 2,734 primary care clinics, including approximately 800 Federally Qualified Health Centers but not accounting for the state's many private primary care, specialty care, and multi-specialty practices.^{47,48} Physician organizations exchange and use data for a multitude of care coordination and delivery functions. Like acute care hospitals, physician practices were eligible for HITECH incentive funding, and EHR adoption rates among California's physicians are high, with approximately 80% having adopted EHRs as of 2017 and 97% of California's family medicine physicians having adopted EHRs by 2020.⁴⁹ The family physicians who had not adopted EHRs were more likely to be in a rural, independent, and/or solo practice.⁵⁰ While limited statewide data on California physician data exchange is publicly available, a survey of California's HIOs found that a greater proportion of hospital-owned or health system-owned physician practices than independent physician practices contribute, view, or receive data and pay to participate. The percentages for all functions across both types of physician organizations are lower than the percentages reported by HIOs nationally.⁵¹

iii. Community Clinics

California's over 2,700 community clinics play a vital role in delivering and coordinating care for under-resourced populations. Like physician organizations, community clinics exchange and use data for a multitude of care coordination and delivery functions. However, limited recent data is publicly available on community clinics' HIT adoption or

⁴⁴ Ibid.

⁴⁵ Ibid.

⁴⁶ "California Physicians: A Portrait of Practice," California Health Care Almanac, California Health Care Foundation, March 2021, <https://www.chcf.org/wp-content/uploads/2021/03/PhysiciansAlmanac2021.pdf>.

⁴⁷ "Licensed and Certified Healthcare Facility Listing – Counts Dashboard-Licensed and Certified Healthcare Facility," California Health and Human Services Open Data Portal, CalHHS, March 24, 2022, https://data.chhs.ca.gov/dataset/healthcare-facility-locations/resource/e0e6729d-47a9-4923-bfbf-b793bcfc8106?inner_span=True.

⁴⁸ Matthew Newmann, "The Changing Landscape of California's Federally Qualified Health Centers," California Health Care Almanac (California Health Care Foundation, January 9, 2021), <https://www.chcf.org/wp-content/uploads/2021/06/RegionalMarketAlmanac2020CrossSiteAnalysisFQHC.pdf>.

⁴⁹ Julia Adler-Milstein et al., "California Health IT Landscape Assessment" (San Francisco, CA: University of California, San Francisco, 2022).

⁵⁰ Ibid.

⁵¹ Ibid.

data exchange capabilities.⁵² A 2014 California Primary Care Association (CPCA) survey found that of the 91 respondents, 81 (89%) had adopted some form of EHR.⁵³

iv. Behavioral Health and Substance Use Disorder Providers

California has almost 100,000 licensed behavioral health professionals and almost 1,100 SUD treatment facilities.^{54,55} The services that behavioral health and SUD providers deliver are an essential component of whole person care. Realizing this vision requires data exchange between behavioral health and SUD providers and other health and human services providers to ensure that services are timely and seamlessly coordinated. However, in California today, behavioral health and SUD providers often lack technical infrastructure – including certified EHR technology – capable of exchanging clinical and behavioral health data, and they face additional state and federal regulatory hurdles to exchanging information.⁵⁶ As mentioned above, many of these providers were not eligible for HITECH incentive funding and must adhere to additional federal and state data exchange laws and regulations that complicate the electronic sharing of information. A plurality of SUD treatment facilities in California reported using both paper and electronic methods for most administrative and care delivery functions.⁵⁷ For example, only slightly more than one-third (36%) of surveyed SUD treatment facilities in California reported using only electronic methods for treatment plan documentation and issuing and receiving lab results, and fewer than 20% are using electronic-only methods for storing and maintaining patient records (18%), sending patient health information (8%), and receiving health information (7%).⁵⁸

v. Clinical Laboratories

The COVID-19 pandemic underscored the importance of incorporating California's over 16,500 licensed clinical laboratories into the data exchange ecosystem.⁵⁹ The limited information publicly available related to clinical lab data exchange comes from a survey of California's HIOs. Two-thirds of California HIOs reported that independent clinical labs contribute data, only 25% of HIOs reported that labs view or receive data from an HIO, and only 17% reported that labs pay to participate.⁶⁰

⁵² "Licensed and Certified Healthcare Facility Listing – Counts Dashboard-Licensed and Certified Healthcare Facility," California Health and Human Services Open Data Portal, CalHHS, March 24, 2022, https://data.chhs.ca.gov/dataset/healthcare-facility-locations/resource/e0e6729d-47a9-4923-bfbf-b793bcfc8106?inner_span=True.

⁵³ "California State Medi-Cal Health Information Technology Plan" (California Department of Health Care Services, May 2021), <https://www.dhcs.ca.gov/provgovpart/Documents/OHIT/CA-State-Medicaid-HIT-Plan-2020.pdf>.

⁵⁴ Timothy Bates and Amber R. Rose, "California's Mental Health Professionals," 2021 Edition – California's Health Care Workforce (California Health Care Foundation, March 2021), <https://www.chcf.org/wp-content/uploads/2021/03/HealthCareWorkforceAlmanac2021MentalHealthQRG.pdf>.

⁵⁵ "Substance Use in California, 2022: Prevalence and Treatment," California Health Care Foundation – Health Care That Works for All Californians, California Health Care Foundation, January 2022, <https://www.chcf.org/wp-content/uploads/static/SubstanceUseDisorderAlmanac2022/index.html>.

⁵⁶ 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. Chuang, Emmeline, 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.

⁵⁷ J. Adler-Milstein et al., "California Health IT Landscape Assessment," February 2022.

⁵⁸ Ibid.

⁵⁹ "Laboratories In-State Map," Laboratories In-State Map (California Department of Public Health, April 2020), <https://www.cdph.ca.gov/Programs/OSPHLD/LFS/Pages/Laboratories-In-State-Map.aspx>.

⁶⁰ Julia Adler-Milstein et al., "California Health IT Landscape Assessment," February 2022.

vi. Skilled Nursing Facilities and Nursing Homes

California's 1,205 skilled nursing facilities (SNFs) and nursing homes generally care for individuals who require subacute care while recovering from an illness or a medical procedure (in the case of SNFs) or individuals who have long-term health needs that cannot be met in a community setting (in the case of nursing homes).⁶¹ One example where data exchange is particularly important for SNFs and nursing homes is during transitions of care. Delivering seamless care requires that the skilled nursing facility or nursing home and the other provider(s) have all the data they need to ensure a smooth transition. HIT and data exchange capabilities of California's SNFs and nursing homes have trailed those of other providers, likely because many were not eligible for incentive funding under HITECH. While California's capabilities are generally better than the national averages, only 10% of surveyed SNFs in California reported that their EHR was fully interoperable with hospital EHRs (7% nationally), with 13% reporting partial interoperability (8% nationally), 60% reporting no interoperability (79% nationally), and 17% reporting not having an EHR (7% nationally).⁶² Additionally, less than half of surveyed California 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%).⁶³ In addition, a smaller proportion of California HIOs reported that SNFs and nursing homes contribute data, view or receive data, or pay to participate compared with reporting by HIOs nationally - specifically, 33%, 42%, and 17% of California HIOs reported that SNFs and nursing home providers contribute data, view or receive data, or pay to participate compared with 53%, 66%, and 70% of HIOs nationally, respectively.⁶⁴

vii. Health Plans

California has approximately 340 regulated health plans.⁶⁵ Limited data exists on health plan HIT adoption and participation in data exchange. Generally, health plans have sophisticated capabilities to exchange and use administrative data – physical, behavioral, and pharmacy claims – but do not routinely exchange human services data.⁶⁶ Health plans also may have limited incentive to share data outside of the

⁶¹ "Licensed and Certified Healthcare Facility Listing – Counts Dashboard-Licensed and Certified Healthcare Facility," California Health and Human Services Open Data Portal, CalHHS, March 24, 2022, https://data.chhs.ca.gov/dataset/healthcare-facility-locations/resource/e0e6729d-47a9-4923-bfbf-b793bcfc8106?inner_span=True.

⁶² Julia Adler-Milstein et al., "California Health IT Landscape Assessment" (San Francisco, CA: University of California, San Francisco, 2022).

⁶³ Ibid.

⁶⁴ Ibid.

⁶⁵ "California Health Insurers: Large Insurers Remain on Top," California Health Care Almanac (California Health Care Foundation, May 2019), <https://www.chcf.org/wp-content/uploads/2019/05/CAHealthInsurersAlmanac2019.pdf>.

⁶⁶ Jonah Frohlich, Kevin McAvey, and Jonathan DiBello, "CalAIM and Health Data Sharing: A Road Map for Effective Implementation of Enhanced Care Management and In Lieu of Services" (California Health Care Foundation, May 2021), <https://www.chcf.org/wp-content/uploads/2021/04/CalAIMHealthDataSharingRoadMapECMILOS.pdf>.

network of providers they contract with. Less than half (42%) of California’s HIOs report that private health plans contribute data, view or receive data, or pay to participate.⁶⁷

B. Public Health and Emergency Services Organizations

i. Public Health Organizations

The COVID-19 pandemic and response revealed the fragmentation of California’s health data infrastructure in supporting public health responses. 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. Indeed, approximately 45% of California hospitals identified the inability of public health systems to receive data electronically as a major challenge.⁶⁸ Further, while 67% of HIOs reported that public health departments view or receive data, only 33% of HIOs reported that public health departments contribute data, and 42% reported that public health departments pay to participate, indicating that linkages to important public health data may be incomplete in California.⁶⁹

In addition, challenges remain in connecting and linking information. For example, vital records are not completely linked to laboratory data, clinical data, medical examiner/coroner data systems, or case reporting systems. And California Reportable Disease Information Exchange (CaREDIE) and the California Immunization Registry (CAIR) systems were not designed to connect, consume, and incorporate health information from HIOs or directly from EHRs at the scale needed to tackle a global pandemic. Reported public health reported data also often lacks basic demographic, occupational, and social determinants of health (SDOH) information. For example, the COVID-19 Equity Dashboard currently shows 20% of reported COVID-19 cases lack race/ethnicity information.⁷⁰

ii. Emergency Services Organizations

During emergencies and disasters, emergency response providers and other first responders, disaster health care volunteers, and emergency departments seek access to health and human services 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

⁶⁷ Julia Adler-Milstein et al., “California Health IT Landscape Assessment” (San Francisco, CA: University of California, San Francisco, 2022).

⁶⁸ Ibid.

⁶⁹ Ibid.

⁷⁰ “COVID-19 Equity Metrics – COVID-19 Demographic Data Completeness,” California Health and Human Services Open Data Portal (California Health and Human Services Agency, October 12, 2021), <https://data.chhs.ca.gov/dataset/covid-19-equity-metrics/resource/7b7909af-763f-44c1-8d1f-da25c022d4cc>.

inform clinical decision-making.⁷¹ PULSE is operational across all counties in the state, and all of California's regional HIOs participate in PULSE; however, some hospitals don't connect to PULSE, either through an HIO or directly to the PULSE service.

During emergencies, California's Search, Alert, File, and Reconcile (SAFR) process enables emergency response providers on the scene 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.^{72,73} SAFR, as of April 2021, was active in 29 of California's 58 counties and connected with eight HIOs, 70 emergency response organizations, and 50 receiving hospitals (specifically for the search and reconcile functions), and connections were planned with eHealth Exchange, Common Well, Carequality, and Superscripts.⁷⁴

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.

C. Human Service Organizations

Human service organizations provide a diverse array of services to support the needs of individuals throughout California. Human services might include housing support, food banks, and many others. Often, it is important for health care and human services providers to coordinate to address the needs of individuals; however, as mentioned above, exchange of human services data is challenged by limited infrastructure and standards. Little quantitative data is available regarding data exchange with and among human service organizations. Anecdotally, national networks, HIOs, and EHRs generally have limited capabilities to exchange SDOH data, including housing data. Closed-loop referral networks and emerging community information exchanges (CIEs) (e.g., Alameda County Care Connect and CIE San Diego) are able to share some SDOH data but are not widespread across California.⁷⁵

D. Individuals

California is home to over 39.2 million people. It is important for individuals to be able to access their health and human services data to inform decisions about their health and well-being. In California, while approximately 90% of individuals reported having access

⁷¹ "Health Information Exchange," ca.gov, California Emergency Medical Services Authority, accessed April 2022, <https://emsa.ca.gov/hie/>.

⁷² "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>.

⁷³ Daniel Smiley and Leslie Witten-Rood, "Health Information Technology for EMS Project" (California Emergency Medical Services Authority, October 2018), https://emsa.ca.gov/wp-content/uploads/sites/71/2021/12/2018_San-Diego_EMS-Plan.pdf.

⁷⁴ "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>.

⁷⁵ Jonah Frohlich, Eric Bartholet, 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>.

to their data, only 12% reported accessing it, indicating additional education and outreach may be beneficial for individuals.⁷⁶

E. Data Exchange Organizations

In addition to EHR-centered data exchange, HIOs and national networks are important intermediaries for the exchange of health care data.

i. HIOs

HIOs are entities that facilitate the exchange of individuals' health information among the enterprises composing a health care delivery system. These entities can be community-based and nonprofit – known in California as regional HIOs – or owned and operated by a private enterprise.⁷⁷ While less data is available on the extent of involvement of enterprise HIOs in California, much has been written about the history and role of California's regional HIOs.^{78,79} To summarize, as of August 2021, 15 regional HIOs in California served participants in at least 39 of 58 counties and exchanged more than 20 million patient encounter messages per month.⁸⁰ Cal-HOP played a role in increasing provider participation in regional HIOs, with 390 qualifying provider organizations achieving the first milestone, basic connection to a qualifying HIO, and 341 (87.4%) achieving the final milestone, adoption of advanced data exchange interfaces.⁸¹

However, gaps in regional HIOs' reach and capabilities remain. There are still approximately 19 counties that are not served by any of California's regional HIOs, and in the counties that are served, not all provider organizations participate.⁸² Additionally, although some HIOs connect to each other through the California Trusted Exchange Network (CTEN) or connect to national networks, not all do.⁸³ This can create difficulties in obtaining patient records when an individual seeks care from an alternative provider that may not connect to the same HIO or national network as the individual's previous provider.

⁷⁶ "COVID-19 Equity Metrics – COVID-19 Demographic Data Completeness," California Health and Human Services Open Data Portal (California Health and Human Services Agency, October 12, 2021), <https://data.chhs.ca.gov/dataset/covid-19-equity-metrics/resource/7b7909af-763f-44c1-8d1f-da25c022d4cc>.

⁷⁷ "Expanding Payer and Provider Participation in Data Exchange: Options for California" (California Health Care Foundation, November 2019), <https://www.chcf.org/wp-content/uploads/2019/11/ExpandingPayerProviderParticipationDataExchange.pdf>.

⁷⁸ 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>.

⁷⁹ Walter Sujansky, "Promise and Pitfalls: A Look at California's Regional Health Information Organizations," chcf.org (California Health Care Foundation, December 8, 2021), <https://www.chcf.org/publication/promise-pitfalls-californias-regional-health-information-organizations/>.

⁸⁰ 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>.

⁸¹ Julia Adler-Milstein, A Jay Holmgren, Grace Krueger, Sarah Rosenthal, Anjali Garg, and Janet Coffman, "California Health IT Landscape Assessment" (San Francisco, CA: University of California, San Francisco, 2022).

⁸² 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>.

⁸³ J. Adler-Milstein et al., "California Health IT Landscape Assessment," February 2022.

ii. National Networks

National networks (e.g., CommonWell Health Alliance,⁸⁴ DirectTrust,⁸⁵ eHealth Exchange⁸⁶) and national data exchange frameworks (e.g., Carequality,⁸⁷ Trusted Exchange Framework and Common Agreement⁸⁸) facilitate the exchange of data between provider organizations and health systems through common data sharing agreements and standards.⁸⁹

Carequality and the CommonWell Health Alliance support multiple EHR vendors, and eHealth Exchange supports organizations and federal agency systems.⁹⁰ TEFCA outlines a common set of principles, terms, and conditions to support the development of a Common Agreement that helps enable nationwide exchange of electronic health information across disparate health information networks.⁹¹

National networks are conduits for a significant amount of data exchange that occurs in California.

- **Carequality:** As of March 2022, 2,537 organizations in California were live on Carequality.⁹² In January 2022, Carequality users in California exchanged over 28 million documents.⁹³
- **CommonWell Health Alliance:** As of March 2022, almost 2,000 California provider sites were connected to the CommonWell Health Alliance and had shared 27.4 million patient records.⁹⁴
- **DirectTrust:** As of March 2021, DirectTrust reported over 73,000 California addresses and 23,000 unique organizations in its network.⁹⁵
- **eHealth Exchange:** Over 300 California hospitals and provider organizations and 11 HIOs connect to eHealth Exchange. These participants are responsible for 2.2 billion transactions (e.g., push notifications, patient discovery, query for documents, documents retrieved) annually.⁹⁶

National networks have several limitations. While national networks allow providers to query their platform to pull clinical summaries (CCDAs) for individual patients, they do

⁸⁴ CommonWell Health Alliance, April 14, 2022, <https://www.commonwellalliance.org/>.

⁸⁵ "What We Do," DirectTrust, April 30, 2020, <https://directtrust.org/what-we-do>.

⁸⁶ eHealth Exchange, March 28, 2022, <https://ehealthexchange.org/>.

⁸⁷ "Interoperability Framework," Carequality, March 28, 2022, <https://carequality.org/>.

⁸⁸ "Trusted Exchange Framework and Common Agreement (TEFCA)," HealthIT.gov (Office of the National Coordinator for HIT, March 11, 2022), <https://www.healthit.gov/topic/interoperability/trusted-exchange-framework-and-common-agreement-tefca>.

⁸⁹ 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>.

⁹⁰ Ibid.

⁹¹ "Trusted Exchange Framework and Common Agreement (TEFCA)," HealthIT.gov (Office of the National Coordinator for HIT, March 11, 2022), <https://www.healthit.gov/topic/interoperability/trusted-exchange-framework-and-common-agreement-tefca>.

⁹² "Active Sites (Search)," Carequality, February 12, 2019, <https://carequality.org/active-sites-search/> and correspondence with Carequality staff, March 2022.

⁹³ Epic, California, Nevada Interoperability Exchange Statistics, August 2021.

⁹⁴ Correspondence with CommonWell Health Alliance staff, March 2022.

⁹⁵ Correspondence with DirectTrust staff, April 2022.

⁹⁶ eHealth Exchange, "How the national network-of-networks solution improves patient care in California," November 2021.

not deliver claims; additional clinical data such as real-time immunization, lab, and encounter data; or other increasingly important information related to social determinants of health (e.g., housing, food, and other social needs).⁹⁷ National networks also generally do not construct singular, longitudinal records for individuals across an individual's various providers.⁹⁸ This can result in disparate clinical summary documents if an individual is treated by several providers.⁹⁹ Further, most national networks have limited capabilities to deliver data at a population level or real-time alerts when an individual is hospitalized or tests positive for COVID-19.¹⁰⁰ Finally, not all EHR vendors or provider organizations participate in the national networks, and data overload and quality issues reduce utilization at the point of care.¹⁰¹

V. Conclusion

The road to the current state of data exchange in California has been built upon multiple federal and state initiatives spanning more than two decades. The capabilities of providers and individuals to exchange and use health and human services data are as diverse as California itself. Some have developed sophisticated data exchange and use processes that are already making a difference in the lives of people they serve; others are still in the early stages of their journey and may benefit from policy, programmatic, and funding support. With the enactment of AB133 and the establishment of its first ever statewide Health and Human Services Data Exchange Framework, California has a once-in-a-generation opportunity to advance data exchange to improve the lives of all Californians.

⁹⁷ "How a HIE Network Will Support California's Health Care Priorities" (Connecting For Better Health, April 2021), <https://connectingforbetterhealth.com/wp-content/uploads/2021/04/How-a-HIE-Network-Will-Support-Californias-Health-Care-Priorities.pdf>.

⁹⁸ Ibid.

⁹⁹ Ibid.

¹⁰⁰ Ibid.

¹⁰¹ 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>.