Consent-to-Share

California's Opportunity to Modernize Cross-Sector Data Sharing

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Executive Summary

California is leading the way in dismantling barriers to health care and social services delivery by promoting essential cross-sector collaboration to maximize health and wellbeing. Whether a professional is looking to support physical or mental health, educational achievement, housing stability, or crime and recidivism reduction, they need to see the full picture of a person to provide the best care. Having access to data enables the delivery of individualized and coordinated whole-person care.

Today, most of the vital information needed to provide individuals with coordinated services exists but is physically and legally sequestered. That means professionals are often unable to work with a comprehensive understanding of a person's health and social history.

Several state-supported initiatives providing health, nutrition, education, safety, and housing recognize that formal bridges must be made to coordinate the delivery of services. As a result, California has a unique opportunity to bring the necessary financial, technical, and operational resources to develop a more streamlined and systematic statewide approach to data sharing across health and social services. To take advantage of this opportunity, California should develop a state-led strategy to establish the legal, technical, and policy frameworks that permit health and social services organizations to routinely and securely share actionable information.

This paper examines the essential policy, legal, and technical components that must be reconciled to scale consent management services from promising county-level pilots to a state-wide information exchange. The basis for this strategy is rooted in informed consent and its ability to facilitate appropriate data sharing, enabling the state to enhance service delivery and improve health outcomes. The comprehensive recommendations included in this paper are essential to realizing California's potential to attain efficient, ethical, and holistic care for its residents.

Recommendations include:

1. **Devise and launch communication and education efforts** to accelerate the adoption of state legal interpretations regarding consent-to-share and ensure their alignment with sub-regulatory guidance.

2. **Advance efforts to develop consent-to-share technology, technical standards, and policy.**

3. **Prioritize the development of a standardized consent form** that is informed by findings from the Authorization to Share Confidential Medical Information (ASCMI) pilot.

4. **Establish statewide consent management programs** in parallel with the execution of the Strategy for Digital Identities and in partnership with agencies beyond the California Health and Human Services Agency (CalHHS).

Introduction

Individuals have the right to **informed consent**, a concept grounded in the principle of autonomy that is foundational to American biomedicine and other fields, to understand the services offered to them, decide which treatments or services they receive, and know how entities may use their information.[1] Unlike other types of consent, which may refer to express permission from a patient to receive a treatment or service or to participate in a research study, **consent-to-share** provides permission for health and social services organizations to exchange patient information with each other. Ideally, consent-to-share should be **dynamic**, meaning individuals can provide or revoke consent at any time, and **granular**, meaning individuals can indicate preferences for which data are accessible to providers at specific points in time.

There are different levels of consent that inform how patients can specify authorization to share or access information. These levels may include general consent to share all records, consent to share potentially sensitive records (e.g., behavioral health, incarceration history, or sexual health), or privacy control over sharing individual fields within records. Additionally, individuals may prefer to control who is able to access different parts of their health data. For example, they may want to limit access to their pregnancy status or their address at an emergency shelter for domestic violence victims to specific professionals.

In California and across the nation, today's approach to consent-to-share includes a patchwork of policies, procedures, and laws across health and social services, resulting in information silos and uncoordinated care. Furthermore, the interpretation and application of laws governing consent-to-share are piecemeal and uneven; thus, in practice, they are typically viewed as overly burdensome and complex to navigate. Too often, that means organizations choose not to share information even when it is legally permissible to do so, or when workflows for obtaining consent-to-share information are available.

The resulting information gaps are particularly apparent for populations that experience the greatest health and social needs, such as individuals experiencing homelessness, aging adults, and low-income individuals and families. Indeed, because they must serve as their own information conduits, the burden falls most heavily on those for whom it is the most challenging to effectively advocate for their own needs, including by having to repeatedly share sensitive information about themselves or legal dependents to determine their eligibility for various critical services. This resharing is not only inefficient; it can also be retraumatizing.

The California state government has recently made major financial investments to launch projects that require service integration and coordination, thereby necessitating data sharing and consent-to-share. At the forefront are two health care initiatives, the Data Exchange Framework (DxF) and California Advancing and Innovating Medi-Cal (CalAIM). The DxF, CalAIM, and similar California efforts in education and other sectors hold the promise of narrowing disparities for those who are most vulnerable and in need of a broad array of services and supports. **Obtaining and making accessible individual-level consent-to-share information expedites care delivery for individuals and families in California.**

This paper explores the concept of consent-to-share, with findings and recommendations that emanate primarily from a health care perspective and can be extended to many whole-person care initiatives for Californians. Specifically, this paper aims to:

1. Explain the need for consent-to-share practices in California.

2. Explore the steps needed to implement consent-to-share.

3. Describe scalable consent-to-share projects and practices that test and refine the use of universal consent forms and consent management systems.

4. Provide recommendations to improve and advance consent-to-share in California.

Methods

BluePath Health and Stewards of Change Institute conducted a literature review of the state of policy and practice related to consent-to-share both in California and in other states across the country. They also conducted semi-structured interviews with subject matter experts, including attorneys, program leads, government funders, and technology experts with experience working to address consent-to-share in cross-sector data-sharing programs. Interviewees who agreed to list their names and affiliations are listed in Appendix 1.

Policy Initiatives Driving the Need for Consent-to-Share

Consent-to-share is a key consideration for each of the policies and programs California develops to facilitate the exchange of health and social services information. CalAIM and the DxF are major drivers of California's data sharing solutions that provide the foundation for the integration of consent-to-share into policy and practice.

Data Exchange Framework (DxF)

In 2021, Assembly Bill 133 (AB-133) called on the California Health and Human Services Agency (CalHHS) to create the DxF as "a first-ever, statewide data sharing agreement that aims to accelerate and expand the exchange of health information among health care entities, government agencies, and social services programs beginning in 2024."[2] **The eight principles that guide the DxF emphasize how consent-to-share is essential to the successful implementation of secure and productive information exchange.**[3] They also clarify expectations for all organizations and state agencies as they embark on the work needed to fulfill requirements set forth by AB-133.

Implementation of the DxF involves governing policies and procedures (P&Ps) that include consent-to-share, and lack of consent management has been noted as a barrier to obtaining necessary demographic information for historically marginalized groups.[4] Notably, the P&Ps apply across both health and social services providers and include references to existing state and federal legal requirements for consent in the form of a Privacy Standards and Security Safeguards P&P.[5]

CalAIM

CalAIM is a suite of policies and programs crafted with the goals of providing whole-person care, addressing social determinants of health, improving care quality, and reducing health care system complexities.[6] Key CalAIM initiatives that hinge on consent-to-share policies include the new Enhanced Care Management (ECM) benefit, which provides care management to specific high-need populations and introduces new Community Supports (CS), such as housing and nutrition, that Managed Care Plans (MCPs) can choose to provide to their members. CalAIM also includes the development of a Population Health Management (PHM) service.[7] PHM is intended to collect, integrate, and analyze health and social needs information in a single repository. Importantly, DHCS indicates that PHM must be able to support intake and screening, including "collecting and tracking consent information," informing users "about data collection and usage practices," and helping beneficiaries determine what personal and health information they are willing to grant their providers (clinical and insurance) access.[8]

Requirements for Effective Consent-to-Share

Clarity on the Legal Landscape

A variety of federal and state privacy and confidentiality laws impact the ability to share information within and across sectors in California. These laws stipulate safeguards based on the information's content or source (e.g., relating to a mental health condition or HIV status or coming from a publicly funded substance use disorder program). Most federal laws set a floor for safeguarding privacy but do not preclude states from providing additional protections. In addition, both the State Health Information Guidance (SHIG) and the CalAIM Data Sharing Authorization Guidance provide summaries of privacy laws that have implications for the sharing of information across sectors, as well as an analysis of laws governing criminal justice, housing, and nutrition program data. **Yet, even with the SHIG and Data Sharing Authorization Guidance, many interviewees expressed that organizations continue to hesitate to exchange data due to the multitude of laws on privacy and their conflicting interpretations.**

The table below highlights the consent provisions of key laws as they are generally applicable to California's population.

Table 1: Key Health and Education Privacy Laws

LAW	WHO IT APPLIES TO	CONSENT PROVISIONS
HIPAA Health Insurance Portability and Accountability Act (Federal)	"Covered entities," including most health care providers, health plans, health care clearinghouses, and their "business associates," as defined in the law	Allows disclosure of most protected health information (PHI) without the individual's authorization for the purposes of treatment, payment, and operations, as defined in the law
42 C.F.R. Part 2 (Federal)	"Federally assisted" programs "who hold themselves out as providing, and provide, substance use disorder diagnosis, treatment, or referral for treatment"	Requires a patient's written consent before a program can disclose protected records that include specific information related to the patient, as well as the specific records that are to be shared. Includes exceptions to the written consent rule, such as medical emergencies and reports of alleged child abuse, among others
FERPA Family Educational Rights and Privacy Act (Federal)	"Educational agencies or institutions" like public schools or school districts that receive funds from programs administered by the U.S. Department of Education	Generally, prohibits educational agencies from releasing information in the "educational record" including health information without written authorization from the adult student or from the parent of minors
Information Blocking Rule, issued by the Office of the National Coordinator for Health Information Technology (ONC) (Federal)	"Actors," including health care providers and developers of health care information technology	Requires actors to provide access to, exchange, or use electronic health information (EHI) as permitted by HIPAA unless other laws require specific authorization that has not been given, or the patient requests that their information not be shared

LAW	WHO IT APPLIES TO	CONSENT PROVISIONS
CMIA Confidentiality of Medical Information Act (California)	"Providers of health care," including businesses "organized for the purpose of maintaining medical information in order to make the information available to an individual or to a provider of health care," among others	Does not require authorization to use or disclose information for specified purposes, including diagnosis, treatment, payment, research, or other specified purposes
Center for Data Insights and Innovation (CDII) Data Sharing Agreement (California)	Signatories to the Data Sharing Agreement	Incorporates and references existing federal and state law related to privacy
Lanterman-Petris-Short Act (California)	State hospitals, developmental centers, and certain public and private institutions that provide mental health services	Generally, prohibits the disclosure, without a patient's authorization, of data related to the provision of involuntary and some voluntary services
AIDS Public Health Records Confidentiality Act (California)	State and local public health agencies	Prohibits the disclosure of public health records containing PHI related to HIV or AIDs without a patient's written authorization, except as required by law
Women, Infants, and Children (WIC) (Federal)	State and local WIC agencies	Requires certain notices of uses, disclosures, and recipients of WIC information when shared for non-WIC purposes

Sources: Code of Federal Regulations, Title 34 § 99.10, Title 42 § 2.12, Title 45 § 160.103, Title 45 § 164.512, Title 45 § 171.102, Title 45 § 171.103; California Civil Code § 56.05-06 and § 56.10(c); "California Health and Human Services Data Exchange Framework: Single Data Sharing Agreement," California Health and Human Services, November 3, 2022; "CalHHS Data Exchange Framework Policy and Procedure: Privacy Standards and Security Safeguards." California Health and Human Services, July 5, 2022; California Welfare & Institutions Code §§ 4000-4390, 6000-6008, § 5328(a)(25), § 5675; California Health & Safety Code § 1250.2, § 121025.

CalAIM Waiver of State Privacy Laws

To expedite the integration of CalAIM ECM and CS into Medi-Cal's existing delivery system, the state legislature granted DHCS the ability to waive specific state privacy and confidentiality laws requiring authorizations for the use or disclosure of specific information.[9] Those include but are not limited to the Confidentiality of Medical Information Act, the Lanterman-Petris-Short Act, and statutes relating to the disclosure of HIV test results and substance use information. The waiver does not apply to federal laws or certain other state laws, such as those related to combatting discrimination or to Medi-Cal enrollees accessing their own records. It will be critical to study the effects of waiving specific laws to inform future efforts to improve consent-to-share both for and beyond the Medi-Cal population. In addition to the waiver of state privacy laws, DHCS published the CalAIM Data Sharing Authorization Guidance (PDF) that provides a summary of privacy laws, guidance, consent practices, and specific use cases to assist organizations as they navigate the CalAIM landscape.[10]

State Health Information Guidance (SHIG)

The State Health Information Guidance (SHIG) is a comprehensive resource compiled and published by CDII that helps organizations clarify and interpret federal and state laws impacting the disclosure and sharing of information related to health and social services.[11] CDII formally reviews and updates the SHIG annually through subject matter expert contributors and a multi-stakeholder advisory group. The SHIG summarizes federal and state laws, provides situation guidance according to key groupings (such as treatment and coordination of care, operations, and public health), and breaks down specific details according to scenarios that provide easy-to-follow flowchart graphics and corresponding narratives.

The SHIG's five volumes include:

- Sharing Behavioral Health Information in California
- Sharing Health Information to Address Food and Nutrition Insecurity in California
- Sharing HIV/AIDS Information in California
- Sharing Health Information of People Living with Intellectual and/or Developmental Disabilities in California
- Sharing Minors and Foster Youth Health Information in California

A sample decision tree from volume five is shown in Appendix 3. Currently, the SHIG awaits updates to incorporate the DxF, the CalAIM privacy law waiver, and the information contained in the DHCS CalAIM Data Sharing Authorization Guidance.

Robust Digital Identity Management Strategy

Health and social services information is stored in separate records systems and maintained in disparate formats. As a result, providers typically do not know whether individual data exists, where it is, or how to access consent-to-share preferences. Additionally, some individuals can have multiple records with slightly different patient identifiers, creating even more difficulty when providers need access to patient information.

To bridge these gaps, AB-133 mandated the development of the Strategy for Digital Identities (Strategy) to ensure that when health and social services information is exchanged, it corresponds to the correct unique individual.[12] The Strategy, published in July 2022, outlines how CDII will develop secure digital identities by supporting a statewide person index for use by both private and public organizations in California while prioritizing consumer privacy and addressing the need for coordinated person identity matching services. The Strategy's approach incorporates select patient demographics from standard formats and data sets to build a unique digital identity that can be maintained and utilized statewide. The Strategy also recommends developing a consent registry (statewide or regional) that is parallel to the statewide person index and recognizes that a dynamic statewide consent registry is fundamentally necessary to preserve consumer privacy in the context of expanding the exchange of health and social services information.[13]

Separately, in 2023, CalHHS released a Request for Information (RFI) "to identify potential solutions to establish and manage the digital identities of individuals for the purpose of linking their internal health and social services information to the correct person within and across CalHHS departments."[14] The RFI seeks a shared technology service to link unique identities across health and social services for use by CalHHS departments, as well as to merge identities that are deemed to represent the same individual. The RFI closed in July 2023; there is not yet public information about the submissions or next steps in this process. Although the RFI does not seek information regarding consent or consent management functionalities from respondents, it holds the potential to assist CalHHS in pursuing a statewide person index and consent registry as outlined in its July 2022 Strategy.

Health Data Standards That Enable Consent

Beyond legal requirements, health data standards are also needed to govern technical consent-to-share practices, including how data are collected, stored, tracked, categorized, and shared. These health data standards enable consent management services to govern how information is represented so that it is universally recognized and accommodates granular technical consent solutions. Consent management services provide software solutions that function as electronic registries and enable a centralized approach to:

- Storing consents from a specific jurisdiction (city, county, region, or state)
- Tracking and authorizing users of the consent management service
- Providing necessary and timely notifications of relevant patient changes
- Allowing individuals to access and change their consent preferences as desired

Currently, electronic health records, care management systems, and other software systems do not always have the technical ability to parse and constrain data sharing at the level required to provide access to specific types of information. As a result, individuals may not be able to provide differing levels of consent that can limit portions of their records from being shared, and providers may have to maintain separate record keeping systems to align with different legal regimes. **Greater granularity for privacy preferences regarding the sharing of health data is needed to increase individuals' privacy, trust, and autonomy.**

Consent-to-share is supported by global standards for the transfer of clinical and administrative health data. The structure and format of electronic health information, however, is governed by specific suites of global health data standards, each with its own approach to consent. These data standards include:

- Health Level 7 (HL7) V2 suite of health IT messaging standards
- HL7 Clinical Document Architecture (CDA®) suite of standards
- HL7 Fast Healthcare Interoperability Resources (FHIR®) suite of standards
- Integrating the Healthcare Enterprise (IHE) Profiles for health IT systems.

HL7 is the global health IT standards-development organization dedicated to providing standards for the exchange, integration, sharing, and retrieval of electronic health information. IHE is a health care industry initiative to promote the coordinated use of established standards to improve the way computer systems in health care share information. These two organizations drive the global definition of standards for health care information exchange. Electronic health records systems and health information exchanges implement their solutions based on standards from one or both organizations.

HL7 V2 is used by 95% of health care organizations in the U.S. and across 35 other countries.[15] HL7 CDA is a newer, document-oriented standard, which is often used to exchange patient records using IHE profiles and/or DirectTrust Direct Secure Messaging, a national data exchange network. A newcomer to the health IT standards world is HL7 FHIR, which enables streamlined implementation of health care applications using contemporary internet protocols.

Different types of information exchange require different standards; standards required for consent management are outlined in the table below.

Table 2: Consent Management Data Standards

HEALTH DATA STANDARDS	PURPOSE	SCOPE
HL7 Composite Privacy Consent Directive - Domain Analysis Model	Defines security and privacy system requirements for health care organizations	Outlines criteria in broad terms without mentioning a specific format
HL7 Healthcare Privacy and Security Classification System (HCS), Release 1	Defines a classification system for labeling and segmenting protected health information	Focuses on classification and labeling of data
HL7 Services Functional Model: Consent Management Service, Release 1	Illustrates a model for consent management services and Application Programming Interfaces (APIs) to comply with privacy regulations	Includes various types of data exchange standards, including HL7 V2, CDA, FHIR, and IHE
HL7 CDA® R2 Implementation Guide: Privacy Consent Directives, Release 1	Provides a standard for exchanging signed consents and generating rules associated with them	Concentrates on the exchange of consent directives and their computable representations (narratives, signed documents, statements)
HL7 FHIR Consent Resource	Introduces a standard for representing patient agreements, restrictions, or prohibitions related to data access and sharing	Specifically designed for FHIR-based systems engaged in the content and representation of consent
IHE BPPC (Basic Patient Privacy Consent)	Provides a mechanism for recording patient privacy consents and enforcing them for IHE information exchanges	Centered on IHE-based exchanges and consent management
IHE PCF (Privacy Consent on FHIR) *(Currently under development)*	Expected to define how to represent patient privacy consents and access control when a FHIR API is used for IHE-based exchanges	Similar to IHE BPPC but tailored to FHIR-based systems

Sources: "HL7 Version 3 Domain Analysis Model: Composite Security and Privacy, Release 1," HL7 International, May 1, 2020; "HL7 Healthcare Privacy and Security Classification System (HCS), Release 1," HL7 International, August 8, 2014; "HL7 Services Functional Model: Consent Management Service, Release 1," HL7 International, July 13, 2021; "HL7 CDA® R2 Implementation Guide: Privacy Consent Directives, Release 1," HL7 International, January 12, 2017; "Resource Consent - Content," HL7 International, March 26, 2023; "Basic Patient Privacy Consents," Integrating the Healthcare Enterprise (IHE) Wiki, November 19, 2021; "Privacy Consent on FHIR (PCF) Home," Integrating the Healthcare Enterprise (IHE), August 4, 2023.

Privacy control over sharing individual fields within records necessitates technical support for granular privacy so that individuals can indicate preferences for which data are accessible to which providers and when. Such granular privacy is supported by HL7 Data Segmentation for Privacy (HL7 DS4P) standards for both CDA documents and FHIR.[16] HL7 DS4P enables a record or document to be "tagged" or "marked" with privacy assertions that express the data classification and indicate possible redisclosure restrictions placed on individual fields within the record or document. **Assurance that data can be properly marked with the patient's privacy requirements may increase the sharing of important, sensitive information.**

HL7 DS4P provides a flexible mechanism for individuals to express their privacy preferences as well as their authorized exceptions to those preferences. Standardized, consistent approaches to the semantics and syntax necessary to do this work across systems are in early stages. This often leaves organizations to develop their own varying and individual implementations. In light of this, the **Shift Task Force** — an independent group of more than 200 expert stakeholders — was formed in 2020 to "improve functionality and standardize efforts to granularly identify and protect sensitive electronic protected health Information (ePHI) to promote equitable interoperability."[17]

In sum, patients and providers need electronic health records, care management platforms, and other technologies to apply data standards that allow for granular consent management. Though these standards exist, health and social services organizations require clear guidance and encouragement to incorporate them into their systems.

Scaling Consent-to-Share

A uniform approach to consent-to-share processes and health data sharing networks for obtaining, storing, and retrieving consent-related information are both essential to achieving scale. Important considerations include:

- the use of a universal consent form
- the implementation of a governance model that includes individuals with lived experiences and oversees participation
- the type of information to be shared
- the permitted uses of shared information
- the benefits and risks of sharing information
- the revocability of consent

A uniform approach has not yet been established at the federal or state level. However, promising programs have been implemented in California and elsewhere. **Taken together, these test cases form the basis of a scalable, statewide consent-to-share strategy.**

Authorization to Share Confidential Medi-Cal Information (ASCMI) Pilots

From January to June 2023, DHCS administered the CalAIM Authorization to Share Confidential Medi-Cal Information (ASCMI) pilots to test a Universal Authorization for Release of Information Form, a voluntary release-of-information document that supports the sharing of Medi-Cal members' physical, mental, and social health data through a standardized process.

DHCS selected three regional initiatives to conduct pilot projects.[18] These initiatives worked in partnership with county government, MCPs, and community-based organizations (CBOs) to test and suggest improvements for the form's efficacy and accessibility through a consent management service.[19] The ASCMI pilot participants were 2-1-1 San Diego Community Information Exchange, Manifest MedEx, and Serving Communities Health Information Organization. See Appendix 2 for the ASCMI consent form and Appendix 5 for more details on individual projects.

The pilots aimed to demonstrate providers' abilities to access the consent management service online and/or via their existing EHR systems to upload signed ASCMI forms, check if a member's signed form is on file, and amend members' consent on their behalf. The pilots were also intended to assess Medi-Cal members' abilities to amend their own consents by accessing the management service online.

Pilot participants and other interviewees are eager to learn from the ASCMI's evaluation results and repeatedly point to the pilots as critical conceptual and concrete breakthroughs in centering consent-to-share, which they say was lacking during DHCS's Whole Person Care[20] and Health Homes initiatives.[21]

Promising Regional Consent-to-Share Practices in California and Other States

Tables 3 and 4 summarize key functionality and processes such as how consent decisions are presented to individuals, how consents are stored and accessed, and what funding streams have been used to create and maintain the consent process. These varied consent-to-share efforts in California and other states highlight the importance of technology solutions to enable efficient consent-to-share in states and local communities.

Table 3: Promising Practices within California

	SAN DIEGO 2-1-1	ALAMEDA CARE CONNECT	SONOMA CONNECT
Program Description	In 2014 San Diego launched its Community Information Exchange (CIE) after three years of planning. CIE is a multidisciplinary network of partners that use standard authorization and consent management services to allow data-sharing across health and social services partner organizations for care coordination.	The Alameda County Whole Person Care (WPC) pilot initiative spanned from 2016 to 2021. During WPC, Alameda Care Connect provided enhanced care coordination and outreach to the most-vulnerable Medi-Cal members, including those who were unhoused or frequent users of crisis services. The data sharing system has been expanded to meet the County's program planning needs, to accommodate CalAIM's billing requirements, and to include data for those who are uninsured.	Sonoma Connect is a coalition of cross-sector organizations that have partnered to deliver a community response to Adverse Childhood Experiences (ACEs) and trauma by connecting individuals to the resources they need." A key tool of Sonoma Connect is the Resource Connection Network, which operates off a technology platform provided by health software vendor NinePatch.
Participants	Over 133 organizations are members of the San Diego Community Information Exchange.	As of April 2023, 55 organizations representing 246 programs and over 1,900 users were accessing the shared community health record (CHR).	The project's planning and ongoing implementation involves 98 organizations from 46 multi-sector organizations (FQHCs, CBOs, County Office of Education, etc.) that identify challenges for CBOs and develop a county network approach to providing care.
Types of Data Shared	▶ Food ▶ Housing ▶ Transportation ▶ Justice-involvement ▶ Health ▶ Education ▶ Financial ▶ Employment	▶ Demographic ▶ Medical and behavioral health ▶ Social services ▶ Housing ▶ Food ▶ Transportation ▶ Employment ▶ Incarceration ▶ Income ▶ Disability	▶ Adverse Childhood Experiences ▶ Social Determinants of Health Data from screening tools ▶ Medical information ▶ Data from other participant agencies

	SAN DIEGO 2-1-1	ALAMEDA CARE CONNECT	SONOMA CONNECT
Developing the Consent Form	Levels of consent were created to enable care coordination across the diverse CIE Partner Network of providers. The consent form was created, shared, and edited by the CIE core governance body, which worked with local CBOs and their participants who may ultimately complete the consent.	Development of the consent-to-share process was led by a Data Governance Committee with members from the County, CBOs, and local health plan representatives.	The consent procedure was initially drafted by community health center network Aliados Health based on a templated document provided by NinePatch. It was then edited to reflect considerations including California state and current federal law, HIPAA protections, emerging data exchange practices, and input from the Action Team.
Obtaining Consent	The CIE is an opt-in model. A participant can provide consent, or opt in, at participating organizations across the CIE Partner Network as they access services through the 2-1-1 client portal. Consent may be provided electronically, telephonically, verbally, or through paper copy, and consent forms have been translated into eight languages. The CIE's standard consent aligns with the authorizations of other organizations, such as local hospitals and the San Diego Regional Taskforce on Homelessness' Joint Multi-Party Agreement, and/or is included in other partners' intake packets for individuals to complete while they opt in for care.	Consent is gathered via the HCSA Information Sharing Agreement (ISA), which is available online via the CHR or in paper form. Once granted, consent is valid for only one year, and participants can revoke or change their consent at any time. Only one consent is required to enable sharing across all relevant participating providers, rather than one by one.	The consent form is completed during intake and the client can give consent based on three tiers: a) participating in Resource Connection Network (RCN) team-based care; b) participating in RCN team-based care with either full RCN network-wide authorizations, only team-member approval, or only client approval; or c) not participating in RCN team-based care. If the client chooses the "client approval" option, they are able to determine whether information is shared with specific organizations or individual care team members. They can decline consent initially and give it later, or they can revoke consent at any time.
Accessing Consent Documents	Consent information can only be shared when a person is seeking services from an organization in the CIE Partner Network. Clients can revoke consent through those organizations and through a client portal where they can view information and choose to opt-out. The CIE has varying levels of permissions at the field level for partner organizations.	The executed consent form is viewable within the CHR client record. Authorized CHR users from partner organizations with viewing rights can see and access the client consent.	The consent forms are public in PDF form. The same is true of the revocation form. At this time, the portal does not allow individuals to access or modify their consent documents, but it does allow a new consent document to be sent from any participating organization to the individual via fax, SMS, or email.

	SAN DIEGO 2-1-1	ALAMEDA CARE CONNECT	SONOMA CONNECT
Governance	CIE has a local shared governance infrastructure comprised of key stakeholders across the community through its CIE Advisory Board. Additionally, CIE hosts Network Partner Meetings and other working groups, including community voice and data governance working groups, to ensure clients and community members play a direct role designing and advising how the CIE functions within the community.	Once the policy and legal teams drafted the ISA, Alameda County engaged with individuals with lived expertise and a health literacy expert to provide user experience and design feedback. Alameda County Care Connect (AC3)'s Consumer Fellows team reviewed the consent form, providing input and recommendations based on their lived experience. Resulting changes included a more comprehensive summary in the form's introduction, altering language about the implications of not signing to feel less threatening, and providing more details about the programs and services covered by the agreement.	The community governance model includes a multi-sectoral community leadership board and venues for other community members to provide ongoing input. The Action Team, charged with platform implementation, has 98 participants, including community members and representatives from 46 organizations.
Funding and Investment	Sustainable and ongoing blended funding includes annual organizational membership fees and per-member per-month (PMPM) rates; grant, foundation, and government funding; and other sources.	Alameda County received $177 million from DHCS for development of the AC3 WPC pilot, which funded many services and infrastructure developments including this data sharing system.	Sonoma Connect relies on grants provided by California's ACEs Aware program and by the state's American Rescue Plan Act.
What's Next	Continuing to center consent on client choice, allowing for client access and control rights; growing data integrations, specifically with local HIE, EHRs and others; and exploring opportunities to expand use cases for consent and integrate into the system of care.	Revising the current ISA to reflect new authorization requirements under the CARES Act Notice of Proposed Rule Making, revising Confidentiality of Substance Use Disorder (SUD) Patient Records.	Moving beyond the pilot to broad implementation and adding in data sharing with care coordination platforms and HIEs.
Consent Management Service	Web-based CIE system; Salesforce	Homegrown	NinePatch
ASCMI participant?	Yes	No	No

Sources: "Whole Person Care Promising Practices: A Roadmap for Enhanced Care Management and In Lieu of Services," Department of Health Care Services, December 2020; "Sonoma Connect," Sonoma Connect/ Sonoma Unidos, accessed September 12, 2023; "CIE Partners," CIE San Diego, accessed September 12, 2023; Emma Beers, Alana Kalinowski, Jennifer Martinez, and Cristi Iannuzzi, "How to Share Data: Proven Strategies for Strengthening Cross-Sector Collaboration between Health and Homeless Systems of Care," NHSDC Fall 2022 Conference, 2022; "CIE Authorization Forms," CIE San Diego, accessed September 12, 2023.

Note: For Sonoma Connect's consent and revocation forms, see Appendix 6 and Appendix 7.

Table 4: Promising Practices Outside of California

	WASHINGTON	VIRGINIA	MICHIGAN
Program Description	The Washington Health Care Authority (HCA) anticipates rolling out their Electronic Consent Management (ECM) program in May 2024. It will be focused on state Medicaid participants "with SUDs [substance use disorders], mental health conditions, and other sensitive conditions [that] need their health information to be exchanged securely among a diverse care team in a manner with which they can understand and participate."	Arlington County, VA pioneered its Shared Authorization to Use and Exchange Information program. The purpose is to facilitate effective service delivery for authorization among participating organizations. It gives individuals a wide variety of choices about what information is shared with whom. It also allows them to authorize ongoing exchange of information instead of a one-time disclosure. The Commonwealth of Virginia has a similar Authorization to Use and Exchange Information for statewide use that was approved by the State Attorney General on 3/10/2008.	Michigan Health Information Network Shared Services (MiHIN) is a Health Information Network based in Michigan that acts as the foremost authority on patient identity and identity management for their network partners. Among its many functionalities, MiHIN utilizes multiple patient identifiers in their active care relationship service (ACRS) to collect, provide, and manage consent.
Participants	Health care providers and Apple Health (Washington Medicaid) clients diagnosed with a substance use disorder	County government including social services, justice, health care, housing, and shelter agencies, as well as a wide variety of CBOs. The individual may also add additional organizations to which their data can be released.	Connected to MiHIN are 148 hospitals, 665 outpatient facilities, 298 skilled nursing facilities, and 44 physician organizations.
Data Shared	The initial use case contemplates the sharing of substance use disorder services consent-to-share data for care coordination. Future use cases include: ➤ Consents to share other types of data related to health and social needs; ➤ Consents for transitions of medical services from Dept. of Corrections to Medicaid providers ➤ Advance directives ➤ Consent for sharing with a medical proxy or guardian	The form allows for fine-grained consent for types of data such as financial information, and includes multiple other slots so individuals can specify exactly what they wish to disclose.	➤ Admission, Discharge, Transfer (ADT) Notifications ➤ Death notifications ➤ Health claims ➤ Health and social services information

	WASHINGTON	VIRGINIA	MICHIGAN
Developing the Consent Form	Washington State HCA has created a standard form that providers will be asked to use.	The form resulted from a multi-year, multi-stakeholder process supported by the Arlington Community Foundation.	The state of Michigan requires all providers to accept a standard consent form. However, providers are not bound to utilize this form when it is not presented by the patient, so most practices choose to use their own.
Obtaining Consent	HCA's ECM will offer flexible options for obtaining consent: (1) a signed paper form scanned into the ECM solution and made available through an EHR integration and/or the ECM web portal access; (2) a digital signature provided through the ECM web application, accessed on a tablet in a clinical setting, through a link send to a patient's email address or accessed within a patient portal; or (3) a digital signature provided through the ECM mobile application using a patient, medical proxy or guardian's smartphone. The initial workflow at the ECM go-live may be constrained to the scanned paper form. When a patient registers for an optional ECM Wallet account, the system will provide current and historical access to their forms, whether a consent request was signed, denied, or revoked. Individuals can revoke or request a change to previously authorized consent forms through the ECM system.	The form is presented to individuals by staff members of the Arlington County Department of Human Services (DHS) or other participating agencies. These staff are responsible for explaining the intent, risk, and benefits of the authorization, and are regularly trained on it. The authorization is routinely offered by DHS to all persons applying for Medicaid.	Patients can provide and revoke consent, but MiHIN recognizes that the privacy and security notices that patients sign when they receive care supersede MiHIN's abilities to block information sharing. MiHIN has included a "contest period" when patients can seek to revoke consent to ensure fully-informed decision-making.

	WASHINGTON	VIRGINIA	MICHIGAN
Accessing Consent Documents	The system can display whether there is an active, valid consent on file based on with whom the patient consents to share their information, and an active form permitting data sharing based on why a patient consents to share health information for a specific purpose. For patients with a treatment relationship with the provider, the system can be queried for active consent forms on file for an individual patient or for a list of the provider's patients. The search result will be null if there is not an established treatment relationship or the provider is not named as a permitted recipient.	There is no specific electronic platform. Instead, the form allows individuals to elect whether their information can be disclosed electronically, on paper, or verbally. Consent also facilitates the work of county case review teams.	MiHIN manages a consent repository that works with the ACRS to facilitate the sharing of data between network partners. They tag sensitive data and limit the flow of information to a separate, smaller network.
Governance	HCA, the Office of the CIO in Washington State, and the Washington Health and Human Services Enterprise Coalition will provide oversight, with contractual terms and obligations in place with the prime vendor (CodeSmart) and the vendor's technology solution sub-contractor (Midato Health). HCA facilitated significant stakeholder engagement during the planning of the ECM program, resulting in the agency's published guide for sharing substance use disorder data in Washington State.	The process is now self-governing. DHS maintains the form and responds to organizations who wish to be included or retracted.	For technical and policy expertise, MiHIN includes "State Agency Partners, The State Health Information Technology Commission (HITC), the Board of Directors, Executive Management Team and the Operational Advisory Committee (MOAC) and its task forces" within their governance model.
Source of funding/ **Level of Investment**	Centers for Medicare & Medicaid Services (CMS) 90% Federal matching funds	Arlington County DHS and the Arlington County Foundation put in-kind resources into launching the project, with voluntary participation by the community at large.	The Health Information Technology for Economic and Clinical Health (HITECH) Act, ONC HIT State Cooperative Agreement, and other federal funding; state funding to develop specific use cases; and funding from local partnerships.

	WASHINGTON	VIRGINIA	MICHIGAN
What's Next	The HCA states that "additional types of consents to be considered in later phases include physical and behavioral health, tribal services, genetic testing, advance directives, and social determinants of health (SDOH)."	Developing a recorded training on the authorization; creating the infrastructure for streamlined electronic data sharing among partners such as the Allegheny County, PA DHS Data Warehouse, including a consent management service; and a content-mediated shared repository for proof of income and proof of identity.	MiHIN is currently piloting their Electronic Consent Management Service (eCMS) in inpatient facilities and SUD clinics. They anticipate widespread adoption of the service throughout the network by the end of 2023.
Consent Management Service	CodeSmart (prime vendor) and Midato Health (technology solution sub-contractor)	There is no management service or central registry for the consent. Each organization obtains a form as needed to either request or disclose information.	Homegrown

Sources: "Electronic Consent Management (ECM)," Washington State Health Care Authority, September 2023; "Washington State Health and Human Services Enterprise Coalition," Healthier Washington Collaboration Portal, Accessed October 6, 2023; "Sharing Substance Use Disorder Information: A Guide for Washington State," HCA, October 2021; "Shared Authorization to Use and Exchange Information," Arlington County, 2019; "Authorization to Use and Exchange Information," Commonwealth of Virginia, March 10, 2008; "Our Network," Michigan Health Information Network (MiHIN)," accessed September 12, 2023; "Annual Report," Michigan Health Information Network (MiHIN), 2022; Interview with Carol Robinson, Midato Health; "Michigan Behavioral Health Standard Consent Form," Michigan Health & Human Services, accessed September 12, 2023; "Governance Model," Michigan Health Information Network, accessed September 12, 2023; "About Michigan Health Information Network," Michigan Health Information Network, accessed September 12, 2023.

Recommendations

Standardized consent policies and practices are essential to multiple ongoing California initiatives, including the DxF and CalAIM, and require support to reduce service delivery fragmentation. Current and emerging health data standards and technology can improve consent-to-share across health and social services systems; however, success also requires statewide leadership and meaningful stakeholder engagement. A unified consent-to-share strategy will help California achieve its vision of coordinated care across health and social services.

Recommendation 1: Devise and launch a communication and education effort to accelerate the adoption of state legal interpretations regarding consent-to-share and to ensure the alignment of these interpretations in sub-regulatory guidance.

- **Utilize existing guidance to expedite consent-to-share policy alignment.** CDII and DHCS have made considerable investments in the production and management of the SHIG and the DHCS CalAIM Data Sharing Authorization Guidance. These efforts should provide the basis for broad-scale education and communication to both agencies and the public. This may include clear guidance as to how Qualified Health Information Organizations (QHIOs) handle consent management for Data Sharing Agreement (DSA) signatories, collaborative updates to privacy policies, longer-term work related to the AB-133 waiver of state privacy laws for CalAIM ECM and CS, and a determination as to whether more permanent and expansive changes to California law are needed.

Recommendation 2: Advance efforts to develop consent-to-share technology, technical standards, and policy.

- **Participate in standards-setting efforts.** CalHHS, CDII, and other state agencies should formally participate in and monitor the consent-to-share activities of the ONC, which is expected to take on a broader federal role in this area, as well as in efforts taking place in the European Union and elsewhere, through standards bodies such as HL7.
- **Ensure state guidance documents mention and enforce the latest standards.** This work should translate into continuous updates to guidance documents such as the DxF P&Ps, the SHIG, and the CalAIM Data Sharing Authorization Guidance to include recommendations or requirements for technical standards that can advance consent-to-share and make clear to stakeholders how consent collection, storage, and sharing should occur.

Recommendation 3: Prioritize the development of a standardized consent form by using the findings from the ASCMI pilot to inform the process.

- **Convene a learning community based on ASCMI pilot findings.** DHCS and CDII should use the ASCMI pilot experience to convene a structured learning community of state and county level agencies and departments, along with health information organizations, to share experiences and incorporate learnings from ASCMI and other test cases into improved consent-to-share practices.
- **Ensure that any standardized consent form is developed to encompass relevant programs and populations**. DHCS and CDII should continue working to develop a consent form that works across programs and populations. DHCS and CDII should also consider how they can adopt model consent language in statute to provide assurances that such language complies with all applicable laws.

Recommendation 4: Establish statewide consent management programs in parallel with the execution of the Strategy for Digital Identities and in partnership with agencies beyond CalHHS.

- **Emphasize consent-to-share as critical to statewide identity management.** With the recent release of the identity management RFI, CDII is exploring strategies to offer record matching and patient linking. However, the request does not include patient consent or authorization. Implementation of the Strategy for Digital Identities should include the concurrent availability of a statewide consent management service or network of services.
- **Ensure cross-sector collaboration by including other state agencies.** Several non-CalHHS state departments could contribute to the realization of the Strategy for Digital Identities and development of shared services across state agencies given their privacy and confidentiality laws are related, including Education, Aging, and Housing and Community Development. CDII should engage these agencies in consent management-related work to efficiently share financial and technological resources.
- **Establish sustainable funding mechanisms.** CDII should work with DHCS to seek 90/10 federal matching funds to support statewide consent-to-share activities and/or recognize aspects of the PHM Service that may satisfy consent management requirements.

Conclusion

Enhancing consent-to-share policy and practice in California is not only essential to providing high-quality, whole-person care, but is also critical to the success of CalAIM and other initiatives that look to address health and social needs through cross-sector data sharing. As state legislators and agency leaders look to continuously improve California's data-sharing policy landscape and make financial investments in information technology infrastructure, management of consent-to-share must be a priority. Medi-Cal's historic CalAIM initiative and CDII's DxF makes this work especially urgent. Learning from current pilots and promising practices, creating scalable solutions, and widely disseminating and utilizing state interpretive guidance will all contribute to a collective, unified, and statewide consent-to-share strategy.

Appendix 1.

Interviewees

Adam Dondro, CalHHS
Aleida Kasir, Community Health Center Network
Amie Miller, California Mental Health Services Authority
Amy Anderson and Beth Paul, Aliados Health
Andrea Frey, Hooper, Lundy & Bookman PC
Angie Bass, Velatura Public Benefit Corporation
Bill York and Camey Christenson, 2-1-1 San Diego
Carol Robinson, Midato Health
Cheryl Northfield, C&C Advisors
Daniel Chavez, Serving Communities Health Information Organization
DeeAnne McCallin, CDII, CalHHS
Elizabeth Este, Breaking Barriers
Erica Galvez, Manifest MedEx
Harman Basra, Community Action Partnership
Jaffer Traish, findhelp
Jana Wright and Alex Lipton, Unite Us
Jennifer Martinez, Wellbrook Partners
Jonah Frohlich, Manatt Health
Karen Farley and Linnea Sallack, California WIC Association
Kimberly Lewis, National Health Law Program
Lisa Bari, Jolie Ritzo, and Jessica Little, Civitas Networks for Health
Michelle (Shelley) Brown, Attorney, Solo Practitioner
Neil Batlivala, Pair Team
Rosario Trejo and Michelle Charime, Downtown Women's Center
Sristi Sharma and Elison Alcovendaz, California DHCS
Tim Pletcher and Emily Mata, Michigan Health Information Network

Appendix 2.

ASCMI Form

State of California - Health and Human Services Agency Department of Health Care Services

Authorization to Share Confidential Medi-Cal Information (ASCMI)

Version 1.0 [Pilot]

December 2022

Disclaimer: The ASCMI Form is intended to be used solely by ASCMI Pilot participants. DHCS makes no representation about the suitability of this form for uses outside of the ASCMI Pilot. The ASCMI Form, including attachments, are subject to change.

First Name	Last Name	Date of Birth	
Mailing Address	City	State	Zip Code
Residential Address	City	State	Zip Code
Phone Number(s)	Email	Beneficiary Identification Card (BIC)	

By signing this form, you authorize certain organizations and individuals to use and share your health and other confidential information for the purposes described in section 1.

1. Purposes

By signing, you authorize your health and other confidential information to be shared only to:

(a) Provide you with, refer you to, or help you access healthcare treatment, benefits, programs, social services, case management, community resources, and other supports ("Services") to meet your needs.

(b) Identify, support, coordinate, improve, and arrange payment for Services that may be provided to you.

(c) Help Medi-Cal provide better care through evaluation, reporting, and population health management.

2. Types of Your Information that You Authorize to be Shared

By signing, you authorize the below types of health and other confidential information about you to be shared only for the purposes stated above.

(a) Protected health information (PHI), including information regarding your health care, medical history, lab test results, and current or future conditions and treatments.

Authorization to Share Confidential Medi-Cal Information (ASCMI)

(b) Mental health information, including current and past diagnoses and treatments of your mental health conditions. This does not include psychotherapy notes, which are only shared if you separately consent.

(c) Substance use disorder information, including your current and past alcohol or drug use diagnoses, medications, treatment, lab tests, trauma history, facility discharges. This includes substance use disorder information about you that comes from a substance/alcohol use disorder provider subject to federal substance use confidentiality regulations (42 C.F.R. Part 2) if you check the box at the end of this form.

(d) Individualized Education Programs, and other information about social services provided in schools.

(e) Medi-Cal eligibility/enrollment information, which includes income and certain other demographic and geographic information pertaining to your eligibility for Services and benefits.

(f) Housing/homelessness information, including your housing status, history, and supports.

(g) Limited criminal justice information, including booking data, dates and location of incarceration, and supervision status. Your consent does not apply to your criminal history, charges, and immigration status.

3. Sources and Recipients of Your Information

By signing, you agree to allow a health information exchange or community information exchange ("HIE/CIE") facilitate the exchange of your health and other confidential information with and between your care partners from which you have received, are receiving, or will receive benefits, treatment, or services (""Your Care Partners"). Information may be shared only for the purposes in part 1. Your Care Partners may include the following:

(a) Healthcare providers, such as hospitals, clinics, physicians, pharmacies, and behavioral health providers.

(b) Managed care plans (MCPs), which administer Medi-Cal benefits and pay for services you receive under Medi-Cal.

(c) Certain community-based organizations (CBOs) that must comply with federal health care privacy laws, including some medically tailored meal providers, housing providers, and asthma remediation providers.

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(d) School-based providers of health or social services, such as nurses, social workers, and counselors.
(e) State health agencies, specifically, the California Departments of Health Care Services, Public Health, Social Services, and Developmental Services.
(f) County agencies, including mental health plans, human/social services or welfare departments, drug Medi-Cal organized delivery systems, and health and public health departments.
(g) Providers & case managers at correctional facilities, such as those at jails, prisons, and youth correctional facilities, only for the purposes in part 1 of this form. You do not consent to the use of your information for criminal investigations or prosecutions, sentencing, parole or probation monitoring, immigration enforcement, or family court proceedings.

Your Care Partners and their contractors agree to obey all applicable laws protecting your information.

4. Expiration, Revocation, or Change of This Form

Once signed, this form will be effective until the first of the following occurs:

(a) 24 months from the date on which you were last enrolled in Medi-Cal;
(b) you revoke this form; or
(c) you make any change to this form, and the modified form becomes effective.

5. Your Rights

You understand that:

(a) you can revoke this form at any time through the consent management service portal or by sending a revocation request signed by you or your representative to the HIE/CIE. ;
(b) a revocation is effective when received but may not apply to information already shared based on your past executed form, which may not be recalled or deleted;
(c) you may decline to sign this form and doing so will not affect your treatment or care, your eligibility for or ability to receive Services, or the payment for Services;
(d) you have a right to receive a copy of this form;
(e) the information you authorize for release could be re-disclosed by Your Care Partners, but only in compliance with this form and applicable law; and
(f) you may obtain a list of Your Care Partners to which your information has been disclosed by contacting the HIE/CIE.

Authorization to Share Confidential Medi-Cal Information (ASCMI)

Each of these rights extend to your representative if authorized by you under applicable law.

6. Sharing Information Without Your Consent

You understand that even if you do not sign this form, under federal and state privacy laws some of Your Care Partners may share your confidential information for treatment, payment, and other purposes, but providers subject to federal substance use confidentiality laws generally may not share your substance use disorder information without your consent.

7. Authorization

By signing this form, I authorize certain organizations and individuals to use and share my health and other confidential information for purposes described in part 1 of this form. Also, if I voluntarily include my phone number above, I consent to the receipt of texts or calls to communicate with me about my consent choices and how my information may be shared (standard message and data rates may apply).

☐ By checking this box, I also authorize the disclosure of substance use disorder information about me that comes from providers subject to federal substance use confidentiality regulations (42 C.F.R. Part 2).

If you are signing on your own behalf, fill out the 1st line. If you are signing on behalf of someone else, fill out the 2nd line. If you are signing on behalf of a minor aged 12-17, the minor should fill out the 1st line and you should fill out the 2nd line.

Beneficiary’s Name	Beneficiary’s Signature	Date (mm/dd/yyyy)
Representative’s Name	Representative’s Signature	Date (mm/dd/yyyy)

Source: “ASCMI Form (PDF)” Department of Health Care Services, updated March 2023.

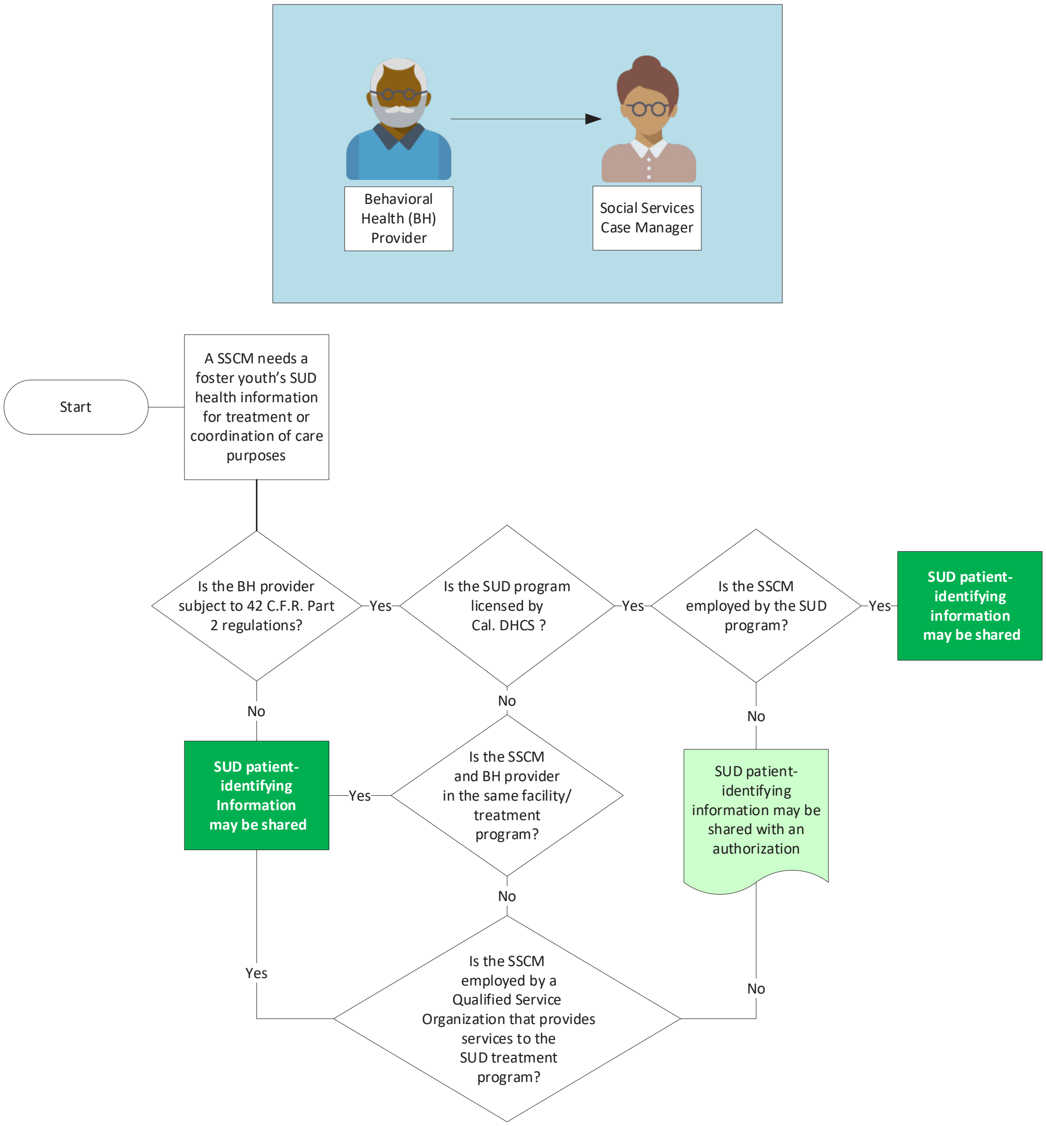
Appendix 3.

Sample from SHIG Guidance

CalOHII State of California Office of Health Information Integrity

State Health Information Guidance Volume 5.1

Graphic – Behavioral Health Provider to Social Services Case Manager – SUD



Source: "State Health Information Guidance 5.1 Sharing Minors and Foster Youth Health Information in California," California Health and Human Services, page 80, April 2023.

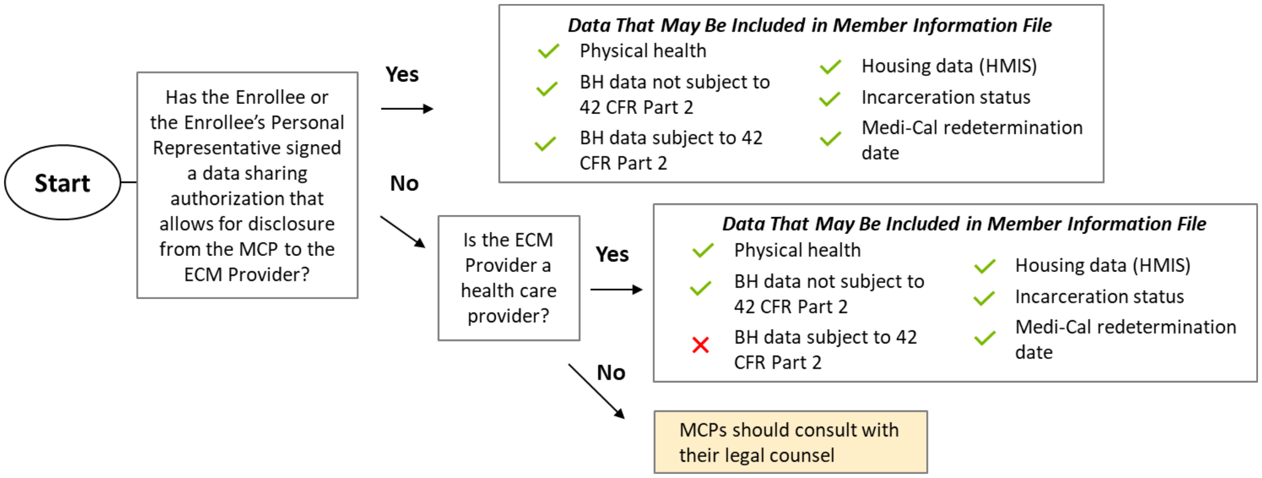
Appendix 4.

Consent in a Given Care Context

Use Case 2-1:

Data Exchange: Enrollee Information File
Function: Enrollee engagement for ECM services
Originating Entity: MCP
Receiving Entity: ECM Provider

Use Case 2-1 Visualization



Source: "CalAIM Data Sharing Authorization Guidance," Department of Health Care Services, March 2022.

Appendix 5.

ASCMI Pilot Program Descriptions

- San Diego County: **Awarded to 2-1-1 San Diego Community Information Exchange** with partners San Diego County Health and Human Services Agency, San Diego Behavioral Health Services, San Diego Medical Care Services, San Diego Advancing and Innovating Medi-Cal Unit, McAlister Institute, Metropolitan Area Advisory Committee on Anti-Poverty, People Assisting the Homeless, Integrated Health Partners, San Diego Health Connect, San Ysidro Health Center, and Health Net.

  The San Diego ASCMI Pilot had the following specific goals: 1) expand data sharing options for San Diegans to include substance use data for purposes of care coordination; 2) complete technology builds and process changes to facilitate expanded data sharing and consent refinement; 3) develop and implement community consent management and referral workflow training; and 4) collect and disseminate pilot project learnings and implications for scalability.

- San Joaquin County: **Awarded to Manifest MedEx (MX)** with partners San Joaquin County Department of Behavioral Health Services, Health Plan of San Joaquin, San Joaquin County Whole Person Care, and Health Net.

  The San Joaquin ASCMI Pilot collaborated with providers including San Joaquin County Whole Person Care, San Joaquin County Behavioral Health Services Access Clinics, TeleCare Corp, and Community Medical Centers to test the ASCMI form and consent management portal in San Joaquin County. MX received feedback from stakeholders on the application of the ASCMI form which was conveyed to DHCS and incorporated into the portal development, helping providers and patients feel more comfortable signing the ASCMI form. An example of an adjustment based on feedback was MXs addition of a consent recipient field on its portal, which makes the portal compliant with Title 42's Confidentiality of Substance Use Disorder Patient Records requirements.

  MX also broke up the consent options so patients could consent to the sharing of individual types of data. This helped patients feel comfortable and in control of their choices, resulting in higher signing metrics. More than 90% of patients who were asked to sign the ASCMI form consented to sharing data, and nearly half consented to disclosing SUD data. The pilot provided insights on success factors for shaping a full roll out that can be proactively addressed prior to the next phase, including the most productive types of training to technological adjustments, such as IP whitelisting. Participants were eager to participate in the pilot and see a real need for consent management forms as a means of improving data sharing for all Californians, not just those enrolled in Medi-Cal.

- Santa Cruz County: **Awarded to Serving Communities Health Information Organization (SCHIO)** with partners Santa Cruz County Behavioral Health Services, Central California Alliance for Health, HSA FQHC, Front Street, Salud Para la Gente, and Janus of Santa Cruz.

  The Santa Cruz ASCMI pilot tested the use of the ASCMI form and community-based consent registry by allowing the new form to be introduced and executed on paper, on a tablet-based system hosted by the provider organization, or on a mobile app downloaded to the Medi-Cal enrollees' own device. In the latter case, the Medi-Cal member had the ability to not just review the consent, but also to sign, change, and revoke it. The tablet and mobile platform used the FHIRed App, developed by the Dell Medical School under a LEAP grant from the ONC. The consent registry, based on consents executed in any of the three modalities, was hosted by the SCHIO platform, which was configured to prominently share and display the status of ASCMI consent as well as a running timeline of the patient's consent decisions.

Appendix 6

Sonoma Connect Consent Form

SONOMA UNIDOS
Resource
Connection
Network
SONOMA CONNECT

Resource Connection Network (RCN)

Consent to Share Personal Information

Purpose:
“So we can serve you better together”

Sonoma Connect | Sonoma Unidos is a group of community members and organizations working together to create the Resource Connection Network (RCN). This system’s purpose is to allow people to connect to the resources they need when they need them. This helps by supporting the referral process between community agencies who work together by sharing information that will better your care. Information shared in the Resource Connection Network will lower duplication of screening and eligibility questions. This document asks for your permission to share your information in the Resource Connection Network. Signing this document will only share your relevant personal information with participating organizations that are a part of your desired care team.

Why is this important?

Sharing this information helps us connect you to resources that can support your health and overall wellbeing. We have heard from the community that there are many helpful resources in Sonoma County. Still, many of them are hard to access or not connected to each other. When your information is shared with your care team, it is easier to coordinate your care and improve the quality of services offered to you. The goal is to give you and your family the best possible support.

Client Information

First Name: ______________________________ Last Name: ______________________________

Previous Name: ____________________________

Date of Birth: ____________________________

Medi-Cal CIN (Optional)**: ____________________**

Signing this form is your choice.

If you agree and sign this form, you are giving permission for your information to be shared with (to and from) the following types of organizations:

- Health care providers
- Community organizations (for example, food banks, legal services)
- Social services providers
- Health plans
- Wellness organizations
- Behavioral health providers
- County Departments (for example, Dept. Of Health Services and Human Services Dept)
- Housing and Homeless providers
- Organizations involved with the justice system

Your information from the types of organizations above may also be shared with Substance Use Disorder (SUD) providers. SUD providers can only receive it to help coordinate your care, resources, and human services.
Note: This authorization does not allow SUD Providers to share your SUD information.

By signing your name below, you agree that your current and future care team may disclose your health information, records, social services information, and other data to the Resource Connection Network. Such data may be shared between the Resource Connection Network participating organizations found here. At your request, you may also receive a printed copy of these organizations for your record by reaching out to your Resource Connection Network care team. Signing this form is your choice. No matter what you choose, it will not change your eligibility to receive services. Service providers that take part in the Resource Connection Network agree to only access and share information that is needed to serve you and are required to protect your information even if it is no longer protected under applicable privacy laws.

Information that may be shared includes:

- Your personal demographics (for example, your name, date of birth, gender, and contact information).
- Your housing information (for example, your type of housing, housing status, reason for housing status).
- Your employment and financial needs.
- The social services that you receive or may be eligible to receive (for example, CalFresh, Medi-Cal, and other public benefits).
- This form will apply to data from all services you receive within the Resource Connection Network providers and partners.

Substance Use Disorder (SUD) information protected by Federal law 42 C.F.R. Part 2 is not included as part of this authorization.

Under California law, your explicit permission is required in order to share mental health and/or HIV test results with other providers or digital systems. This specially protected information will not be shared with participating providers via the network, therefore consent to release this information is not applicable to this form. Your care providers may ask you to complete a separate consent to share this information, as needed, to treat you or provide services to you.

Your Rights:

- You may refuse to sign this form. Your refusal will not affect your ability to receive treatment, payment, or eligibility for benefits otherwise available to you.
- You have a right to receive a copy of this form.
- You may revoke (take back) or change your consent/permission at any time. You can start this process by talking with any of your Resource Connection Network providers. Your service provider may contact the tenant admin to revoke or change consent at your request, or you can submit a change request in writing to the following address : 1310 Redwood Way Ste 135, Petaluma, CA 94954. If you want to change what information can be shared, you can complete a new authorization/form to reflect any change(s). If you decide not to share sensitive information, it will not affect the services you receive from your providers, but you may receive more limited care coordination services through the Resource Connection Network.
- Any information previously shared with current or past treating providers cannot be recalled and your cancellation of sharing only applies to information shared after notification of the cancellation.
- Your cancelation of consent will take effect when the Resource Connection Network is notified, except to the extent that others have already acted dependent upon this authorization.
- You are entitled to receive a copy of this form and the current list of participating organizations. You can also receive and review a copy of your health and social services information that is shared by this form.
- Signing this form does not change what Personal Health Information can be shared under State and Federal Laws.

If you choose not to sign this form:

If you decide not to sign this form, you will **still** receive medical services, treatment, or other services. It will, however, limit the actions that the network of providers that collaborate on the Resource Connection Network can do together to help you, and we will not be able to coordinate these services for you at this time.

Please call 707-792-7900 for information regarding RCN privacy practices.

- Some information shared under this Authorization may be re-shared with others under certain conditions and may no longer be protected by State and Federal confidentiality laws. Certain information may require my written permission to be redisclosed, unless specifically permitted or required by law.
- I understand that treatment, payment, enrollment, or eligibility for benefits may not be conditioned on my signing of this form. However, I understand that the Resource Connection Network providers and organizations may not be able to coordinate my services without a signed form.
- This form expires on (date or event): ______________________
    - This form will remain in effect for one year from the date of my signature or until I withdraw authorization.
- I have read this form or have listened to it read to me. I authorize the use and sharing of my health and social services information as described above.

Client Name : ____

Client Signature: ____

Client or Legal Representative (Required)

If the form is **signed** by a person other than the client, please include the name and relationship to the client:

____ ____

Full Name *Relationship*

Today's Date: ____________________________________

Month / Day / Year (Required)

Source: "Resource Connection Network (RCN): Consent to Share Personal Information," Sonoma Connect.

Appendix 7

Sonoma Connect Consent Revocation Form

Resource Connection Network Revocation of Information Sharing Authorization Form

Last Updated 06/22/23

The purpose of this form is to obtain authorization to revoke client consent in the Resource Connection Network system. In the client's profile, user will upload signed document into the Document Vault and select revoke consent next to the client's consent form. For questions regarding revoking consent please email Harman Basra, Network Manager, hbasra@aliadoshealth.org

Client Name: ____ Date of Birth: __________

Medi-Cal CIN (If known): __________________

I wish to revoke my authorization. (Please send to your Care Team member)

Signature of Client or Client's Legal Representative:

____ ________/________/________

Month *Day* *Year*

If signed by Client's Legal Representative, state relationship and authority to do so:

____

Source: "Resource Connection Network Revocation of Information Sharing Authorization Form," Sonoma Connect, 2023.

Endnotes

1. "5. Social Workers' Ethical Responsibilities to the Social Work Profession," NASW Code of Ethics: Ethical Standards, National Association of Social Workers (NASW), 2021; T. L. Beauchamp and J.F. Childress, Principles of Biomedical Ethics (Oxford: Oxford University Press, 1979).

2. "Data Exchange Framework," Center for Data Insights and Innovation (CDII), 2023.

3. *Data Exchange Framework Guiding Principles (PDF)*, California Health and Human Services (CalHHS) and CDII, July 1, 2022.

4. Lisa Bari and Shruti Kothari, "Why Health Data Sharing Needs To Be A Priority For LGBTQ+ Advocacy," *Health Affairs*, August 14, 2023.

5. *CalHHS Data Exchange Framework Policy and Procedure: Privacy Standards and Security Safeguards (PDF)*, CalHHS, July 5, 2022.

6. "Medi-Cal Transformation: Our Journey to a Healthier Claifornia for All," Department of Health Care Services (DHCS), August 10, 2023.

7. To implement both ECM and CS, MCPs contract directly with community-based and other local/county social services organizations that have their own interpretation of consent-to-share policies related practices. As such, these two programs form the basis of the use cases for data sharing outlined in the CalAIM Data Sharing Authorization Guidance published in March of 2022 applicable to adults only. This Guidance concludes that the vast majority of necessary data sharing for the purposes of coordination with local and county jails and housing systems operating federal HUD Housing Management Information Systems (HMIS) is permissible without explicit consent-to-share under both federal and state law, as amended by AB-133. However, the Guidance notes the ongoing exception of substance use disorder treatment information that is protected by 42 C.F.R. Part 2 and that there are other provisions, including county laws and organizational policies of housing organizations for example, that do require explicit consent-to-share. A newer version of the Guidance that is currently available for review and comment accounts for the broader set of information sharing needed to achieve the full vision of CalAIM, given the expansion of ECM and CS to children, youth and incarcerated populations. Much of this care coordination will require explicit consent-to-share as it involves collaborative care with schools under the Family Educational Rights and Privacy Act and Individuals with Disabilities Education Act provisions and their California counterpart the California "Pupil Records" Law, as well as compliance with the federal Child Abuse Prevention and Treatment Act and the similar California welfare codes, and privacy guidelines for U.S. Department of Agriculture nutrition programs. See Appendix 4 for a visual of how consent works in a given care context.

8. DHCS finalized a vendor for the PHM Service contract in 2022 and planned to test the PHM Service in the first quarter and launch and scale the service in the third quarter of 2023, however, testing has not yet begun and the envisioned design for consent management has not yet been articulated. "Invitation for Proposal 21-10375 Population Health Management Service," DHCS, September 7, 2022; "CalAIM Population Health Management Service Advisory Group," DHCS, December 5, 2022.

9. Lauren Larin and Julie Silas, "How to Share Data: Practical Guide for Health and Homeless Systems of Care" (PDF), *California Health Care Foundation (CHCF)*, May 2022; California Advancing and Innovating Medi-Cal Act, Welfare and Institutions Code § 14184.102.

10. *CalAIM Data Sharing Authorization Guidance* (PDF), DHCS, March 2022; *CalAIM Data Sharing Authorization Guidance Version 2.0* (PDF), DHCS, June 2023.

11. "State Health Information Guidance (SHIG)," CDII, April 2023.

12. California Assembly Bill 133 (AB-133), 2021.

13. *Strategy for Digital Identities* (PDF), CalHHS, July 1, 2022.

14. "RFI #50040755 CalHHS Person Identity Matching Solution," Cal eProcure, June 28, 2023.

15. "HL7 Version 2 Product Suite," HL7 International, accessed September 11, 2023.

16. "HL7 Implementation Guide: Data Segmentation for Privacy (DS4P), Release 1," HL7 International, May 13, 2014; "Security Label DS4P Home Page," HL7 International, August 12, 2021.

17. Chethan Sarabu et al., "Shifting into Action: from Data Segmentation to Equitable Interoperability for Adolescents (and Everyone Else)," *Appl Clin Inform* 14, no. 3 (2023): 544-554.

18. "CalAIM ASCMI Pilot," DHCS, accessed September 7, 2023.

19. In addition to utilizing the ASCMI form, the pilot stipulated the development of a "consent management service that is accessible to members, ECM providers, Community Supports providers, physical and behavioral health providers, hospitals and others via electronic health record (EHR) system and/or website." This service must have the capabilities to be able to securely store individual consent using the ASCMI form, allow ECM and CS providers to view patient-client consent, and allow individuals to amend their consent at any time. "RFI 22-006 Authorization to Share Confidential Medi-Cal Information (ASCMI) Form," Cal eProcure, November 4, 2022.

20. "Whole Person Care Pilots," DHCS, accessed October 10, 2023.

21. "Health Homes Program," DHCS, accessed October 10, 2023.