Legislative

Report

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CALIFORNIA HEALTH & HUMAN SERVICES AGENCY

Center for Data Insights and Innovation



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# **Executive Summary**

In 2020, the California Health and Human Services Agency (CalHHS) established the Center for Data insights and Innovation (CDII) through legislation as a resource to ensure compliance of state law on confidentiality of medical information and further innovation through better use of data. CDII was created to provide health information-sharing guidance that balances the need for patient privacy with the benefits of data sharing to support and encourage integrated care and services to assist California health and social services organizations.

Since its creation, CDII has been responsible for several key CalHHS initiatives. CDII administers the State Committee for the Protection of Human Subjects (CPHS), spearheads the California Health and Human Services Data Exchange Framework (DxF) initiative, oversees the Agency Data Hub and Open Data Portal to integrate and standardize data across all CalHHS departments, collects data and publishes reports on the quality of care and patient services, and strengthens the security of data processes within CalHHS.

In 2024, developing the DxF remained a top priority with statewide data exchange beginning on January 1, 2024. CDII continued to oversee the Agency Data Hub and Open Data Portal, collect and report data on the quality of care and patient services, and reinforce CalHHS' security for data processes.

By continuing to lead inter-departmental collaboration, CDII strives to incubate and innovate data-driven ecosystems of products and services designed to improve data sharing and analytics processes for CalHHS while encouraging increased stakeholder engagement from our partners.

#### Mission and Vision Statements

Our **mission** at CDII is to improve the lives of all Californians by turning data into insights, knowledge, and equitable action. We accomplish this through our **vision** of developing, supporting, and improving programs within CalHHS to be person-centered, equity-focused, and data-driven.

# **Guiding Principles**

In alignment with CalHHS' Strategic Priorities to advance healthier outcomes, CDII has adopted four Guidina Principles:

**Focus on Equity** – Advise on and lead strategic data initiatives with CalHHS-wide data standards, projects, and outcomes to improve equitable service delivery across all CDII programs.

**Use Data to Drive Action** – Build tools and provide insight on projects that help deliver quality data and insights to decision-makers and provide reporting on key topics.

**Put the Person Back in Human-Centered Design** – Improve ease of data-sharing and integration through data standards and mappings.

**Cultivate a Culture of Innovation** – Increase data literacy across CalHHS by creating communities of data practitioners and promoting data-driven decisions.

# Major Highlights in 2024

The Center for Data Insights and Innovation (CDII), is steadfast in our mission to align data-sharing strategies, improve tactics in data analytics, and deliver engaging, person-centered communications to help build the California Health and Human Services (CalHHS) data community. Highlights of CDII's major endeavors for 2024 are as follows:

- Data Exchange Framework Many healthcare entities were required by law to sign the DxF Data Sharing Agreement and begin exchange by January 31, 2024. As of November 1, 2024, the number of signed DSAs reached over 2,500, representing over 4,400 Participants engaging in data exchange.
- Agency Data Hub and Open Data Portal The Agency Data Hub and Open Data Portal continued to support CalHHS analytical initiatives and data-sharing capabilities.
- **Insights Lab** In 2024, Insights Lab established foundational data-sharing agreements; built new, and streamlined existing, data pipelines; and enhanced data products and dashboards.
- Policy and Governance Program CDII's Policy and Governance Program
  is responsible for ensuring applicable State departments are compliant
  with the Health Insurance Portability and Accountability Act (HIPAA), and
  other related state and federal laws. This program maintains, and
  publishes annually, the Statewide Health Information Policy Manual
  (SHIPM) and State Health Information Guidance (SHIG).
- Quality Reporting CDII's public reporting programs, inherited from the former Office of the Patient Advocate (OPA), provide Californians with analyzed information to help make informed health care decisions. CDII produces three annual Health Care Quality Report Cards and an annual Health Care Complaint Data Report.
- Committee for the Protection of Human Subjects (CPHS) CPHS serves as the Institutional Review Board (IRB) for all departments and offices under CalHHS. Over 1,500 projects came before CPHS for review this year.
- Data Expo The annual Data Expo is a learning forum open to all CalHHS staff during which attendees engage in presentations by subject matter experts in data-centric fields while also learning about

new data-related projects and initiatives at CalHHS. This year, attendance reached over 1100 with attendees having the option to attend in-person or virtually.

# Data Exchange Framework



Assembly Bill 133 (2021), codified as Health and Safety Code Section 130290, required the California Health & Human Services Agency (CalHHS) to consult with stakeholders and local partners to establish, on or before July 1, 2022, the CalHHS Data Exchange Framework (DxF). CalHHS delegated authority to the Center for Data Insights and Innovation (CDII) to perform these tasks and help implement the DxF.

The DxF includes a single Data Sharing Agreement (DSA) and common set of Policies and Procedures (P&Ps) that govern and require the exchange of health and social services information (HSSI) among health care entities and agovernment agencies in California. The DxF is a critical component of CalHHS' strategy for ensuring that health and human services organizations have the information they need at the right time to be able to provide person-centered care.

#### Establishment of the DxF (August 2021 - July 2022)

Per legislation, CDII and CalHHS convened a diverse, multi-stakeholder Advisory Group and a DSA Subcommittee to design and support implementation of the DxF. These committees met monthly between September 2021 and June 2022 to provide recommendations on the development of the DxF. CDII considered these recommendations and in July 2022, published the DSA, an initial set of P&Ps, and the Strategy for Digital Identities.

DxF Implementation Preparation and Launch (August 2022 – January 2024) After the publication of the DSA and initial set of P&Ps, CDII and CalHHS began to implement an approach for achieving additional legislatively mandated milestones described in Assembly Bill 133.

The first of these milestones required that certain entities sign the DSA by January 31, 2023, including:

- General acute care hospitals
- Physician organizations and medical groups
- Skilled nursing facilities that currently maintain electronic methods
- Health care service plans and disability insurers
- Clinical laboratories
- Acute psychiatric hospitals

CDII established a DSA Signing Portal and engaged in a communications campaign to encourage compliance.

The second milestone required that the majority of entities that were required to sign the DSA begin exchanging data according to DxF requirements by January 31, 2024. Some entities are permitted until January 31, 2026, to start exchanging data, including:

- Physician practices of fewer than 25 physicians
- Rehabilitation hospitals
- Long-term acute care hospitals
- Acute psychiatric hospitals
- Critical access hospitals
- Rural general acute care hospitals with fewer than 100 acute care beds
- State-run acute psychiatric hospitals
- Nonprofit clinics with fewer than 10 health care providers

CDII established enabling programs to support signatories in exchanging data, including a:

- DxF Grants program for eligible signatories;
- Qualified Health Information Organization (QHIO) Program to identify intermediaries that can support exchange; and
- DxF Participant Directory for signatories to document their exchange choices as a means of communicating to other signatories their preferred means of sending and receiving data.

Additional information on these programs can be found later in this report.

CDII also established the DxF Implementation Advisory Committee (IAC), a successor to the Advisory Group, and the DSA P&P Subcommittee to continue its stakeholder-driven approach to DxF implementation.

## DxF Implementation and Strategic Planning (February 2024 – Present)

Following the launch of exchange under the DSA beginning January 31, 2024, CDII focused its efforts on supporting participants in meeting DxF requirements with continued guidance from the IAC and the DSA P&P Subcommittee (see additional information later in this report).

CDII also engaged in a comprehensive cross-departmental planning effort to identify DxF priorities, resulting in a three-year DxF Roadmap. The **DxF Roadmap** was released as a draft for public comment in November 2024 and was published in early 2025.

## Data Exchange Framework Program Progress

In 2024, CDII continued to advance critical programmatic priorities including DxF Participant Engagement, the QHIO and Grants Programs, and DxF P&P Development.

#### **DxF Participant Engagement**

In 2024, CDII engaged the broader health and social service community to support DxF Participants in meeting DxF requirements and increase DSA signature rates. CDII conducted targeted outreach to entities that are required to sign the DSA, but had yet to do so, working with state departments and industry associations to host DxF educational events and listening sessions. CDII also continued to develop educational materials on topics such as the DxF's privacy and security provisions.

In 2025, CDII plans to continue to prioritize participant engagement to support entities implementing the DxF. Specific planned activities include hosting a DxF Summit on March 20, 2025, and developing a comprehensive DxF "Welcome Guide" to support entities in understanding and complying with DxF requirements.

#### Qualified Health Information Organization (QHIO) Program

CDII established the QHIO Program under the DxF to provide all DxF Participants with the option to leverage a DxF-designated intermediary to facilitate secure health and social services data exchange. While Health and Safety Code Section 130290 allows DxF Participants to exchange data through any HIE network, HIO, or technology that adheres to the DSA and its P&Ps, the QHIO Program allows Participants to use an intermediary which has demonstrated a commitment to the DxF by signing the DSA and meeting qualifications established by CDII.

As part of the QHIO designation process, CDII established QHIO criteria, a set of QHIO requirements, and a process to qualify intermediary applicants through a public application process. The application required attestations through which information exchange intermediaries confirmed their current or anticipated organizational readiness, data privacy and security standards, and technical capabilities to support data exchange under the DxF. In October 2023, CDII announced the designation of nine QHIOs to support secure, statewide data exchange.

The QHIOs have played a critical role in promoting the secure exchange of health information under the DxF, empowering health and social services providers across California to provide the best possible care. As of September 2024, two-thirds of DSA Signatories who had completed the Participant Directory selected a QHIO to facilitate data exchange, confirming the central role QHIOs have in facilitating statewide data exchange in California.

In 2024, the QHIO Program Guide was formalized, outlining requirements a QHIO must meet to become qualified and maintain qualified status. CDII expects to

confirm continued QHIO compliance by QHIO entities with these requirements in 2025.

## **DxF Grant Program**

To support the implementation of the DxF, the Governor and California State Legislature allocated \$50 million in the 2022/23 SFY budget for the **DxF Grant Program**. This funding supports much needed technical assistance for health and social services organizations implementing data exchange under the DxF.

The DxF Grant Program identified three opportunities to support DxF implementation:

- **DxF Educational Initiative Grants** provided \$2.8 million in funding to eight not-for-profit associations to deliver DxF education and training in calendar year 2023. These grants supported a range of activities, from webinars and one-on-one coaching sessions to the creation of a speaker's bureau and learning collaboratives, reaching an estimated 10,000 individuals in 2023.
- DxF Signatory Grants support DxF signatories who seek assistance with DxF compliance and onboarding. These include grants for:
  - QHIO Onboarding to provide funding assistance to DSA Signatories who choose to connect to a QHIO to help meet their DxF requirements.
  - Technical Assistance (TA) to provide funding for assistance to organizations who choose a customized pathway to meet their DxF requirements. TA funding may be used for workflow optimization, adoption of an Electronic Health Record (EHR), or to supplement the cost to onboard to an intermediary such as a QHIO or a national network or framework.

More than 500 DxF Signatory Grant applications representing over 800 DxF Signatories were received during three application rounds in 2023. Following review of these applications, \$40.8M was awarded to 790 grantees.

During 2024, the DxF Signatory grantees worked toward their goals and reported their progress quarterly to CDII's third party administrator. Through these quarterly progress reports, grantees report achievement of milestones that trigger the release of grant awards:

- Fifty percent of the grantee's award is released upon reaching the first DxF Signatory Grants milestone which indicates the grantee has contracted for services to support DxF exchange.
- The remaining fifty percent of the grantee's award is released when the second DxF Signatory Grants milestone is reached which indicates the grantee has met their goals and is ready for data exchange.

As of September 2024, 61% of grantees had achieved their first grant milestone, and an additional 8% of grantees had achieved both milestones. Grantees will continue advancing toward their goals in 2025 with all milestones due by March 31, 2026.

### DxF Policies and Procedures (P&Ps) Development

In 2024, CDII developed and amended several P&Ps in response to DxF operational needs and stakeholder feedback. CDII will continue to consider P&P needs to reflect state health information needs and to align with federal requirements in 2025.

# Data and Engineering Division

The Data and Engineering Division within CDII is comprised of the Agency Data Hub and the Open Data Portal.

# Agency Data Hub

The Agency Data Hub (Data Hub) is an ecosystem of services and tools in a cloud-based analytics platform. The Data Hub was developed to operationalize the Center for Data Insights and Innovation (CDII)'s guiding mission to improve the lives of all Californians by turning data into insights, knowledge, and equitable action.

The Data Hub provides services to promote data-sharing and collaboration between California Health and Human Services Agency (CalHHS) departments and researchers, with the goal of transforming program-centric analytics into person-centered insights.

As identified in the CalHHS IT & Data Strategic Plan/Foundations and Approaches/CalHHS Integrated Data Infrastructure, the Data Hub provides a focal point for data-sharing across CalHHS and assists with data curation, consolidation, management, and analytics, made possible by matching clients across departments to enable an integrated view of client participation across CalHHS programs and services. This improves interoperability between multiple CalHHS departments, and reduces the effort required by universities and independent researchers to integrate data across programs. The Data Hub is instrumental in integrating, securing, and analyzing the data needed for various efforts:

- Building and supporting CalHHS analytics efforts to support equity goals and bring together CalHHS data with data from the California Interagency Council on Homelessness (Homelessness Data Integration). The Data Hub provides ongoing support for Insights Lab data products, including, production support and platform operations support.
- 2. Client Linkage Successfully completed the Lift & Shift, migrating University of Southern California's Children's Data Network (CDN) client matching code to run natively within the Data Hub. This will help connect CalHHS programs and data sources for administrative, client-level records. The Data Hub established authority (via data sharing agreement and existing governance) to store and process client data from three departments, with plans to provide the service to all CalHHS Departments and Offices in coming years.
  - Data Sharing Agreements between CDII and the Departments of Social Services (CDSS), Health Care Services (DHCS), and Developmental Services (DDS) completed.

3. Continue to host and support the California Department of Social Services (CDSS) Early Childhood Integrated Data System (ECIDS) –. Through this collaborative work, CDII and CDSS have identified critical areas where to build capacity within research teams across our partners—another major win for future sustainability. This ECIDS partnership has successfully assisted in establishing a better understanding of early childhood challenges across the state, as it includes public census data matched with participation data from CDSS' childcare programs. Assessing this data enabled CDSS to analyze resource allocation and program access. CalHHS is committed to addressing childcare access by continuing to analyze current ECIDS data and fold in additional data from other partners.

# Open Data Portal

The CalHHS Open Data Portal (ODP) is a research data repository that provides the public with a single-entry point to access CalHHS departments' deidentified, publishable data. De-identified data is defined under the HIPAA Privacy Rule (45 C.F.R. part 164.514) as information (1) that does not identify the individual and (2) for which there is no reasonable basis to believe the individual can be identified from it. CDII is responsible for administering the ODP in accordance with Health and Safety Code section130205(b).

CalHHS launched the ODP initiative in 2016 to increase public access to one of the State's most valuable assets – non-confidential health and human services data. ODP's goals are to spark innovation, promote research and economic opportunities, engage public participation in government, increase transparency, and inform decision-making. "Open Data" describes data that are de-identified, freely available, and formatted according to national technical standards to facilitate visibility and reuse of published data. The ODP provides access to standardized data that can be easily retrieved, combined, downloaded, sorted, searched, analyzed, redistributed, and reused by individuals, businesses, researchers, journalists, developers, and government to process, trend, and innovate. The ODP remains the primary location for researchers to review and download datasets and statistics for study.

# Insights Lab

Within the Center for Data Insights and Innovation (CDII), the Insights Lab provides a more in-depth understanding of the needs of all Californians to drive person-centered California Health and Human Services Agency (CalHHS) program service delivery. As the applied research arm of CalHHS' data ecosystem, Insights Lab focuses on cross-departmental research to generate CalHHS-wide insights and drives a culture of data-informed policy and decision making. The Insights Lab leads multiple data initiatives within CalHHS to inform and enhance person-centered services, such as the Homelessness Data Integration Product, the Equity Dashboard, and the All-Hazards Dashboard. In 2024, Insights Lab's focus was on establishing foundational data-sharing agreements; building new, and streamlining existing, data pipelines; and enhancing data products and dashboards.

## Homelessness Data Integration

One of the overarching goals of CalHHS is to make the delivery of health and human services more person-centered, with a particular focus on vulnerable populations, including those living in deep poverty. Given these aims and paired with the unprecedented levels of homelessness throughout California, CDII seeks to better equip the State to provide effective responses and resolutions to homelessness and related issues. The homeless data integration project brings together CalHHS data with data from the California Interagency Council on Homelessness (Cal ICH) for the first time, unlocking a wealth of insights to shape policy that advances the Governor's priority of preventing and ending homelessness.

The CalHHS Integrated Homelessness Dataset will be the most comprehensive dataset available to date on California's homeless populations, increasing understanding of the number of individuals who are homeless while also better understanding what array of services are being provided in which circumstances. Because client records will be linked across CalHHS datasets, longitudinal analyses become possible, providing insights into the permanence of program outcomes by identifying whether individuals, once housed, return to homelessness programs from different departments over time. It will additionally allow insight from a whole-person perspective into the service utilization of CalHHS programs, trends in a person's journey from homelessness to housing, and disparities in services and outcomes by subpopulation.

The homeless data integration project was commissioned in 2023 by Corrin Buchanan, now CalHHS Undersecretary, in close collaboration with the California Interagency Council on Homelessness (Cal ICH). This project is a landmark multi-agency, multi-departmental collaboration and was recognized as such in 2024 with an award from Government Technology in the "Best Collaborations" category. The data collaboration begins by integrating data from Cal ICH's Homeless Data Integration System (HDIS), Medi-Cal data from the

Department of Health Care Services (DHCS), and multiple datasets from the California Department of Social Services (CDSS), to include the California Work Opportunities and Responsibilities to Kids (CalWORKS) and California Statewide Automated Welfare System (CalSAWS) programs, and programs from CDSS's Housing and Homeless Division (HHD).

The CDII Insights Lab achieved a number of meaningful milestones this year relating to homelessness integration including working with partners to drive forward data sharing agreements, data sharing logistics, and building frameworks for meaningful collaboration. In August of 2024, the data sharing agreement was fully executed with the first four partners: CalHHS, Cal ICH, CDSS, and DHCS. Folded into that agreement was the development of data flow between parties, and alignment on the approach to linkage and integration.

Additionally, both Cal ICH and CDSS have begun data transfer to CDII's Agency Data Hub, which will manage data linkage, integration, and access, and DHCS data transfer is expected to begin soon. Being program-agnostic and purpose-built for secure, multi-party data analytics collaborations, the Agency Data Hub is ideally suited as the data ecosystem for this robust data effort. The close of 2024 finds CDII busy with data engineering efforts, maximizing automation and streamlining data management to create a scalable, sustainable data landscape to support data science and analytics. Because of its achievements in 2024, CDII is poised to start 2025 by linking clients across datasets and building the integrated dataset.

CDII is simultaneously seeking to engage the best leadership, expertise, and thought partnership for guidance on the use of this dataset. In an effort to eliminate the silos that would typically result from differing data access permissions, CDII is facilitating a Learning Agenda Steering Committee, chaired by CalHHS, to jointly develop a learning agenda for the integrated homelessness dataset. The initial coordination for the steering committee has been completed, with the first meeting scheduled for the first week of the new year. The Learning Agenda Steering Committee initially includes the Business Consumer Services and Housing Agency (BCSH), Cal ICH, CalHHS, CDII, DHCS, and CDSS, as the initial data sharing partners, as well as the California Department of Aging, which has been actively engaged in research and analytics to understand the impact of rising homelessness on California's aging populations.

In addition, Cal ICH data and the CalHHS Integrated Homelessness Dataset will be available at the department level, enabling CDSS and DHCS to produce reports, policies, and data products focused on their unique missions and specific programs. For example, CDSS will utilize individual-level HDIS data to measure programmatic outputs, outcomes, and participation in the Housing and Homeless Division (HHD) programs administered by CDSS. Meanwhile, DHCS will use HDIS data to quantify and analyze trends among Medi-Cal members

who are homeless or have unstable housing and are eligible for care coordination and other benefits but are not receiving services.

Given the severity of California's homelessness crisis, many other CalHHS departments are eager to join the data integration effort, both to better serve their own populations and to contribute to the State's ability to leverage data in meaningful ways. If funding opportunities allow, CDII seeks to bring new State partners onboard in 2025 and beyond. Through these coordinated efforts, CDII is chipping away at State siloes that obscure insights into service delivery and outcomes, unlocking critical insights into California's homeless populations through the integration of key datasets across the state, and enabling datadriven policy and data-informed program design.

## Equity Dashboard

The Equity Dashboard has played a pivotal role in propelling CalHHS' efforts toward equity by enhancing transparency and ease of tracking demographic data collection. As part of this work, CDII collaborates with CalHHS departments, offering valuable insights into current demographic data collection within programs and services. Available to CalHHS staff, the Equity Dashboard includes race, ethnicity, sexual orientation, and gender identity demographic data from various departments, such as Department of Rehabilitation (DOR), Department of Managed Health Care (DMHC), Department of Health Care Services (DHCS), Department of State Hospitals (DSH), Department of Development Services (DDS), California Department of Aging (CDA), and California Department of Public Health (CDPH). In October 2024, CDII successfully completed and obtained approval for a data sharing agreement. This critical milestone allows DHCS, DDS, and the California Department of Social Services (CDSS) to securely transmit client-level data to CDII. This collaboration enhances CDII's capacity to analyze and integrate data, providing actionable insights that support program improvement and policy decisions across CalHHS departments.

Additionally, CDII continues to lead the CalHHS Data Standards Community, working collaboratively with the State of California Office of Data and Insights to refine race and ethnicity data standards. In 2024, the community conducted a comprehensive gap analysis, comparing the newly released Office of Management and Budget (OMB) standards from March 2024, California legislative mandates, and the diverse demographic composition of California. This analysis incorporated statistical methods, an extensive literature review, and feedback from community members, ensuring the standards align with both federal guidelines and state-specific needs. The Data Standards Community remains an integral forum for CalHHS departments to share best practices, identify challenges, and align on standardized approaches for collecting and reporting demographic data.

CDII continues to monitor the CalHHS Strategic Goals and Priorities, along with the equity metrics established in 2022. These metrics serve as benchmarks to

assess collective progress toward delivering tangible results for Californians. Departments and offices have identified measurable impact goals tied to each strategic priority, with equity measures developed in collaboration with the CalHHS Justice, Equity, Diversity, and Inclusion (JEDI) subcommittee. In 2024, CDII provided updated data visualizations to support these efforts, ensuring that strategic decisions are guided by data-driven insights. CDII's work reflects its dedication to ensuring that data serves as a powerful catalyst for equity and innovation within CalHHS.

#### All-Hazards Dashboard

The All-Hazards Dashboard (AHD) is a situational awareness and decision-making tool developed by CDII in partnership with departments from across CalHHS. The AHD supports a unified approach to emergency response, focusing on CalHHS-licensed facilities and vulnerable populations across California. The AHD is part of a broader initiative to strengthen CalHHS-wide emergency management functions.

In 2024, the AHD achieved significant advancements, including the completion of the shelter data ecosystem. Through the California Shelter Status and Inventory (CaSSI) Application, staff can now enter shelter information in a web application and utilize reporting tools. This has fully digitized and automated previously manual processes for data collection and reporting. Shelter-related tools store information centrally in the Data Hub, enabling integration, historical data maintenance, and fit-for-purpose querying tools. This ensures real-time, accurate information on shelter locations, census counts, and resource needs. The Shelter Data Ecosystem begins with data collection tools, progresses to data sharing with California Governor's Office of Emergency Services (CalOES) and culminates in the creation of a public dashboard for the Department of Social Services (CDSS) to add to their website. This comprehensive approach enhances transparency and accessibility, ensuring stakeholders and the public have reliable access to critical shelter information during emergencies.

New datasets, such as language data, California Medical Assistance Teams (CAL-MAT), Volunteer Emergency Services Team (VEST), Functional Assessment Services Team (FAST) and Operational and Evacuation Status Facilities for CDSS, were integrated into the AHD, enhancing its scope and utility. The AHD also expanded its collaboration efforts, working with other departments and agencies to strengthen inter-agency coordination and improve emergency response capabilities by data alignment and sharing.

The AHD team conducted several presentations in 2024, including at the Bay Area ArcGIS Community GIS (Geographic Information System) Group Meeting at the University of California, Berkeley. These sessions allowed GIS professionals to explore CalHHS' unique situational awareness and decision-making tools.

The AHD is a vital tool for emergency preparedness, response, and recovery within CalHHS. It ensures seamless coordination, transparency, and efficiency by providing real-time data on hazards, shelter status, and resource needs. Key contributions include:

- **Supporting the Shelter Ecosystem:** Validates and shares real-time shelter data, fostering public trust and effective inter-agency coordination.
- Streamlining Emergency Reporting: Automates critical updates for executives, reducing manual workloads and enabling timely decisionmaking.
- **Enhancing Situational Awareness:** Centralizes data for unified, multi-hazard monitoring, ensuring prioritized resource allocation.
- **Strengthening Collaboration and Transparency:** Serves as a hub for interagency efforts and transparent communication during emergencies.
- Providing Historical Data: Informs risk mitigation, planning, and cost recovery.

The All-Hazards Dashboard (AHD) is the cornerstone of CalHHS' emergency response framework, providing a unified, near-real-time view of emergencies such as public safety power shutoffs (PSPS), earthquakes, wildfires, and evacuations. By integrating data across departments and agencies, the AHD ensures efficient, coordinated responses that protect California's most vulnerable populations.

The AHD is a vital resource for preparedness, response, recovery, and resilience. It is a helping tool that assist CalHHS to be equipped to face the increasing frequency and complexity of emergencies with innovation and impact. It represents a critical investment in the safety, efficiency, and well-being of Californians.

# Data and Insights Plan

CalHHS is committed to achieving a Healthy California for All through focusing on whole person care and integrating health and human services data points. In March 2024, CalHHS released its CalHHS IT and Data Strategic Plan aimed at guiding a data-driven ecosystem connecting health and human services programs. To support this plan, CDII has collaborated with the Office of Technology and Solutions to create a CalHHS Data and Insights Plan. The plan will provide CalHHS offices and departments with a unified blueprint for data collection, usage, and compliance with legal and security requirements to protect data. The plan is expected to be released later in 2025.

# Policy and Operations Branch

The Policy and Operations Branch of the Center for Data Insights and Innovation (CDII) contains the Policy and Compliance Oversight Program and Quality Reporting Programs. The Policy and Compliance Oversight Team is responsible for overseeing statewide compliance with state and federal health information privacy laws by establishing policies, monitoring programs, and reporting on compliance activities. The Quality Reporting Programs are responsible for producing annual quality report cards of health care quality and access, and a legislative report of complaints made by consumers about health care services.

## Policy and Compliance Oversight Program

CDII's Policy and Compliance Oversight program assumes statewide leadership, coordination, policy formulation, direction, and oversight responsibilities for compliance with state and federal health information privacy laws and implementing regulations (Health and Safety Code section 130203(a)). CDII exercises full authority relative to state entities to establish policy, provide direction to state entities, provide guidance on data-sharing, monitor progress, and report on compliance activities (Health and Safety Code section 130203(a)).

The goals of CDII's Policy and Compliance Oversight Program are to: (1) Create a collaborative culture of compliance for state departments, (2) Keep Californians' health information safe, and (3) Provide technical assistance and leadership on California's HIPAA compliance. The legislative language identifies five broad categories of responsibilities that guided the Policy and Compliance Oversight team's tasks and priorities throughout 2024:

- 1. **Leadership**: Provide training and tools, represent the State on health datasharing and consult on Health Information Portability and Accountability Act (HIPAA) and other federal and state law interpretation.
- 2. **Coordination**: Coordinate and communicate with affected entities (e.g., California Department of Technology and State Chief Data Officer).
- 3. Policy Formulation: Develop policies and standards.
- 4. **Direction**: Provide recommendations to CalHHS on HIPAA and other laws, provide technical assistance, and support integrated health and social services by providing guidance on health information.
- 5. **Oversight**: Assess and monitor compliance activities.

#### Leadership Accomplishments:

Published 12 monthly communications to state departments. CDII
provides updates on the CDII Policy and Compliance Oversight team
activities as well as federal Health and Human Services (HHS) updates.

- Tracked, evaluated, and provided analysis (as needed) on more than 350 pending federal and state bills.
- Developed recommendations and plans for state department training and education related to HIPAA compliance and reviewed and started development of new training modules for stakeholders impacted by HIPAA rules.
- Led and provided the State's feedback on Notice of Proposed Rule Making(s) with the federal government which included gathering comments from state departments.

## Policy Formulation Accomplishments:

- Revised the Statewide Health Information Policy Manual (SHIPM) in June 2024. CDII maintains the SHIPM a mandatory policy manual that provides State departments with guidance on protecting patient privacy and helps state entities avoid fines and sanctions resulting from unauthorized disclosures of health information. The SHIPM is a living document updated annually with changes to all applicable state or federal laws. The June 2024 revision is the latest SHIPM publication.
- Revised the State Health Information Guidance (SHIG) in December 2024.
  The SHIG was a collaboration of the former California Office of Health
  Information Integrity (CalOHII), absorbed by CDII, with various organizations
  to develop specific materials to help clarify federal and state laws that
  affect the disclosure and sharing of health information. The SHIG is five
  volumes and is reviewed, revised, and republished annually.
  - The SHIG efforts include comprehensive research, drawing from a broad group of stakeholders that reflect cross-industry insights and experience, to provide a clear understanding of the problems different groups were facing in the field. The SHIG volumes include how sharing of information can affect older Americans who are impacted by the topics listed below.
  - The five volumes of the SHIG cover the following topics: 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, and sharing minors and foster youth information in California.

#### Direction

 Provided technical assistance to state entities and responded to their health information privacy and security questions.  Provided assistance to other states looking at California's SHIPM and SHIG products.

## Oversight Related Activities:

- Conducted compliance reviews focused on Patient Rights for five state organizations. Conducted compliance reviews focused on Breach and Incident Management for three state organizations.
  - These evaluations (or compliance reviews) are based on the SHIPM, which is described above. State entities, including all state departments, boards, commissions, programs, and other organizational units of the executive branch of state government that are required to comply with HIPAA, must comply with the California SHIPM policies.

#### In 2024, the oversight team also:

- Continued reviewing and revising the CDII Policy Compliance Oversight Program to create a more user-friendly experience for state organization stakeholders.
- Performed monthly monitoring of nine state covered entities and business associate organizations' Corrective Action Plans (CAPs).
- Evaluated state organizations yearly attestations regarding their compliance with SHIPM.
- Reviewed yearly breach reporting documents against known incidents or breaches.
- Reviewed and revised the self-paced Compliance Oversight Program training, to assist stakeholders in learning about what a compliance review entails, and how to prepare for a review.
- Created a self-help tool for stakeholders regarding complete and thorough Risk Analysis/Risk Assessment requirements of the HIPAA regulations and SHIPM.
- Created self-help tools for stakeholders to utilize when determining whether their compliance program is compliant with current federal and state laws.
- Triaged, and followed up as necessary, on 597 reported breach incidents of state entities subject to CDII oversight.
- Triaged and followed up as necessary, on 131 reported incidents and breaches of state entities that are Impacted by Data.

# Quality Reporting Programs

CDII Policy and Operations Branch includes health care quality reporting programs that were formerly a part of the Office of the Patient Advocate (OPA). CDII is statutorily required to produce annual publications about

health care quality and access issues, including a quality-of-care report card, an annual legislative report about the complaints by consumers about health care coverage, and report card information based on timely access data from the Department of Managed Health Care (DMHC). CDII supports the data analysis and production of three annual online **Healthcare Quality Report Cards** about health plans and medical groups. These Report Cards are designed for consumers to have easy-to-understand and reliable data to inform their health care decisions.

Prior to publication, CDII undertakes many steps, including:

- Updating the Report Cards annually to reflect current data availability, and analyzing the most current data which regularly changes based on the latest medical care standards and health care system collection targets.
- Conducting multiple levels of quality assurance reviews to ensure the reliability of the ratings, including a review by stakeholders.
- Creating data displays and educational content and translating the Report Cards into Spanish and Chinese.
- Consumer testing the Report Cards to ensure the primary audience understands and finds value in the information.

As of December 31, 2024, the Health Care Quality Report Cards contained more than 17,000 data points about the clinical quality, patient experience, and cost of health care in California. The Health Plan Report Card released in December 2024 provided quality and patient experience ratings for the 16 largest Health Maintenance Organizations and Patient Provider Organizations plans in California, with nearly 60 composite star ratings and individual measure scores on different health care topics.

The Medical Group – Commercial Report Card released in May 2024 provided quality, patient experience, and cost ratings for 197 medical groups that serve Californians in commercial health plans. This Report Card shows 30 individual measure scores and composite star ratings, which combine measures into topic ratings and overall ratings. The Medical Group - Medicare Report Card, also released in May 2024, provided quality ratings for 173 medical groups that serve Californians in Medicare Advantage plans, with composite star ratings and 13 individual measure scores.

CDII also produces an annual report about health care complaints from California consumers to the Department of Managed Health Care (DMHC), Department of Health Care Services (DHCS), California Department of Insurance, and Covered California. For this multi- departmental report, CDII collects and analyzes complaint records and other information from seven state

consumer assistance centers that typically handle around five to seven million consumer contacts each year for various health care issues. The four departments report data using standardized complaint data categories established by CDII.

#### **Future Public Reporting Efforts:**

CDII is continuing OPA's collaboration with DMHC to develop a new Health Care Quality Report Card to incorporate timely access data about health plans. The new Timely Access Report Card will rely on DMHC survey data and the performance benchmarks. In 2024, CDII conducted additional consumer testing to inform the development of associated Report Card displays and ensure the information will be meaningful to consumers. CDII anticipates that the DMHC's measurement year 2023 data, which is undergoing DMHC quality assurance and evaluation processes, will be available for public reporting in 2025.

# Committee for the Protection of Human Subjects

Under the federal Common Rule, the Committee for the Protection of Human Subjects (CPHS) is the Institutional Review Board (IRB) for all departments under the California Health and Human Services Agency (CalHHS) when they engage in research involving human subjects. The CPHS is guided by principles delineated in the Belmont Report, which was issued by the U.S. Department of Health, Education, and Welfare in April 1979. These principles include Beneficence, Respect for Persons, and Justice. The role of CPHS is to ensure that research involving human subjects is conducted ethically and with minimal risk. Additionally, under the Information Practices Act, CPHS is required to review and approve all research-related requests for personally identifiable information held by any state department. CPHS administrative staff support the operations of the committee.

In 2024, CPHS refined several administrative processes to enhance research oversight and compliance. CPHS also advanced discussions on handling HIPAA waiver requests, departmental Letters of Support, and streamlining of reviews involving vital statistics data. Comprehensive updates to policies and procedures were implemented, providing clarity on handling adverse events, unanticipated problems, and voting policies, thereby enhancing the efficiency and transparency of CPHS operations. Additionally, CPHS administrative staff refined the application forms and platform to provide additional guidance on what information researchers should provide, improving the researcher experience in submitting applications for CPHS review.

## 2024 CPHS Project Breakdown:

CPHS utilizes IRBManager, an electronic protocol submission and approval system for managing all research projects submitted for review and approval. Depending on the type of research being executed, CPHS review may be conducted at a convened public meeting. The full committee addresses CalHHS research projects that have any contact with human subjects and may also discuss data-only projects.

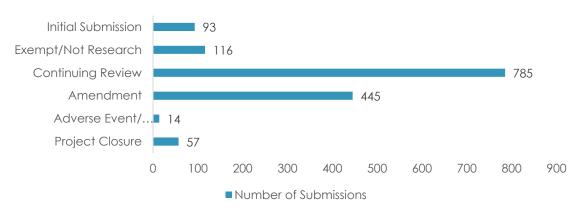
Over the course of 2024, CPHS worked on 1,510 projects in six project types. These project types are initial submissions, exempt, amendments, continuing review, adverse event/unanticipated problem, and study closure. Each project type is described in more detail below:

- Initial Submissions: Initial submissions are new research studies that are being reviewed by CPHS for the first time.
- Exempt/Not Research:
  - Exempt: An investigation involving human subjects may be considered research, but still may be exempt from CPHS review under the federal Common Rule. CPHS uses the exemption categories specified in part 46.104 of the federal Common Rule (45)

- C.F.R., Part 46). These studies are reviewed once by CPHS to determine if the study qualifies for the exemption.
- Not Research: Not all data collection or usage activities qualify as research requiring CPHS review. Investigators uncertain about their project's status can submit a "Not Research" application to CPHS for determination. CPHS adheres to the federal Common Rule's definition of research, which specifies that certain scholarly, public health surveillance, criminal justice, and authorized operational activities are not considered research.
- Amendments: Once a research study has been approved by CPHS, any
  proposed changes to a research protocol must be submitted through an
  amendment to be reviewed and approved by CPHS before being
  instituted.
- Continuing Review: Most research studies are approved for a one-year period, though projects that are deemed more than minimal risk by CPHS must be approved for shorter periods. For a project to continue past the approval period, a continuing review application must be submitted and approved by CPHS before the required renewal date.
- Adverse Events/Unanticipated Problems: An adverse event is an incident that has or could cause harm to research participants or to people whose data is being analyzed. An unanticipated problem is an unexpected departure from the approved research procedures, or a data breach where harm has not or is not expected to occur. Researchers are required to report any adverse events and/or unanticipated problems within 48 hours. The Committee will review the report and any corrective actions taken and may accept them or request additional corrective actions and measures to safeguard participants' welfare.
- Study Closure: Upon concluding a research study, investigators must submit a closure report to CPHS, confirming that participant enrollment, interventions, and follow-ups; data analysis; closure of all study sites; and related reports or publications are complete; and provide a detailed plan for data destruction to ensure confidentiality and compliance with data protection regulations.

Below is a breakdown of the all the projects by type that CPHS reviewed this year.

# Number of Submissions Reviewed by CPHS in 2024 by Review Type



## Data Expo

The Data Expo was started by the CalHHS Data Subcommittee in 2016. It began as a showcase of CalHHS data achievements and has become an increasingly large informational and networking event for data professionals across CalHHS departments and offices.

CDII coordinated and produced the annual California Health and Human Services Agency (CalHHS) Data Expo on October 3, 2024. The Data Expo is an internal event for all departments and offices within CalHHS. The event was hosted by Center for Data Insights and Innovation (CDII) Director, John Ohanian. The 2024 Data Expo was a live, four-hour hybrid event comprising of almost 100 in-person attendees and an online audience of over 1,000 attendees. The theme for 2024 was Cultivating a Culture of Innovation, a topic chosen to inspire and share latest advances in data that drive person-centered insights.

This year's keynote speaker was Richard Figueroa, Deputy Cabinet Secretary in the Office of Governor Gavin Newsom, who presented the CDII Innovator of the Year Award to former Undersecretary Marko Mijic. The 2024 Data Expo featured a diverse set of panelists including Deanne Wertin, Chief Deputy Director, Office of Technology and Solutions Integration; Agnieszka Rykaczewska, Deputy Director of Insights Lab, Center for Data Insights and Innovation; Jason Lally, California's State Chief Data Officer, Office of Data and Innovation; Michael Hodnett, Senior Attorney – Provider Networks, Department of Managed Health Care; Corrin Buchanan, Deputy Secretary for Policy and Strategic Planning, CalHHS; Aparna Ramesh, Chief of Research and Data Insights Branch within the Research and Automation Data Division, Department of Social Services; Glenn Tsang, Policy Advisory for Homelessness and Housing, Department of Health Care Services; Sarah Steenhausen, Deputy Director of the Division of Policy, Research and Equity, Department of Aging; Brendon McCarthy, Acting Undersecretary, CalHHS; Rupam Sarmah, Chief Technology Innovation and Integration Officer, Department of Developmental Services; Efraín Cornejo, Chief of Business Operations Branch, Department of Public Health; Joe Sullivan, Chief Information Officer, Emergency Medical Services Authority; Tara Zimonjic, Chief Planning Officer and Planning and Management Branch Chief within Office of Information Services, Department of Health Care Access and Information; and Michael Valle, Deputy Director and Chief Information Officer, Department of Health Care Access and Information.

Through the four thought-provoking panel discussions, panelists shared strategic plans for California's and CalHHS' future of data, examples of key data innovations to drive person-centered insights, and CalHHS Al highlights. These sessions were complemented by two live demonstrations of innovative data tools by the Department of Managed Health Care

(DMHC) and Department of Health Care Access and Innovation (HCAI). Additionally, CDII produced four spotlight videos to highlight key data initiatives from Department of Rehabilitation (DOR), Department of State Hospitals (DSH), Department of Managed Health Care (DMHC), and the CalHHS Data Subcommittee. For in-person attendees, the event concluded with a network session.

CDII took over the responsibility of organizing the Data Expo in 2021. Since then, the number of people who registered for the event has increased by 46% and attendance has grown by 54%. Of the 1,299 people who registered for the 2024 event, 1130 people from 15 CalHHS departments and offices attended the event. Results from an exit poll provided to attendees showed that 92% of respondents rated the 2024 Data Expo as good to excellent, with 48% rating it as excellent. Year after year, the Data Expo continues to see a promising increase in registration and attendance numbers, and CDII aims to keep that trend going.

CDII established a Data Expo webpage on its website which contains the event's agenda, panelists' PowerPoint slides, resources, and archived Data Expo videos. To learn more about the 2024 Data Expo, visit CDII's **Data Expo webpage**. Plans for the 2025 Data Expo are already well underway, with a proposal to expand participation and engagement by featuring in-person networking events.

## Conclusion

CDII was formed by CalHHS to both strategize and organize data-sharing policies, and to find stories within the data to close knowledge gaps and expedite decision-making. Data is a fundamental asset for all government organizations and private-sector businesses. The priority is for data to be fully utilized without compromising privacy and security. Data infrastructure and security are critical to the delivery of every single service provided by CalHHS to all Californians.

Improving and streamlining data collection, stewardship, and sharing practices will foster person-centered decision-making, rather than program-centered ones. CDII's targeted data-sharing efforts will help improve health and social services outcomes through developing systems with usable analytics that are part of a larger integrated system to identify underserved populations, detect service gaps, and better target programs and services. CDII seeks to be an example, not only within CalHHS but within the State, on how government can change paradigms towards progress.

Throughout 2024, CDII continued to grow and develop its programs, achieving short-term goals and laying the foundations to pursue long-term objectives aimed at improving whole-person care in California. Into 2025 and beyond, CDII will continue to evolve internal operations to incorporate equity, diversity, and whole-person views into each project, striving to improve outcomes and programs for all Californians.

## **END OF REPORT**