

Gap #4: Intra- and Inter-Sector Data Exchange Capabilities

Relevant AB133 Provisions

Identify gaps, and propose solutions to gaps, in the life cycle of health information, including gaps in:

- [the] storage, maintenance, and management of health information.
[§130290(c)(3)(B)(iii)]
- Linking, sharing, exchanging, and providing access to health information.
[§130290(c)(3)(B)(iv)]

On or before January 31, 2023, the California Health and Human Services Agency shall work with the California State Association of Counties to encourage the inclusion of county health, public health, and social services, to the extent possible, as part of the California Health and Human Services Data Exchange Framework in order to assist both public and private entities to connect through uniform standards and policies. It is the intent of the Legislature that all state and local public health agencies will exchange electronic health information in real time with participating health care entities to protect and improve the health and well-being of Californians.
[§130290(e)]

California's health, public health, and human service agencies are stewards of valuable information that they need to manage programs and services they deliver to clients, individuals, and families. Most have mixed capabilities to electronically exchange timely and usable information with other health and human service organizations that could benefit from accessing it to provide a more complete picture and help them deliver a richer complement of coordinated services.

In California, county governments, in particular, have far-reaching responsibilities, partnering with the state to provide critical physical and behavioral health care services to their residents. Responsibilities of California's 58 counties include serving as the primary operator of health programs for low-income individuals without other forms of coverage and providing an array of behavioral health services, administered in part through county-operated mental health plans.³⁴

California's state and local public health agencies also play a critical role in promoting and protecting public health, collaborating with health care organizations to carry out core public health activities, including disease surveillance and case reporting. However, despite long-standing working relationships, significant barriers to effective data exchange between public health and health care organizations remain. In 2019,

³⁴ Deborah Reidy Kelch, "Locally Sourced: The Crucial Role of Counties in the Health of Californians," California Health Care Foundation, October 2015, <https://www.chcf.org/wp-content/uploads/2017/12/PDF-LocallySourcedCrucialRoleCounties.pdf>.

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45% of Californian hospitals identified the inability of public health systems to receive data electronically as a major challenge to reporting health information.³⁵ Researchers have cited underinvestment in public health infrastructure as a factor that has prevented more widespread public health data exchange across sectors, exacerbated by factors such as limited interoperability with health care EHRs and the challenges of onboarding and managing interfaces with multiple health systems.^{36,37,38}

With increasing recognition of the impacts of social factors on health, there is also growing support for the exchange of information about an individual’s social needs and the state and local government programs the individual may be participating in. However, efforts to increase data exchange between government entities, human service providers, and others involved in maintaining or improving health are complicated by operational, legal, and regulatory challenges for exchanging data across sectors (see **Gap #E1** and associated opportunities).

Opportunity #4.1: Upgrades to California County HIT Infrastructure

Summary: The state should leverage and expand federally funded programs to upgrade state and local health, public health, and human service information technology infrastructure and to provide a glidepath for entities using such infrastructure to participate in information exchange.

The state should make strategic investments in state and county physical and behavioral health, public health, and human service capacity to strengthen their participation in information exchange, as envisioned by AB133. California should prioritize the building of infrastructure to support data exchange and should develop an approach for ensuring the long-term sustainability of county technology infrastructure investments, identifying funding and resources to defray ongoing costs. Development and rollout of the capacity-building program would require close collaboration between state and local entities to leverage and align on priority objectives and initiatives.

The state should seek funding from federal sources to support upgrades to technology that can foster data sharing between state and county entities and stakeholder groups referenced in AB133.³⁹ The program should leverage and align with federal

³⁵ Adler Milstein, Julia, 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).

³⁶ Nason Maani and Sandro Galea, “COVID-19 and Underinvestment in the Public Health Infrastructure of the United States,” *The Milbank Quarterly* 98, no. 2 (April 2020): 250–259, <https://doi.org/10.1111/1468-0009.12463>.

³⁷ DeSalvo, Karen, Bob Hughes, Mary Bassett, Georges Benjamin, Michael Fraser, Sandro Galea, J. Nadine Gracia, and Jeffrey Howard, “Public Health COVID-19 Impact Assessment: Lessons Learned and Compelling Needs,” *National Academy of Medicine*, April 7, 2021. <https://nam.edu/public-health-covid-19-impact-assessment-lessons-learned-and-compelling-needs/>.

³⁸ Catherine J. Staes, James Jellison, Mary Beth Kurilo, Rick Keller, and Hadi Kharrazi, “Response to Authors of ‘Barriers to Hospital Electronic Public Health Reporting and Implications for the COVID-19 Pandemic,’” *Journal of the American Medical Informatics Association* 27, no. 11 (2020): 1821–1822, <https://doi.org/10.1093/jamia/ocaa191>.

³⁹ AB133 requires that specified entity types execute the DxFS. Specified entities include general acute care hospitals, physician organizations and medical groups, skilled nursing facilities, health service plans and disability insurers, Medi-Cal managed care plans, clinical laboratories, and acute psychiatric hospitals.

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modernization efforts, such as the Centers for Disease Control and Prevention (CDC) Data Modernization Initiative, which uses Coronavirus Aid, Relief, and Economic Security (CARES) Act funds to convene public health jurisdictions and other private- and public-sector entities to strengthen the nation’s public health data infrastructure.⁴⁰

Opportunity #4.2: Public Agency Data Exchange Policy and Contracting Requirements

Summary: The state should, through policy, procurement processes, and contract amendments, contractually obligate vendors to share information with health and human service organizations to advance goals envisioned by AB133.

The state should enact and support policies that expand health and human service data reporting and exchange requirements. Legislation pertaining to health and human service programs and initiatives could include provisions requiring applicable entities to share data to advance goals envisioned by AB133. For example, California’s AB977 requires that, beginning in January 2023, entities operating state homelessness programs report a set of specified data elements into their local Homeless Management Information System (HMIS) as a condition of receiving state funds.⁴¹ Data housed in regional HMIS systems is collected and warehoused in a statewide data system with the goal of supporting improved matching of data on homelessness to “programs impacting homeless recipients of state programs.”⁴²

In addition to enacting supportive legislation, the state could also include requirements for publicly funded programs to incorporate data sharing requirements into procurements and vendor contracts. Such policies would apply to use cases defined pursuant to the DxF and would include flow-down requirements for vendor contracting such as HMIS vendors and EHR vendors in correctional facilities. In one county-based example, Merced and San Joaquin counties have established contracts that require EHR vendors operating in their county jails to share health information with local data exchange intermediaries upon release of incarcerated individuals, to encourage coordinated transitions between the correctional facility and community settings.⁴³

⁴⁰ “Data Modernization Initiative,” Centers for Disease Control and Prevention, accessed April 27, 2022, <https://www.cdc.gov/surveillance/surveillance-data-strategies/dmi-investments.html>.

⁴¹ Cal. Welf. & Inst. Code §8256(d).

⁴² Cal. Welf. & Inst. Code §8257(b)(13).

⁴³ 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>.

B. Data Exchange Standards

Gap #1: Demographic and Human Service Data Exchange Standards and Capacity

Relevant AB133 Provisions

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

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

Identify gaps, and propose solutions to gaps, in the life cycle of health information, including gaps in:

- Health information creation, including the use of national standards in clinical documentation, health plan records, and social services data. [§130290(c)(3)(B)(i)]
- Translation, mapping, controlled vocabularies, coding, and data classification. [§130290(c)(3)(B)(ii)]

Understanding who our systems of health serve and the barriers to health they confront is essential for ensuring the effective and equitable delivery of services to improve their lives and well-being. Demographic data – indicators of an individual’s race, ethnicity, sex assigned at birth, gender identity, sexual orientation, and spoken language, among other characteristics – provide health and human service organizations with critical information about the health and service needs of those they serve, and allow for the early identification and mitigation of access and service delivery inequities and health disparities. Social determinants of health (SDOH) data – including indicators of an individual’s human needs that expand upon the health care system (e.g., housing stability, food security, personal safety) and the human services they may utilize – similarly provide health and human service organizations insight into the health-determining needs of their populations, and where opportunities may exist to connect individuals to services to support their overall, whole person health and well-being.

However, the standardized collection, curation, and use of demographic and SDOH data in California remain uneven and developing. Strengthening demographic and SDOH data collection, curation, and use in our systems of health is critical for supporting California’s underserved and under-represented populations and addressing the health disparities they may confront.

Demographic Data

The COVID-19 pandemic illuminated the stark inequities in health service access and the devastating disparities in health outcomes that exist and persist among Californians, and reinforced the importance of collecting better and more usable demographic data about the populations and communities we serve. Demographic information available to health and human service providers is frequently incomplete and inaccurate, or is collected against varying standards, making its use challenging.

Race, ethnicity, and language data, for example, has traditionally been collected by health and human service programs and organizations on a voluntary basis, with little context provided for how such information would be used to support the individual, often resulting in low response rates. In California, a quarter of COVID-19 cases still have missing race and ethnicity data, two years into the pandemic.⁴⁴ Analysis of national-level data similarly illustrates challenges that organizations face in collecting demographic information, with two-thirds of commercial health plans, half of Medicaid plans, and over one-quarter of Medicare plans reporting missing race data for at least half of their membership.⁴⁵

Different health and human service organizations collect race, ethnicity, and language information using different standards, making integration and comparability challenging. Even demographic data points with long histories of collection, such as gender, generally don't reflect our current understanding of these attributes and aren't collected with other contextual information (e.g., gender identity) to ensure that they may be meaningfully applied to support service delivery and health improvement. Federal standards for attributes like gender identity and sexual orientation are not widely implemented, and where information on these characteristics has been collected, it is frequently collected against local standards, which can vary significantly.

Social Determinants of Health (SDOH) Data

National and federally recognized standards for human service data exchange have not been broadly adopted, and the standardized collection, exchange, and use of information on SDOH remain limited. While health and human service organizations are increasing efforts to collect and use data on SDOH – which are estimated to

⁴⁴ Based on report date of April 19, 2022. California Health and Human Services Agency, "COVID-19 Demographic Data Completeness," October 12, 2021, <https://data.chhs.ca.gov/dataset/covid-19-equity-metrics/resource/7b7909af-763f-44c1-8d1f-da25c022d4cc>.

⁴⁵ Judy H. Ng, Faye Ye, Lauren M. Ward, Samuel C. Haffer, and Sarah Hudson Scholle, "Data on Race, Ethnicity, and Language Largely Incomplete for Managed Care Plan Members," *Health Affairs* 36, no. 3 (March 2017): 548–552, <https://doi.org/10.1377/hlthaff.2016.1044>.

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account for approximately 80% of health outcomes^{46,47} – such efforts remain largely in their early stages.

SDOH data can be collected *directly* from interactions with an individual (e.g., patient screening, observed conditions noted in clinical records or on claims), but such data may not be collected in alignment with modern federal standards such as United States Core Data for Interoperability (USCDI) version 2, as some standards are relatively nascent.⁴⁸ Use of SDOH-relevant ICD-10-CM codes in claims or encounters also remains limited, as health care organizations frequently do not have financial incentives or training to accelerate use.^{49,50}

SDOH data may also be collected *indirectly* from changes in an individual's engagement with human service programs (e.g., CalFRESH enrollment, identification in HMIS). However, this data may not always be accessible in a timely manner to health care organizations that could use it to inform an individual's care due to various legal, operational, and technical barriers to data exchange.⁵¹

In addition to obstacles to data collection, health and human service organizations also face challenges with SDOH data exchange. At present, data exchange intermediaries, including national networks, regional HIOs, and EHR vendor networks, generally have limited capabilities to exchange structured and standardized SDOH and other human service data.^{52,53,54}

Standardized collection, exchange, and use of demographic and SDOH data can strengthen the ability of health and human service organizations to address the needs of individuals, improve the quality and cultural appropriateness of care delivery, and identify and reduce health disparities.

⁴⁶ Sanne Magnan, "Social Determinants of Health 101 for Health Care: Five Plus Five," National Academy of Medicine, October 9, 2017, <https://nam.edu/social-determinants-of-health-101-for-health-care-five-plus-five/>.

⁴⁷ Manatt Health, "Medicaid's Role in Addressing Social Determinants of Health," Robert Wood Johnson Foundation, February 1, 2019, <https://www.rwjf.org/en/library/research/2019/02/medicaid-s-role-in-addressing-social-determinants-of-health.html>.

⁴⁸ USCDI version 2 was released by ONC in July 2021. More information about USCDI is available [HERE](#).

⁴⁹ SDOH-relevant IC-10-CM codes are primarily found within categories Z55–Z65 under *Factors influencing health status and contact with health services*. See CMS' Official Guidelines for Coding and Reporting for more detail, available [HERE](#).

⁵⁰ Centers for Medicare & Medicaid Services, "Utilization of Z Codes for Social Determinants of Health among Medicare Fee-for-Service Beneficiaries, 2019," Data Highlight No. 24, Office of Minority Health, September 2021, <https://www.cms.gov/files/document/z-codes-data-highlight.pdf>.

⁵¹ Kevin C. McAvey and Alisha Reginal, "Unlocking Race and Ethnicity Data to Promote Health Equity in California: Proposals for State Action," Manatt Health, April 19, 2021, <https://www.manatt.com/insights/white-papers/2021/unlocking-race-and-ethnicity-data-to-promote-health>.

⁵² California Health and Human Services Agency, Data Exchange Framework Data Sharing Agreement Subcommittee Meeting #1, November 8, 2021, https://www.chhs.ca.gov/wp-content/uploads/2021/11/CalHHS_DxF-DSA-Subcommittee_Meeting-1_Nov-8-2021.pdf.

⁵³ "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>.

⁵⁴ Mark Elson, "Issue Brief Health Information Exchange in California: 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>.

Opportunity #1.1: Demographic Data Collection and Use Standards, Requirements, and Incentives

Summary: The state should establish demographic data standards, requirements, and incentives through public and private payers to encourage data collection, exchange, and use among health and human service organizations in California.

The state should establish standards, requirements, and incentives through public and private payers to encourage the collection, exchange, and use of demographic data among public and private health and human service organizations in California. State regulations and codes should be amended, where possible, to support harmonized data collection and broader use, while maintaining federally and state mandated data privacy requirements (see **Opportunity #E1.3**).

California may work with health and human service organizations to establish and require demographic data collection and reporting on data elements including, but not limited to, race, ethnicity, gender, sexual orientation, gender identity, age, income, and disability status. State standards should align with federal standards, such as USCDI version 2 when finalized, and others such as those maintained by the U.S. Office of Management and Budget⁵⁵ and the U.S. Centers for Disease Control and Prevention.⁵⁶ Industry alignment on demographic data standards would support data exchange including by augmenting organizations' abilities to match data to the correct individual as described in the Strategy for Digital Identities (see **Opportunity #C2.1**). California should also establish a process to evaluate relevant new federal standards as they are released, to determine need for implementation.

California should promote common standards across public and private organizations, learning from other state experiences. For example, in 2021, Connecticut passed legislation⁵⁷ that required:

- State agencies, boards, or commissions to collect demographic information to follow a set of collection and reporting standards;
- The collection of self-reported demographic information in EHRs; and
- That a state office be charged with evaluating standard race and entity categories in consultation with stakeholders.

The introduction of data standards may be paired with and reinforced by data collection, reporting, and use requirements by public and private payers in California. For example:

⁵⁵ "Office of Management and Budget (OMB) Standards," National Institutes of Health, U.S. Department of Health and Human Services, accessed April 28, 2022, <https://orwh.od.nih.gov/toolkit/other-relevant-federal-policies/OMB-standards>.

⁵⁶ Centers for Disease Control and Prevention, "Race and Ethnicity Code Set Version 1.0," March 2000, <https://www.cdc.gov/phn/resources/vocabulary/documents/CDC-Race-Ethnicity-Background-and-Purpose.pdf>.

⁵⁷ Conn. Public Acts 2021, No. 21-35, § 11, <https://www.cga.ct.gov/2021/ACT/PA/PDF/2021PA-00035-R00SB-00001-PA.PDF>.

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- DHCS is promoting increased demographic data collection to reduce disparities and inequities through CalAIM,⁵⁸ and is increasingly using available data to identify potential differences in health outcomes between racial and ethnic population groups, sharing findings with health plans to guide interventions.⁵⁹
- Covered California continues to increase its race and ethnicity data reporting and use expectations, requiring Qualified Health Plans (QHPs) to achieve 80% self-identification of race and ethnicity data for their Covered California enrollees and to work with Covered California to reduce identified disparities.⁶⁰

Nationally, CMS has prioritized its expansion of the “collection, reporting and analysis of standardized data” – including race, ethnicity, language, sexual orientation, gender identity, and disability status – in its Medicare Equity Plan,⁶¹ as broader federal action in this area has been encouraged.⁶²

Health and human service organizations subject to new data collection, reporting, and use requirements may require technical assistance and processes for continuous improvement to support implementation of new data collection and use practices.

Opportunity #1.2: Social Determinants of Health (SDOH) Data Collection and Use Standards, Requirements, and Incentives

Summary: The state should establish SDOH data collection and sharing requirements and incentives through public and private payers to encourage data use among health and human service organizations in California.

The state should adopt federal SDOH data standards and should establish requirements and incentives to encourage data collection, exchange, and use in California, helping health and human service entities better understand individuals’ broad health and human service needs – and the barriers they might confront in addressing them. State regulations and codes should be amended, where possible, to support harmonized data collection and broader use, while maintaining federally and state mandated data privacy requirements (see **Opportunity #E1.3**).

Specifically, the state should evaluate and eventually adopt USCDI version 2 standards, which include standards pertaining to SDOH care goals, assessments, health concerns,

⁵⁸ Department of Health Care Services, CalAIM, accessed April 28, 2022, <https://www.dhcs.ca.gov/CalAIM/Pages/calaim.aspx>.

⁵⁹ Bailit Health, “Analyzing Health Disparities in Medicaid Managed Care,” State Health and Value Strategies, February 24, 2021, <https://www.shvs.org/wp-content/uploads/2021/02/Analyzing-Health-Disparities-in-Medicaid-Managed-Care.pdf>.

⁶⁰ Covered California, Attachment 1 to Covered California 2023-2025 Individual Market QHP Issuer Contract: Advancing Equity, Quality, and Value, April 19, 2022, https://hbex.coveredca.com/stakeholders/plan-management/library/2023-2025_QHP_IND_Attachment_1_4-19-22_Clean.pdf.

⁶¹ Centers for Medicare & Medicaid Services, “Paving the Way to Equity: A Progress Report (2015-2021),” Office of Minority Health, January 2021, <https://www.cms.gov/files/document/paving-way-equity-cms-omh-progress-report.pdf>.

⁶² Grantmakers In Health and National Committee for Quality Assurance, “Federal Action Is Needed to Improve Race and Ethnicity Data in Health Programs,” October 2021, <https://www.gih.org/publication/federal-action-is-needed-to-improve-race-and-ethnicity-data-in-health-programs/>.

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and interventions.⁶³ Widely used among health care organizations, USCDI is a set of health data classes and elements developed by the U.S. Office of the National Coordinator for Health Information Technology that supports standard, nationwide, and interoperable health information exchange. California should also establish a process to evaluate new federal standards as they are released (e.g., USCDI version 3) for potential implementation over time.⁶⁴

The adoption of statewide SDOH data standards may be paired with common data collection, data quality, and performance reporting requirements and incentives through public and private payers to support system change. To inform state approaches, California should examine the experiences of other states that have incorporated SDOH screening and referral requirements in their Medicaid managed care contracts and used quality reporting requirements and incentive payments to monitor and reward progress in meeting SDOH-related goals.⁶⁵ Health and human service organizations subject to requirements or incentives pertaining to SDOH data collection, exchange, and use practices may require technical assistance to support implementation.

Establishing statewide SDOH data collection, exchange, and use requirements and incentives would build upon significant system investments in California and would position California as a leader among states advancing whole person health and health equity. In California, the Department of Health Care Services is reshaping its Medi-Cal program and delivery system through an expansive reform effort – CalAIM – prioritizing the identification and mitigation of social needs for high-risk, high-utilizing enrollees through increased service integration among counties, health plans, and community-based organizations (CBOs).⁶⁶ Nationally, CMS has encouraged state Medicaid and Children’s Health Insurance Program (CHIP) initiatives to adopt strategies like CalAIM that address SDOH, including instituting new data collection and reporting requirements, investing in systems capable of exchanging SDOH data, and establishing programs that can put such data to meaningful use.⁶⁷

Health and human service organizations subject to new data collection, reporting, and use requirements may require technical assistance and processes for continuous improvement to support implementation of new data collection and use practices.

⁶³ Office of the National Coordinator for Health Information Technology, “United States Core Data for Interoperability (USCDI),” HealthIT.gov, accessed April 28, 2022, <https://www.healthit.gov/isa/united-states-core-data-interoperability-uscdi>.

⁶⁴ ONC is currently developing USCDI version 3, with an expected release date in July 2022. The draft version of USCDI version 3, which was released for public comment, retains the SDOH-related elements contained in version 2. More information is available on the ONC website [HERE](#).

⁶⁵ States pursue a number of strategies to advance the collection, exchange, and use of SDOH information, including requirements for entities to screen individuals for social needs or to capture SDOH data using ICD-10-CM “Z” codes. More information can be found in a Kaiser Family Foundation brief describing Medicaid Authorities and Options to Address SDOH, available [HERE](#).

⁶⁶ Department of Health Care Services, CalAIM, accessed April 28, 2022, <https://www.dhcs.ca.gov/CalAIM/Pages/calaim.aspx>.

⁶⁷ Centers for Medicare & Medicaid Services, “CMS Issues New Roadmap for States to Address the Social Determinants of Health to Improve Outcomes, Lower Costs, Support State Value-Based Care Strategies,” January 7, 2021, <https://www.cms.gov/newsroom/press-releases/cms-issues-new-roadmap-states-address-social-determinants-health-improve-outcomes-lower-costs>.

Opportunity #1.3: Cross-State Agency Data Sharing Enhancements

Summary: The state should strengthen data exchange relationships between state agencies, supporting the exchange of program enrollment and relevant demographic and SDOH information to support a coordinated approach to health care and human service delivery across disparate programs and settings.

The state should enhance cross-agency program enrollment, service utilization, demographic, and SDOH data sharing, in alignment with state and federal law, to support cross-program service coordination and greater shared understanding of population health and human service needs. The state should also permit access to this data by external health and human service organizations that are serving Californians, to the extent allowable by state and federal law, in order to improve service delivery.

Examples of the types of state agency data that may be shared to support coordinated service delivery are shown in **Table 1**.⁶⁸

Table 1. Sample of State Government Departments/Offices and Relevant Data

State Government Department/Office	Relevant Programs or Topics	Relevant Data Systems	Data Types
Department of Health Care Services (DHCS)	Medi-Cal	Medi-Cal Eligibility Data System (MEDS)	Program enrollment and identified social needs (if captured on claims or encounters)
California Department of Social Services (CDSS)	CalFresh, Child Welfare and Adult Protective Services	California Statewide Automated Welfare System (CalSAWS) Child Welfare Services/Case Management System (CWS/CMS), SOC 242 Form	Program enrollment and other food insecurity indicators Child welfare and adult protective services involvement indicators and identified health and social needs
Business, Consumer Services and Housing Agency (BCSH) –	Homelessness	Homeless Data Integration System (HDIS) ⁶⁹	Housing services enrollment and other housing stability indicators

⁶⁸ Table 1 provides *examples* of entities and data types that may be involved in efforts to enhance cross-agency data sharing. The list of entities and data types is not intended to be understood as comprehensive. Sharing of some data types described in the table may require revisions to state government department/office program policy or to governing law.

⁶⁹ The Homeless Data Integration System (HDIS) is a statewide data warehouse that compiles and processes data from all 44 local homelessness response systems in California. More information on HDIS is available on the BCSH website [HERE](#).

California Interagency Council on Homelessness (Cal ICH)			
Attorney General’s Office	Criminal Justice	Criminal Justice Statistics Center	Justice involvement indicators including information on probation events and transitions
California Department of Developmental Services (CDDS)	Developmental Disabilities	SANDIS	Diagnostic and evaluative information
California Department of Public Health (CDPH)	Public Health	California Immunization Registry (CAIR) California Reportable Disease Information Exchange (CalREDIE)	Public health programmatic data (e.g., immunizations, case and lab reports)

As California continues to scale programs that support whole person care, the state may evaluate incentivizing health and human service organization connections to health information exchanges, community information exchanges (CIEs), and other data exchange intermediaries to support cross-program and cross-sector exchange of program, service utilization, and individual demographic and SDOH data.

Investments in cross-state agency data sharing may require the state to identify new resources – including sources of funding – to support implementation. Each agency should investigate, identify, and evaluate federal funding opportunities to support initiative goals. For example, DHCS should explore the possibility of leveraging enhanced federal Medicaid matching funds, as described in CMS guidance, for “state expenditures to design, develop, install, or enhance” interoperable systems capable of identifying individuals’ SDOH needs and sharing that information with appropriate medical and social support services.⁷⁰ (See **Opportunity #F1.1** for more information.)

Opportunity #1.4: Recommendations to the Federal Government to Improve Demographic and SDOH Data Collection Nationally

Summary: The state should develop and advance recommendations to the federal government to improve demographic and SDOH data exchange standards nationally.

The state should advance recommendations to the federal government to improve demographic and SDOH data collection nationally. The collection of demographic and

⁷⁰ Anne M. Costello, SHO# 21-001 RE: Opportunities in Medicaid and CHIP to Address Social Determinants of Health (SDOH), Centers for Medicare & Medicaid Services, January 7, 2021, <https://www.medicare.gov/federal-policy-guidance/downloads/sho21001.pdf>.

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SDOH data remains uneven across health and human service organizations, with variation in data standards – and data standards implementation – even among federal agencies.

While it seeks to align with federal requirements, California should develop an approach to advocate for and advance standards that reflect local learnings and priorities. The approach should include a process to identify opportunities to comment on national data standards, including those promulgated by federal agencies such as ONC, CMS, the Health Resources and Services Administration (HRSA), the U.S. Department of Health and Human Services Office for Civil Rights (OCR), and the Substance Abuse and Mental Health Services Administration (SAMHSA), as well as those proposed by non-governmental organizations such as the American Medical Association; the University of California - San Francisco/Social Interventions Research and Evaluation Network-supported The Gravity Project; and the Sequoia Project. For instance, California – through its Center for Data Insights and Innovation – could collect and advance recommendations to the federal government to address misalignment between HRSA’s demographic standards and those of the USCDI, which creates reporting burden for health care providers that may have to report to different payers using differing standards.

The state should also develop processes to assess whether new proposed federal standards and regulations should be incorporated into the DxF and its DSA, and should potentially provide guidance to implicated health and human service organizations on how they may effectively implement these standards and regulations. For example, CalHHS could develop a consolidated response to the emerging draft USCDI version 3 standards, which support more consistent functional, cognitive, and other disability status data collection, sharing, and use, to reflect local learnings and potentially improve proposed standards before they are finalized.

C. Provider Information and Person Identity Management

Gap #1: Robust Provider Information

Relevant AB133 Provisions

Identify gaps, and propose solutions to gaps, in the life cycle of health information, including gaps in linking, sharing, exchanging, and providing access to health information. [§130290(c)(3)(B)(iv)]

Collection and management of provider information is critical for identifying the methods, standards, and routes for exchanging health and human service information to support care coordination and other DxF use cases. However, complete provider information (e.g., name, practice locations, organizational affiliates, and the available means to exchange health information such as Direct addresses and endpoints) is not always available or accessible to all health and human service organizations across California, creating barriers to effective information exchange and service delivery.

Provider identities are often assigned and/or managed by federal, national, or state provider directories, the scopes and utility of which may vary based on their purpose. Provider directories may be established for more consumer-facing purposes (e.g., helping individuals identify in-network providers close to where they live or work) or to support provider-to-provider communications (e.g., listing the means, data exchange intermediaries, and addresses available to send data to or request data from a provider). Examples of provider directories used to support provider-to-provider communications in California include those maintained by the California Trusted Exchange Network (CTEN), Carequality,⁷¹ DirectTrust,⁷² and the National Plan & Provider Enumeration System (NPPES), which is the CMS program responsible for assigning National Provider Identifiers (NPIs).⁷³

Federal and state policies require and govern the use of provider directories for a limited set of use cases. For example, CMS' recent Interoperability and Patient Access final rule and California's SB137 require that certain payers maintain or make available provider directory information.^{74,75} The CMS Interoperability and Patient Access final

⁷¹ "Active Sites," Carequality, accessed April 29, 2022, <https://carequality.org/active-sites-search/>.

⁷² "DirectTrust (Home)," DirectTrust, accessed April 29, 2022, <https://directtrust.org/>.

⁷³ National Plan and Provider Enumeration System, Health Information Exchange (HIE) Page, Centers for Medicare & Medicaid Services, accessed April 29, 2022, <https://nppes.cms.hhs.gov/webhelp/nppeshelp/HEALTH%20INFORMATION%20EXCHANGE.html>.

⁷⁴ Centers for Medicare & Medicaid Services, Interoperability and Patient Access Fact Sheet, March 9, 2020, <https://www.cms.gov/newsroom/fact-sheets/interoperability-and-patient-access-fact-sheet>.

⁷⁵ Health Care Coverage: Provider Directories, Cal. S. B. 137 (2015-2016), Chapter 649, (Cal.Stat.2015). Full text available [HERE](#).

rule also separately encourages providers to maintain accurate digital contact information that can be used to exchange health information electronically.⁷⁶

Despite their importance, provider directories are often limited in their ability to support many of the use cases envisioned by AB133 and the DxF and its DSA. For example:

- Participation in provider directories is often voluntary or limited to the participants of a given network, limiting the directories' scope and ability to support communication and information exchange between disparate entities and sectors.⁷⁷
- Many provider directories are not designed for the purpose of facilitating health information exchange and lack critical digital contact information that would facilitate electronic exchange.
- Provider directories are only as useful as the timeliness of their data, and as provider contact and system affiliation information can often change, protocols and incentives or regulatory requirements must be in place to ensure that providers are reflecting those changes in the directory.

Basic provider information and accurate information about how to exchange health and human service information with providers are critical for creating a shared understanding of the health and human service organizations supporting Californians' health and well-being, knowing whom those organizations are serving and for what services, and connecting health and human service organizations as they strive to deliver more coordinated and whole person care. California presently lacks a comprehensive provider directory strategy capable of advancing these objectives.

Opportunity #1.1: Provider Directory and Reporting

Summary: The state should support the establishment of a statewide provider directory and should require signatories of the DxF DSA to contribute data to encourage provider-to-provider communication and information exchange.

The state should support the establishment of a statewide provider directory and should develop supporting policies to encourage communication and information exchange between disparate health and human service entities. The provider directory may be newly established or may leverage and build upon existing directories and approaches and should be designed for the purposes of enabling provider-to-provider communication. The provider directory should eventually include and be accessible to health care and human service organizations to encourage coordinated delivery of a

⁷⁶ Centers for Medicare & Medicaid Services, Interoperability and Patient Access Fact Sheet, March 9, 2020, <https://www.cms.gov/newsroom/fact-sheets/interoperability-and-patient-access-fact-sheet>.

⁷⁷ As an example, CMS encourages providers to report digital contact information in NPPES but does not levy financial penalties or restrictions on providers that fail to do so. More information on digital contact information in NPPES is available [HERE](#).



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comprehensive range of health and human services to individuals. The provider directory should include, among other identifying data elements, information on provider digital contact information for various existing industry standards (e.g., Direct messaging address, Fast Healthcare Interoperability Resources® [FHIR®] URL).

All signatories of the DxF DSA should be responsible for submitting required data elements, including digital contact information, to the provider directory using a standardized process, as well as for supporting the maintenance and timely updating of such information on an ongoing basis. DxF Governance should consider technical approaches and specifications to support provider identification and data exchange and should clarify requirements and guidance for DxF participants in the DxF DSA and P&Ps.

Gap #2: Person Identity Management

Relevant AB133 Provisions

On or before July 31, 2022, the California Health and Human Services Agency shall develop in consultation with the stakeholder advisory group in subdivision (c) a strategy for unique, secure digital identities capable of supporting master patient indices to be implemented by both private and public organizations in California. [§130290(h)]

The effective exchange and use of health care and human service data to support treatment and care is dependent upon linking data to the right individual. Many health care providers, health plans, and data exchange intermediaries have robust person resolution and record-linking technologies within their organizations. However, no robust or systematic coordination of digital identities, person resolution, or data linking exists across organizational boundaries in California, limiting the efficacy of cross-organizational data exchange.

As a result, organizations often fail to locate existing health records for individuals they serve that might exist at other organizations to support care coordination and management, because the organizations' health information systems fail to agree on a single personal "identity." Conversely, records for different individuals may be inappropriately matched, presenting an inaccurate picture of a person's health and human service information – and potentially risks to health, if incorrectly linked data is used to guide clinical care. Both issues can lead to delays in effective service provision, poorer health outcomes, or even errors in service delivery.

Opportunity #2.1: Strategy for Digital Identities

Summary: The state should adopt the Strategy for Digital Identities called for in AB133 as a component of the DxF.

California stakeholders have significant experience in person resolution, person matching, and record linking through participation in existing networks. This experience was leveraged to create a Strategy for Digital Identities that focused on linking health and human service information to a real person across organizational and sector boundaries.

For more details, please refer to the Strategy for Digital Identities document, which will be made available on the [CalHHS DxF website](#) by July 31st, 2022.

D. Individual Data Access

Gap #1: Individual Data Access

Relevant AB133 Provisions

Identify gaps, and propose solutions to gaps, in the life cycle of health information, including gaps in linking, sharing, exchanging, and providing access to health information. [§130290(c)(3)(B)(iv)]

Identify how all payers will be required to provide enrollees with electronic access to their health information, consistent with rules applicable to federal payer programs. [§130290(c)(3)(I)]

Individuals consistently face challenges in accessing and contributing to their health and human service records – directly or through selected third parties – in a manner that is convenient, timely, and compliant with federal access requirements.

Under the federal Health Insurance Portability and Accountability Act (HIPAA), individuals have a legal, enforceable right to access their health records maintained by a covered entity such as a provider or health plan.⁷⁸ Research has shown that providing individuals access to their own health information is associated with improvements in doctor-patient communication, treatment adherence, and individual empowerment – and is of great interest to many individuals.⁷⁹ According to a national survey conducted in 2020, the majority of respondents reported they would want to access their own health information, with particularly high interest in accessing laboratory test results (89%) and history of medical conditions (88%).⁸⁰

Despite individuals' right to access their information and their interest in doing so, numerous barriers to access exist, including complex access requirements; fragmented data; financial costs (e.g., printing fees); and, often, health care organization non-compliance. Even for individuals who are able to access their information, their ability to contribute data – that is, to engage in bidirectional exchange – is often limited despite its potential benefits, such as facilitating submission of patient-reported outcomes or even corrections to errors in an individual's medical record.

⁷⁸ U.S. Department of Health and Human Services, "Individuals' Right under HIPAA to Access Their Health Information 45 C.F.R. §164.524," Health Information Privacy, accessed April 29, 2022. <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/access/index.html>.

⁷⁹ Stephen E. Ross and Chen-Tan Lin, "The Effects of Promoting Patient Access to Medical Records: A Review," *Journal of the American Medical Informatics Association* 10, no. 2 (2003): 129–138, <https://doi.org/10.1197/jamia.m1147>.

⁸⁰ "Most Americans Want to Share and Access More Digital Health Data," The Pew Charitable Trusts, July 27, 2021, <https://www.pewtrusts.org/en/research-and-analysis/issue-briefs/2021/07/most-americans-want-to-share-and-access-more-digital-health-data>.

Recent policy has taken steps to support data access for individuals, including through ONC's 21st Century Cures Act final rule, which includes provisions that aim to curtail information blocking,⁸¹ and CMS' Interoperability and Patient Access final rule, which requires CMS-regulated payers to make individuals' data, including claims and encounter data, available to individuals via a secure, standards-based Application Programming Interface (API).⁸² While these federal rules have the potential to advance information access for individuals, barriers remain, including stakeholder concerns regarding data confidentiality and privacy, which have surfaced and been heightened as a result of the push for more open exchange of data.

Opportunity #1.1: Policies to Ensure That Individuals Have Meaningful Access to Their Longitudinal Health Information

Summary: The state should adopt and expand policies to ensure that individuals have meaningful access to their longitudinal health information across all health care organizations that are required to execute the DxF DSA, allowing all Californians to be meaningfully engaged in their care and make informed health care decisions.

The state should adopt policies to ensure that individuals have meaningful access to their longitudinal health information across all health care organizations subject to AB133, allowing them to make informed health care decisions.

Potential policies and requirements to advance this objective may include building upon federal rules that increase individuals' access to their health information to include all health care organizations subject to the DxF and its DSA. Specifically, the state could expand on ONC's Cures Act final rule⁸³ to apply the federal information-blocking provisions to the state's licensed health plans and health care organizations required to execute the DxF DSA.⁸⁴ The state could also expand on CMS' Interoperability and Patient Access final rule⁸⁵ to require that signatories of the DxF DSA implement and maintain a secure, standards-based API (e.g., Health Level 7® (HL7®) FHIR® Release 4.0.1) that allows individuals to easily access their health information through third-party applications of their choice.

The state should also evaluate where California law governs individuals' access to their longitudinal health information and may need to be modified, as federal rules often defer

⁸¹ "ONC's Cures Act Final Rule," Office of the National Coordinator for Health IT, accessed April 29, 2022, <https://www.healthit.gov/curesrule>.

⁸² Centers for Medicare & Medicaid Services, Interoperability and Patient Access Fact Sheet, March 9, 2020, <https://www.cms.gov/newsroom/fact-sheets/interoperability-and-patient-access-fact-sheet>.

⁸³ 21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program, 85 Fed. Reg. 25642 (May 1, 2020).

⁸⁴ Organizations required to sign the DxF DSA include general acute care hospitals, physician organizations and medical groups, skilled nursing facilities with electronic records, some health care service plans and disability insurers, clinical laboratories, and acute psychiatric hospitals. More details can be found in California Health and Safety Code §130290(f)(1-6).

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

to state law. Examples of relevant state law include California Health and Safety Code 123110, which gives individuals the right to inspect and receive a copy of their patient records by request and upon payment of any reasonable costs.⁸⁶

Supportive policies may also provide individuals with bidirectional access to their health information maintained by health care organizations – including to add self-reported health information and to correct inaccurate information to the extent allowed by law – in a manner that accommodates their preferred language, readability level, and disability status while also supporting access for those Californians who have limited access to technology or broadband or have low health and information technology literacy.

Health care organizations should be expected to provide individuals with education and support on how to access, update, and use their health information to inform their decision-making.

Opportunity #1.2: Policies to Strengthen Understanding and Trust for Individuals Sharing Data

Summary: The state should assess, strengthen, and adopt policies that will support individuals in understanding how their health and human service information may be used and will help establish trust in the systems in place that govern its use.

The state should adopt policies to ensure that individuals understand how their health and human service information may be used and to build trust in the systems in place that govern its use.

California should review its fair information practices and policies, consider updates, and develop stronger guidelines for data use that can be linked with the DxF DSA and referenced in future state policy guidance. Guidelines may include and address:

- Transparent data policies;
- Limitations on health information collection, use, and disclosure;
- Consent procedures;
- Data quality, integrity, and security protections; and
- Accountability processes through appropriate audit trails and enforcement.

Guidelines should be clear on how individuals' health and human service information may be shared and where individuals have the ability to provide or withhold consent prior to its exchange and use, in alignment with state and federal laws. The U.S. Department of Health and Human Services Office of Civil Rights' guidance on the right

⁸⁶ Cal. Health & Safety Code §123110. Available [HERE](#).

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of individuals under HIPAA to access their health information⁸⁷ and ONC’s 2018 Model Privacy Notice⁸⁸ provide examples of clear guidance to inform individuals about data access and privacy policies.

California should develop practices and policies to hold DxF DSA participants accountable for participation in the appropriate exchange and use of individuals’ health information, including by monitoring and evaluating participation and adherence to policies regarding the sharing, safeguarding, and use of health information; integrating explicit protections against misuse of health data; supporting health care organization training on individuals’ access to health information; and supporting mechanisms to solicit and process feedback from individuals to improve data access.

⁸⁷ U.S. Department of Health and Human Services, “Individuals’ Right under HIPAA to Access Their Health Information 45 C.F.R. §164.524,” Health Information Privacy, accessed April 29, 2022, <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/access/index.html>.

⁸⁸ Office of the National Coordinator for Health IT, 2018 Model Privacy Notice, accessed April 29, 2022, <https://www.healthit.gov/sites/default/files/2018modelprivacynotice.pdf>.

E. Data Exchange Law, Regulations, and Policy

Gap #1: Data Exchange Law, Regulations, and Policy

Relevant AB133 Provisions

The California Health and Human Services Data Exchange Framework shall align with state and federal data requirements, including...applicable state and federal privacy laws related to the sharing of data among and between providers, payers, and the government, while also streamlining and reducing reporting burden.”

[§130290(a)(3)]

Address the privacy, security, and equity risks of expanding care coordination, health information exchange, access, and telehealth in a dynamic technological, and entrepreneurial environment, where data and network security are under constant threat of attack. [§130290(c)(3)(F)]

Identify ways to incorporate relevant data on behavioral health and substance use disorder conditions. [§130290(c)(3)(E)]

Identify gaps, and propose solutions to gaps, in the life cycle of health information, including gaps in linking, sharing, exchanging, and providing access to health information. [§130290(c)(3)(B)(iv)]

Numerous federal and state laws, regulations, and policies that govern the exchange of physical, behavioral health, and human service data create real or perceived barriers to sharing information that is necessary to inform whole person care and population health goals.

Legal protections safeguard the privacy and security of personal information. The federal Health Insurance Portability and Accountability Act (HIPAA) is a foundational regulation that governs the disclosure of protected health information (PHI), setting national standards for its collection, exchange, and use.

However, many data types created and used by health and human service organizations are also protected by myriad other federal and state laws, regulations, and policies. For example, certain data types, including those pertaining to behavioral health, HIV/AIDS, sexual health, and minors, are governed by specific federal and state rules and regulations that require individuals’ authorization to disclose information for data sharing purposes. Beyond the domain of clinical health care, the collection and exchange of data curated by human service organizations or government agencies – including data related to housing, food security, education, and criminal history – may

require separate, individual authorization to be shared and are often protected by additional regulations and rules specific to the data collecting entity and data type.^{89,90}

While critical to ensuring appropriate stewardship of personal information and building trust among exchange partners, legal protections for subsets of health and human service data can present barriers to meaningful data exchange. In a study of California’s Whole Person Care (WPC) pilots, 16 pilots (64%) reported patient privacy and confidentiality regulations as a major implementation challenge.⁹¹ For example, lack of alignment in data sharing requirements between HIPAA and the Federal Educational Rights and Privacy Act (FERPA) presents regular challenges to data exchange between educational institutions and health care providers, limiting efficacy of support coordination for youth with disabilities. Some WPC pilots additionally noted that even when legal barriers were eliminated, fear and risk aversion affected organizations’ willingness to exchange data.⁹²

Effective data sharing requires health and human service organizations to have a common understanding of when information sharing is permissible and to have the capability to obtain, manage, and share information about an individual’s authorization to release and share data. However, managing authorization and consent can be challenging, with organizations’ operational approaches – and the effectiveness of these approaches – varying widely, hampering efforts to share authorizations across organizational boundaries.

Opportunity #1.1: “Universal” Release-of-Information Authorization Form

Summary: The state should support the adoption and use of a “universal” release-of-information authorization form to enable standardized data exchange in support of state priority use cases and the goals of AB133.

The state should support the adoption and use of a “universal” release-of-information authorization form. Universal authorization forms are characterized by their standardized structure and broad acceptance and use by disparate organizations, addressing legal-interpretation inconsistency and operational/review inefficiency to enhance trust and transparency between exchange partners and individuals. Broad-based adoption and use of universal authorization forms may improve the ability of

⁸⁹ Jonah Fröhlich, 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>.

⁹⁰ Department of Health Care Services, “CalAIM Data Sharing Authorization Guidance,” Department of Health Care Services, March 2022, <https://www.dhcs.ca.gov/Documents/MCQMD/CalAIM-Data-Sharing-Authorization-Guidance.pdf>.

⁹¹ Emmeline Chuang, Nadereh Pourat, Leigh Ann Haley, Brenna O’Masta, Elaine Albertson, and Connie Lu, “Integrating Health And Human Services In California’s Whole Person Care Medicaid 1115 Waiver Demonstration,” *Health Affairs* 39, no. 4 (April 2020): 639–648, <https://doi.org/10.1377/hlthaff.2019.01617>.

⁹² Ibid.

individual organizations to collect and manage authorizations, reduce administrative burden, and lower barriers to data sharing across entities and sectors.

The scope of the universal authorization form should be determined in alignment with state priorities and the requirements of the DxF and its DSA. The state should develop the form to prioritize data types where authorization, collection, and sharing challenges are most acute and to prioritize use cases related to state investments in health and human services, including applications stemming from CalAIM, the public health emergency, and other priorities. The state should identify and address as appropriate the legal barriers to use of a universal authorization form (e.g., language requiring a new consent for each separate use of a given piece or set of information).

The state should develop the form leveraging lessons from other states and California's WPC pilots. For example, in 2015, the Michigan Department of Health and Human Services (DHHS) released a standard consent form for sharing behavioral health information, the Behavioral Health Standard Consent Form, to address challenges with sharing such data.⁹³ In 2018, Michigan DHHS released a policy bulletin specifying that the form must be "accepted, honored, and used" by all Medicaid providers that are requesting release of behavioral health-related information, in cases when such consent is required.⁹⁴ California may also use policy levers to require or encourage use of the universal authorization form to maximize its benefits. In Michigan, for example, the state Legislature required that all entities involved in treating those with certain behavioral health conditions honor and accept the form unless held to more stringent protections under federal law.⁹⁵

California should provide technical assistance to support organizations in understanding how and when to use the final authorization form to build knowledge as well as trust between users. Technical assistance should leverage existing state resources, such as the State Health Information Guidance (SHIG),⁹⁶ and should provide organizations with support for collecting, using, and exchanging sensitive information, including that which may be specially protected.

⁹³ "MDHHS-5515: Behavioral Health Consent Form Background Information," Michigan Department of Health and Human Services, accessed April 29, 2022, https://www.michigan.gov/mdhhs/-/media/Project/Websites/mdhhs/Folder3/Folder46/Folder2/Folder146/Folder1/Folder246/MDHHS_5515_Behavioral_Health_Consent_Form_Background_Information.pdf.

⁹⁴ Kathy Stiffler, MSA# 18-44 RE: Standard Consent Form., Michigan Department of Health & Human Services, November 30, 2018, https://www.michigan.gov/documents/mdhhs/MSA_18-44_639601_7_641574_7.pdf.

⁹⁵ "MDHHS-5515: Behavioral Health Consent Form Background Information," Michigan Department of Health and Human Services, accessed April 29, 2022, https://www.michigan.gov/mdhhs/-/media/Project/Websites/mdhhs/Folder3/Folder46/Folder2/Folder146/Folder1/Folder246/MDHHS_5515_Behavioral_Health_Consent_Form_Background_Information.pdf.

⁹⁶ "State Health Information Guidance (SHIG)," Office of Health Information Integrity, California Health and Human Services Agency, accessed April 29, 2022, <https://www.chhs.ca.gov/ohii/shig/>.

Opportunity #1.2: Consent Management Service

Summary: The state should consider support for a consent management service that would allow individuals to electronically manage – and health and human service organizations to access – their expressed consents to disclose and share certain types of health and human service information.

The state should consider support for establishing a consent management service that would allow individuals to electronically provide, revoke, and manage their consent for access and use of their health and human service information. Health and human service organizations would then be expected to access the consent management service to validate whether – and with whom – they are permitted to exchange applicable data types for individuals under their care. A statewide service could improve care coordination and continuity for individuals and reduce the burden on individual health care entities to obtain and manage authorizations to share data.

The design and structure of a potential consent management service should be aligned with state priorities and the requirements of the DxF and its DSA. The state should consult with stakeholders to develop an overarching approach for the oversight and management of a potential service to include identifying the data types, types of consent, and scope of health care organizations the service would support as well as determining the entities that would be expected to participate.

The state should expect to provide technical assistance to health and human service organizations and individuals to support the transition to electronic modes of consent management. Activities of such technical assistance could include educating organizations and individuals on the purpose and use of the consent management system, building trust, communicating the benefits of the system, and ensuring that the design of a potential service prioritizes individual privacy rights and supports health equity.

Consideration of a consent management service should be pursued in concert with other aligned opportunities. Specifically, strong person identity management, as described in the DxF Strategy for Digital Identities (see **Opportunity #C2.1**), is a prerequisite for effective consent management that crosses organizational boundaries. Additionally, development of a universal authorization form (see **Opportunity #E1.1**) would support the standardization of consent information, laying the groundwork for the design and implementation of an electronic consent management service that would be available and useable by disparate entities across the health and human service sectors.

Opportunity #1.3: Promote Federal and State Regulatory Alignment

Summary: The state should identify state and federal information exchange requirement misalignments and promote efforts to harmonize requirements, where possible.

The state should identify unnecessary legal and regulatory misalignments that make it more difficult for health and human service organizations as well as state and local government agencies to exchange health information in support of the health of all Californians, while protecting patient privacy. For example, the state may evaluate state laws governing developmental disability information, which require release of consent for each use and disclosure, potentially prohibiting regular data sharing among the various entities involved with an individual's care.⁹⁷ The state may also evaluate and address laws and policies that hamper widespread adoption of standards for demographic data and other data types among public and private entities (see **Gap #B1 and associated opportunities**).

The state should seek opportunities to harmonize data sharing requirements and create protected pathways for data sharing that maintain robust individual privacy protections and consent requirements. Where federal regulations present a barrier, the state should actively advocate for federal regulation mediation.

The state has taken initial steps to identify and address policy misalignments to support data exchange. Examples include the development of State Health Information Guidance (SHIG) which clarifies federal and state laws that affect disclosure and sharing of health information;⁹⁸ and the recent release of the DHCS CalAIM Data Sharing Authorization Guidance which provides guidance to clarify data sharing authorities and support data exchange between the entities that provide services and manage care under CalAIM.⁹⁹

⁹⁷ Cal. Welf. & Inst. Code §4515.

⁹⁸ "State Health Information Guidance (SHIG)," Office of Health Information Integrity, California Health and Human Services Agency, accessed April 29, 2022, <https://www.chhs.ca.gov/ohii/shig/>.

⁹⁹ California Department of Health Care Services, CalAIM Data Sharing Authorization Guidance, March 2022, <https://www.dhcs.ca.gov/Documents/MCQMD/CalAIM-Data-Sharing-Authorization-Guidance.pdf>.

F. Health and Human Service Information Exchange Financing

Gap #1: Financing to Support Health and Human Service Information Exchange

Relevant AB133 Provisions

Identify federal, state, private, or philanthropic sources of funding that could support data access and exchange. [§130290(c)(3)(K)]

Many barriers to data exchange are rooted in challenges for health and human service organizations in accessing financing to make needed health information technology investments. These barriers include but are not limited to:

- The limited adoption of EHRs and other technology capable of sharing information electronically among health and human service organizations (**Gap #A1**);
- Challenges with onboarding to qualified data exchange intermediaries (**Gap #A2**); and
- Insufficient data infrastructure in state and local public health departments (**Gap #A4**).

Funding is needed to establish an environment in California that is supportive of health and human service data exchange and to provide direct support for the organizations participating in exchange, particularly those that are under-resourced. Research suggests that financing programs can, when carefully considered and well implemented, meaningfully improve data exchange.¹⁰⁰

While some federal and state investment opportunities – including HITECH-funded EHR incentive programs¹⁰¹ and Cal-HOP¹⁰² – have recently concluded, many federal, state, private, and philanthropic funding opportunities remain that should be leveraged to overcome identified gaps.

¹⁰⁰ Julia Adler-Milstein and Ashish K. Jha, “HITECH Act drove large gains in hospital electronic health record adoption,” *Health Affairs* 36, no. 8 (2017): 1416–1422.

¹⁰¹ “CMS Medicare and Medicaid EHR Incentive Programs: Milestone Timeline,” Centers for Medicare & Medicaid Services, accessed April 29, 2022, <https://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/EHRIncentProgTimeline508V1.pdf>.

¹⁰² Cal-HOP, California Department of Health Care Services, accessed April 2022, <https://www.dhcs.ca.gov/provgovpart/Pages/Cal-HOP.aspx>.

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Opportunity #1.1: Leveraging Governmental, Private, and Philanthropic Sources of Funding

Summary: The state should identify and pursue federal, state, private, and philanthropic funding opportunities to finance data exchange priorities consistent with the vision and goals of the DxF and AB133.

To support robust exchange of health and human service information in California, the state should identify, pursue, and leverage federal, state, private, and philanthropic funding opportunities. These funding opportunities, which vary in intended purpose and amount of funding available, should be assessed and pursued to finance data exchange priorities consistent with the vision and goals of the DxF and AB133. Potential funding opportunities that California should assess and consider leveraging are described below.

CMS Medicaid Enterprise Systems (MES) Enhanced Funding

States are eligible to receive enhanced federal funding for activities related to their Medicaid Enterprise Systems (MES), an umbrella term that refers to states' Medicaid eligibility and enrollment (E&E) systems as well as Medicaid Management Information Systems (MMIS), the state IT infrastructure that supports Medicaid program management and administrative functions such as claims processing, beneficiary and provider management, clinical decision support, care management, and program integrity.¹⁰³ MES enhanced funding may be used to support Medicaid systems initiatives related to claims, enrollment, health information exchange, and public health such as the development of master person indexes, provider directories, and other functions that allow Medicaid providers, beneficiaries and other users individuals to access claims, clinical or other health information.^{104,105}

States can receive a 90% federal match for system design, development and installation activities including planning activities, building interfaces and establishing connectivity, and initial software leasing or licensing.¹⁰⁶ States can receive a 75% federal match for activities related to maintenance and operations such as system or software maintenance and ongoing software leasing or licensing. The federal share of funds may also depend on the cost allocation methodology that is proposed by states and accepted by CMS. The methodology can vary based on the use case or module

¹⁰³ 42 C.F.R. 433.111(b)(1).

¹⁰⁴ "Federal Financial Participation for HIT and HIE," Medicaid.gov, Centers for Medicare & Medicaid Services, accessed May 11, 2022, <https://www.medicaid.gov/medicaid/data-systems/health-information-exchange/federal-financial-participation-for-hit-and-hie/index.html>.

¹⁰⁵ CMS maintains a repository of state-submitted outcome statements and metrics for MES projects pertaining to health information exchange. The MES Certification Repository is available [HERE](#).

¹⁰⁶ Vikki Wachino, SMD# 16-004 RE: Mechanized Claims Processing and Information Retrieval Systems-Enhanced Funding, Centers for Medicare & Medicaid Services, March 31, 2016, <https://www.medicaid.gov/federal-policy-guidance/downloads/SMD16004.pdf>

(e.g., based on Medicaid covered lives as a percentage of state population, based on Medicaid providers as a percentage of all providers).¹⁰⁷

To request federal funding for MES initiatives, state Medicaid agencies submit planning, implementation, and operations advance planning documents (APDs) to CMS describing the funding need and proposed use of federal dollars and demonstrating compliance with applicable conditions and standards. CMS has emphasized the importance of reusing existing information technology assets and taking an incremental, modular approach in state projects seeking enhanced funding, with the goals of reducing costs, mitigating project risk, and improving collaboration between states.^{108,109}

CMS Medicaid Matching Funds

States can pursue alternative mechanisms to access federal Medicaid matching funds to support activities related to the adoption and use of information exchange technologies when such activities may not be eligible or otherwise appropriate for MES enhanced funding. States can leverage matching funds as determined by the Federal Medicaid Matching Rate (FMAP), which determines the federal share of the cost of providing needed services to Medicaid beneficiaries.¹¹⁰ California's FMAP in federal fiscal year 2023 is expected to be 50%.¹¹¹ Medicaid administrative costs are funded separately but typically also at a 50% federal match rate, with some exceptions. States have leveraged these non-MES matching funds to support information exchange priorities. Arizona, for example, has leveraged federally matched dollars to establish a data sharing incentive program that increases payments for eligible entities that share data with Health Current, the state's designated health information exchange.^{112,113}

CMS Medicaid Waivers

Under sections 1115 and 1915 of the Social Security Act, states can seek CMS approval of waivers of certain federal Medicaid requirements to allow for state flexibility in the use of federal funds to support Medicaid data infrastructure and exchange. For

¹⁰⁷ "Health IT Advisory Council (July 15, 2021)," Connecticut Office of Health Strategy, July 15, 2021, https://portal.ct.gov/-/media/OHS/Health-IT-Advisory-Council/Presentations/OHS_HITAC_Meeting-Presentation_071521.pdf.

¹⁰⁸ Vikki Wachino, SMD# 16-010 RE: CMS-2392-F Mechanized Claims Processing and Information Retrieval Systems – Modularity, Centers for Medicare & Medicaid Services, August 16, 2016, <https://www.medicaid.gov/sites/default/files/federal-policy-guidance/downloads/smd16010.pdf>

¹⁰⁹ Timothy Hill, SMD# 18-005 RE: CMS-2392-F Mechanized Claims Processing and Information Retrieval Systems – Reuse, Centers for Medicare & Medicaid Services, April 18, 2018, <https://www.medicaid.gov/sites/default/files/federal-policy-guidance/downloads/smd18005.pdf>

¹¹⁰ "Medicaid Financing: An Overview of the Federal Medicaid Matching Rate (FMAP)," Kaiser Family Foundation, September 2012, <https://kff.org/wp-content/uploads/2013/01/8352.pdf>.

¹¹¹ FMAPs for all states will be increased by 6.2 percentage points if the public health emergency is renewed October 2023. In this scenario, California's FMAP would be 56.2%. Source: [Kaiser Family Foundation](#)

¹¹² "Differential Adjusted Payment (DAP) Program CYE 2023," Health Current, accessed May 11, 2022. <https://healthcurrent.org/programs/ahcccs-programs/differential-adjusted-payment-dap-programcye2023/>.

¹¹³ Arizona's Differential Adjustment Payment (DAP) program uses the directed payment authority in 42 C.F.R. §438.6(c) which "provides states with the flexibility to implement provider payment initiatives, requires certain payment levels by [managed care organizations] to providers, and provides specific services critical to ensuring timely access to high-quality care". Source: [Health Current](#).

example, California has recently received authorization under a Section 1115 waiver for Providing Access and Transforming Health (PATH), a five-year, \$1.85 billion initiative to support infrastructure and capacity building, including the strengthening of data exchange capacity in the Medi-Cal delivery system.¹¹⁴

CDC Section 317 of the Public Health Service Act

States access federal funding through Section 317 of the Public Health Service Act to advance public health data infrastructure priorities. The Section 317 Program, enacted in 1962, is administered by the CDC and provides flexible funding for immunization program operations and infrastructure as well as vaccine purchase at the local, state, and national levels. Program funding can be used toward the development and implementation of immunization information technologies. For example, funding has been used to enhance interoperability of public health systems with the clinical systems used by other health care organizations as well as to help develop reminder and recall systems that send providers and individuals a notification when the individual is due or past due for a vaccination.¹¹⁵ The Section 317 Program is a discretionary program, and thus funding varies from year to year subject to the annual appropriations process; the program was provided an appropriation of \$651 million for federal fiscal year 2022.¹¹⁶

State Taxes

States can also establish taxes to fund data exchange priorities. Taxes, which may be broad-based or targeted, can serve to establish a state-level funding source that can help augment – and in some cases, draw down – federal financing that can be used to advance data infrastructure and exchange. For example, California’s Mental Health Services Act (MHSA), passed by voters in 2004, is funded by a 1% income tax on personal income in excess of \$1 million per year and is used to finance a broad set of programs and priorities that support the public behavioral health system, including infrastructure and technology.¹¹⁷

Federal, Private, and Philanthropic Grants

States can also leverage other federal funding sources – in addition to those previously mentioned – as well as grants from private and philanthropic sources to blend and braid funding to finance investments in data infrastructure and capacity across the state. Federal agencies, including the HRSA and the Federal Communications Commission,

¹¹⁴ “CalAIM Providing Access and Transforming Health (PATH),” Department of Health Care Services, accessed April 29, 2022, <https://www.dhcs.ca.gov/CalAIM/Pages/CalAIM-PATH.aspx>.

¹¹⁵ National Vaccine Advisory Committee, “Protecting the Public’s Health: Critical Functions of the Section 317 Immunization Program — A Report of the National Vaccine Advisory Committee,” *Public Health Reports* 128, no. 2 (2013): 78–95. <https://doi.org/10.1177/003335491312800203>.

¹¹⁶ “The 317 Coalition - FY 2023 Labor-HHS Appropriations Bill,” The 317 Coalition, accessed May 11, 2022, https://www.317coalition.org/_files/ugd/cbc5b5_800ce7cc5bf84350b8e48e593041b1f6.pdf.

¹¹⁷ Mental Health Services Act, California Department of Health Care Services, accessed May 11, 2022, https://www.dhcs.ca.gov/services/MH/Pages/MH_Prop63.aspx.

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support an array of objectives foundational to data exchange, such as enhanced telehealth capacity¹¹⁸ and broadband access.¹¹⁹ States should also promote federal funding opportunities that provide funds directly to delivery system organizations (e.g., the U.S. Department of Housing and Urban Development’s annual discretionary funding allocations to Continuum of Care programs that address homelessness,¹²⁰ the Administration for Community Living’s funding in support of Aging and Disability Networks¹²¹). Private and philanthropic dollars should also be assessed and leveraged to augment – and in some cases, draw down – federal funds in support of state data infrastructure and exchange priorities.

¹¹⁸ “Telehealth in the Third COVID Legislative Package,” Alliance for Connected Care, accessed May 11, 2022, <https://connectwithcare.org/telehealth-in-the-third-covid-legislative-package/>.

¹¹⁹ Rural Health Care Program, Federal Communications Commission, accessed May 11, 2022, <https://www.fcc.gov/general/rural-health-care-program>.

¹²⁰ “Continuum of Care (COC) Program Eligibility Requirements,” HUD Exchange, U.S. Department of Housing and Urban Development, accessed April 29, 2022, <https://www.hudexchange.info/programs/coc/coc-program-eligibility-requirements/>.

¹²¹ “Program Areas,” Administration for Community Living, accessed April 29, 2022, <https://acl.gov/programs>.