



CALIFORNIA HEALTH & HUMAN SERVICES AGENCY
Center for Data Insights and Innovation
LEGISLATIVE REPORT 2024



03.29.2024

Submitted by:

CDII Director John Ohanian

This report can be found at: <https://www.cdii.ca.gov/about/about-cdii/>
A physical copy of this report can be acquired by calling: (916) 654-3454

Table of Contents

Table of Contents.....	2
Executive Summary	3
Mission and Vision Statements	3
Guiding Principles	3
Major Endeavors in 2023	4
Data Exchange Framework	5
Data and Engineering Branch.....	9
Agency Data Hub	9
Open Data Portal.....	10
Insights Lab	11
Policy and Operations Branch.....	15
Policy and Compliance Oversight Program	15
Quality Reporting Programs	17
Committee for the Protection of Human Subjects	19
Data Expo	21
Conclusion.....	23

Executive Summary

In 2020, the California Health and Human Services Agency (CalHHS) established the Center for Data Insights and Innovation (CDII) 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 the creation of CDII in 2021, 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 2023, developing the DxF remained a top priority. 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, we have adopted four Guiding 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 of our 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 Endeavors in 2023

At the Center for Data Insights and Innovation (CDII), we are 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 ongoing major endeavors for 2023 are as follows:

- **Data Exchange Framework** – The Data Exchange Framework (DxF) is not a new technology or centralized data repository; instead, it's an agreement that will accelerate and expand the secure exchange of health information among health care entities, government agencies, and social service programs. Many healthcare entities were required by law to sign the DxF Data Sharing Agreement by January 31, 2024.
- **Agency Data Hub and Open Data Portal** - The Agency Data Hub (Data Hub) service platform was developed to build on the 2020 Research Data Hub initiative. The Data Hub is a secure, cloud-based, data-sharing ecosystem for curating, hosting, and sharing integrated CalHHS data collected by CalHHS departments and offices. The Open Data Portal (ODP) platform was launched by CalHHS to increase public access to one of the State's most valuable assets – non-confidential health and human services data.
- **Insights Lab** - The Insights Lab builds partnerships with internal and external stakeholders to drive purposeful data initiatives and helps transform CalHHS information into actionable insights. The Insights Lab provides statewide leadership in data standards, sharing, analysis, and literacy (in alignment with CalHHS priorities) and is responsible for the All-Hazards Dashboard, the CalHHS Equity Dashboard, the Research Request Form, and other data research endeavors.
- **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 also maintains and publishes 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 them 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** - CDII staff support the operations of the Committee for the Protection of Human Subjects (CPHS). CPHS' role is to ensure that research involving human subjects is conducted ethically and with minimal risk. Under the federal Common Rule, Food and Drug Administration regulations, privacy rule of HIPAA, and the California Information Practices Act (IPA), CPHS serves as the Institutional Review Board (IRB) for all departments and offices under CalHHS. Under HIPAA and the IPA, CPHS is required to review and approve all research-related requests for California state data that can be linked to an individual that is held by any state department. Also, CPHS is guided by the principles delineated in the Belmont Report.
- **Data Expo** - The Data Expo is an annual 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.

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 and common set of policies and

procedures that will govern and require the exchange of health and human services information among health care entities & government agencies in California. To meet this mandate, CDII and CalHHS convened a stakeholder Advisory Group (AG) and a Data Sharing Agreement (DSA) Subcommittee. CalHHS and CDII provided leadership to, and oversight of, the AG and DSA Subcommittee, which met (approximately) monthly between September 2021 and June 2022. The subcommittee provided input and recommendations on the development of key issues; those recommendations were then presented to the DxF Stakeholder Advisory Group, and their recommendations were advanced to CDII and CalHHS leadership for consideration.

Establishment of the DxF

In July 2022, the DSA, initial Policies and Procedures (P&Ps), and Strategy for Digital Identities were published on the CalHHS DxF web page. After the publication of the DSA and P&Ps, CDII and CalHHS established a DxF Implementation Advisory Committee (IAC) - the successor to 2022's Advisory Group - and the DSA Policies and Procedures (P&P) Subcommittee and convened them approximately every six weeks in 2023 to refine existing and develop additional P&Ps, advise on implementing the Signatory Grant Program, advise on creating the Qualified Health Information Organization (Qualified HIO or QHIO) Program, and supported a public comment process in advance of the January 31, 2024 DxF implementation date. In total, CalHHS and CDII have published 16 policies and procedures:

1. [Process for Amending the DSA](#)
2. [Development of and Modifications to Policies and Procedures](#)
3. [Breach Notification](#)
4. [California Information Blocking Prohibitions](#)
5. [Data Elements to be Exchanged](#)
6. [Early Exchange](#)
7. [Fees](#)
8. [Individual Access Services](#)
9. [Individual Access Services Alternative to Electronic Access](#)
10. [Participant Directory](#)
11. [Permitted, Required, and Prohibited Purposes](#)
12. [Privacy Standards and Security Safeguards](#)
13. [Qualified Health Information Organization](#)
14. [Real-Time Exchange](#)
15. [Requirement to Exchange Health and Social Services Information](#)
16. [Technical Requirements for Exchange](#)

A Glossary of Defined Terms has also been developed and published in 2023. It consolidates in one place defined terms found across the DSA and its P&Ps.

Data Exchange Framework “Information is Power Webinar Series”

In September 2022, CDII launched the “DxF Information is Power Webinar Series.” Throughout 2023, DxF leaders and advisors leveraged these public webinar

sessions to educate stakeholders and members of the public on the purpose, benefit, and scope of the DxF, sharing details on key findings from previous stakeholder engagement meetings, such as IAC meetings and Grant Listening Sessions. Additionally, the webinar series provided a venue for updates to stakeholders and members of the public on the DxF Educational Grant Initiatives, the DSA Signatory Grants Program, and the January 31, 2024, implementation date to begin data exchange.

Data Exchange Framework Grant Program

To support the implementation of the DSA, the Governor and State Legislature allocated \$50 million for the [Data Exchange Framework \(DxF\) Grant Program](#), in the 2022/23 SFY budget. This funding supports health and social services organizations with much needed technical assistance to provide a smooth implementation of the DxF. The first part of the Grant Program, launched in October 2022, where CDII held an application window for 2023 DxF Educational Initiative Grants Program. The education portion of the DxF Grant Program recruited trusted health care and stakeholder associations as CDII partners to help health and human services providers and other DxF organizations understand and implement DxF requirements by providing direct outreach and tailored DxF resources to the Educational Initiative Grantees' constituents. This outreach included technical assistance, policy support, and education on the requirement of organizations to sign the DxF Data Sharing Agreement (DSA).

Also in October 2022, CDII organized, coordinated, and hosted two DxF Grant Program Listening Sessions. In these stakeholder engagement sessions, CDII invited stakeholders and the public to join one of two public listening sessions to provide input on the design of the DxF DSA Signatory Grants Program. The input and feedback received during the listening sessions helped to shape the design of the program to accurately address the technical assistance and operational needs of DxF Signatories.

In May 2023, CDII hosted a DSA Signatory Grants Town Hall to kick-off the start of the DSA Signatory Grant Program Round 1, followed by numerous office hours to answer applicant questions on how to apply for a grant. DSA Signatory Grants Informational Webinars were conducted for Rounds 2 and 3 in addition to office hours throughout the Summer of 2023. In November 2023, CDII hosted Grantee Kick-Offs to provide grantees information on Milestones, Progress Reports, and navigating the DxF Grants Portal to ensure that grantees were informed and could receive grant funding if a Milestone was achieved.

Throughout three rounds of the DSA Signatory Grants Program, more than 500 applications were submitted representing over 800 DxF Signatories. Nearly all applicants were awarded grant funding after thorough review of applications

and eligibility. The entirety of the Governor's \$50 million dollar investment in this initiative is in the process of being allocated during the first quarter of 2024.

The following provides details on the three types of DxF Grants offered through the DxF Grant program to support implementation of the DSA:

- **DxF Educational Initiative Grants** for associations to improve awareness and increase the number of DxF signatories and Participants through direct outreach and education.
- **Qualified Health Information Organization (QHIO) Onboarding Grants** to provide assistance to DSA Signatories who choose to connect to a Qualified Health Information (Exchange) Organization (Qualified HIO or QHIO) to help meet their DSA requirements. A QHIO is an organization qualified by CDII that provides technical capabilities to support the exchange of health and social services information between DxF Participants. They serve as intermediaries, assisting health and human services organizations who have chosen to become customers of the QHIO. QHIOs help initiate, receive, and respond to requests for information. QHIOs also send information on behalf of their contracted participants. A QHIO is an HIO that has demonstrated its ability to meet DxF data exchange requirements and other requirements set forth by CDII through an application attestation process.
- **Technical Assistance (TA) Grants** provide funding for organizations that sought technical assistance support to meet DSA requirements via their own selected pathway toward DxF implementation readiness and exchange capabilities. Workflow optimization, adoption of an Electronic Health Record (EHR), or funding to supplement the cost to onboard to an intermediary such as a QHIO or a national network or framework are some examples of how TA funding might be spent by the Grantee.

Establishing the Qualified Health Information Organization Program

QHIOs help organizations meet DxF requirements by providing an efficient means of obtaining the data exchange capabilities that many health and human services entities may not have. Health and Safety Code section 130290 allows DxF Participants to exchange data through any health information exchange network, health information organization, or technology that adheres to the DSA and its P&Ps. Of those options, QHIOs offer Participants the option of leveraging an intermediary which has demonstrated a commitment to the DxF by signing the DSA and applying to and being qualified by CDII.

As part of the DxF implementation, 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 where information exchange intermediaries confirmed their 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. California's newly designated QHIOs will play 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. This milestone in interoperability will help ensure every Californian, regardless of where they seek care, can be assured their health and social services providers have access to a more complete picture of their health and are able to work together to provide the best possible care.

2023 DxF Implementation Readiness

Over two and a half years, the collective efforts of CalHHS, CDII, industry stakeholders, advisors, providers, payers, advocacy organizations, and other individuals helped make the successful launch of the DxF possible. By the time the DxF launched on January 31, 2024, more than 2,100 Organizations had signed the Data Exchange Framework Data Sharing Agreement, representing more than 3,000 facilities ([link to the full list of signatories](#)). The DxF and DSA are leading the transformation to safer, more effective, whole-person care for all Californians. CDII is proud to be an integral part of these efforts.

Data and Engineering Branch

The Data and Engineering Branch 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.

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, 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 by CDII's dashboard teams by providing many benefits including, but not limited to, the following:

- 1. Supporting Agency analytics efforts** - This includes emergency management (All-Hazards Dashboard), supporting equity goals (CalHHS Equity Dashboard), and ongoing support for Insights Lab data products.
- 2. A Secure Research Enclave** - Secure space to study Agency data without removing it from the Data Hub. This enhances security and control of Agency data, reduces barriers to smaller research institutions, and provides departments with a secure and isolated location to collaborate on joint data analytics and reporting efforts.
- 3. Secure Analytics** - The Data Hub provides high quality data visualization tools for the secure analysis of detail-level data.
- 4. Continue to host and support the California Department of Social Services (CDSS) Early Childhood Integrated Data System (ECIDS) pilot** - By hosting the needed cloud-based project workspace and providing ongoing data strategy and architecture support for the proposed program, this pilot will better inform future data sharing with the Cradle to Career Data System being launched at Government Operations Agency.

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' de-identified, 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 section 130205(b), and pursuant to AB 133 (Statutes of 2022).

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 2023, Insights Lab's focus was on building out data-sharing frameworks, streamlining data pipelines, and enhancing integrated data products and dashboards. Additionally, Insights Lab began collaboration with other California State agencies on data sharing efforts, further breaking down siloes to generate holistic insights on populations served by CalHHS.

Homelessness Data Integration Product

Since its inception in 2020, CDII has taken several steps in advancing CalHHS' mission to better understand the diverse population it serves. CDII aims to leverage data to understand current conditions in our communities, the impact of existing programs, and determine opportunities to improve service delivery. In 2023, CDII began collaboration with the California Interagency Council on Homelessness (Cal ICH), aimed at providing a comprehensive understanding of how CalHHS serves and impacts California's homeless populations.

Commissioned by the CalHHS Deputy Secretary for Policy and Strategic Planning, the initiative seeks to integrate data from Cal ICH's Statewide Homelessness Data Integration System (HDIS) with data on services provided by CalHHS departments and programs, starting with the California Department of Social Services (CDSS) and the Department of Health Care Services (DHCS).

This project marks a significant milestone as it will bring together CalHHS data with Cal ICH data for the first time, unlocking a wealth of insights to shape policy that advances the Governor's priority of preventing and ending homelessness. This will allow insight into the service utilization data of CalHHS programs and data captured in HDIS starting with CDSS and DHCS programs, identify trends in

a person's journey from homelessness to housing, and identify disparities by subpopulation.

The initial focus is to link data from the HDIS with data from Medi-Cal, CalSAWS, CalWORKs, and CDSS' Housing and Homeless Division programs. By leveraging the Data Hub, CDII will create the CalHHS Integrated Homelessness Dataset which will provide a complete list of all individuals who are identified as homeless or housing insecure in any of the datasets. It will also indicate services these individuals have received from particular CalHHS programs.

In addition, Cal ICH data 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.

Launched in 2023, the first phase of the project establishes the framework for data sharing, integration, and analysis. This required close collaboration and coordination to understand each data systems' legal and technical constraints and to ensure appropriate security and privacy safeguards.

As the project progresses, other CalHHS departments will have the opportunity to join and add to the CalHHS dataset, creating a collaborative data ecosystem. With this project, CDII aims to uncover patterns, correlations, and opportunities for a broader understanding of the outcomes of CalHHS services and to drive effective, data-driven policy solutions to end homelessness.

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. The CalHHS Equity Dashboard, a cross-agency tool, is poised to assist CalHHS and departmental leadership in measuring progress on CalHHS' equity initiatives.

As part of the work of the Equity Dashboard, CDII collaborates with CalHHS departments, offering valuable insights into current demographic data collection within programs and services. In 2023, CDII created data pipelines, streamlining the incorporation of program and demographic data into the Equity Dashboard. Released to CalHHS staff in June 2023, the current iteration of 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).

Additionally, CDII continues its work on data standardization for race, ethnicity, sexual orientation, and gender identity data elements. In February 2023, CDII first convened the Data Standards Community, which aims to provide CalHHS departments and offices with guidelines for demographic data best practices. As part of the Data Standards Community, departments shared current race, ethnicity, sexual orientation, and gender identity demographic data standards, with presentations from CalHHS departments including DMHC, DOR, CDSS, CDPH, HCAI, DHCS, and DSH. Additionally, CDII compiled departmental, federal, state, and industry demographic data collection standards and practices to create a data catalog focusing on race and ethnicity, sexual orientation, and gender identity.

In 2023, CDII was also tasked with creating data visualizations for the CalHHS Strategic Priorities and Impact Goals. Guiding Principles and Strategic Priorities were originally established in 2022 to shape CalHHS values and mobilize CalHHS into action. Departments and offices identified measurable impact goals designed to advance each strategic priority. These impact goals, driven by data, aim to measure collective progress in delivering tangible results for those served. Each impact goal includes one or more associated equity measure, developed by departments and offices in collaboration with the CalHHS-wide Justice Equity Diversity and Inclusion (JEDI) subcommittee.

As the Equity Dashboard continues to evolve, CDII is dedicated to providing data solutions that enhance CalHHS' efforts to promote equitable health outcomes for all Californians.

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 2023, the AHD continued to add new data streams as well as a brand-new user-centric design. The initial data sources for the AHD were primarily CalHHS departments responsible for licensed facilities which serve vulnerable populations. Data is also received from authoritative sources for emergency events and federal government agencies, like the U.S. Census Bureau. The AHD leverages the power of the Data Hub to build automated data pipelines directly from these sources to eliminate the need for slower, manual processes. This reduces administrative and technical burden while providing near-real time information to provide situational awareness of natural or man-made hazards.

For example, the AHD eliminates over five manual processes for data collection and reporting by allowing employees to enter shelter information in a web application and use reporting tools through the California Shelter Status and Inventory (CaSSI) Application in the AHD. CaSSI allows staff to easily update emergency mass care and sheltering information across the state centrally, quickly, and easily. This information is stored in the Data Hub for integration and use by others, and for maintenance of historical data. The shelter-related tools have completely automated and digitized a previously manual effort, allowing staff to query the information using fit-for-purpose tools.

The Data Hub organizes, filters, and pushes the data to the AHD to provide an accurate situational awareness picture, helping to ensure critical services and resources are available after a disaster. Uniquely, the AHD provides a person-centered lens to disaster response by providing information about affected vulnerable populations by age or program. These programs include the Supplemental Nutrition Assistance Program (SNAP), Women, Infants, and Children (WIC), In-Home Supportive Services (IHSS), and more.

In October 2023, the All-Hazards Dashboard received the prestigious National Association of State Chief Information Officers (NASCIO) 2023 State IT Recognition Award in the category of "Data Management, Analytics & Visualization." In addition, the AHD project and team has been nominated for the Special Achievement in Geographic Information Systems (GIS) (SAG) Award 2024. This award highlights GIS users that have shown vision, leadership, hard work, dedication, and innovation in their use of Esri's Geographic Information System technology.

The AHD has inspired GIS users across the nation. The AHD team demonstrated the dashboard capabilities to other states' Health and Human Services (HHS) workers. The demos assisted leaders with usability ideas and examples to secure funding so respective states can create their own tools. CDII is also providing guidance and assistance to the Montana Department of Public Health & Human Services with the creation of their high-profile dashboard project in partnership with the Montana Partnership to End Childhood Hunger and No Kid Hungry. This effort will develop a nutrition security dashboard for the state of Montana.

The AHD continues to contribute to the public's trust in the State's ability to manage emergencies effectively. This confidence is crucial to encourage public cooperation and adherence to emergency directives when emergencies arise. Hazardous events across the United States and California no longer have a "season" or a specific time during which they can be reliably anticipated. The AHD is the first of its kind across the nation. As the AHD continues to grow, CalHHS will be better equipped to assist our communities and departments before, during, and after emergencies.

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 legislative language identifies five broad categories of responsibilities that guided the Policy and Compliance Oversight team's tasks and priorities throughout 2023:

1. **Leadership:** Provide training and tools, represent the State on health data-sharing and consult on Health Information Portability and Accountability Act (HIPAA) 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, 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 400 pending federal and state bills.
- Developed recommendations and plans for state department training and education related to HIPAA compliance and review 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 2023. CDII maintains the SHIPM to provide State departments with a resource that provides 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 2023 revision](#) is the latest SHIPM publication.
- Revised the State Health Information Guidance (SHIG) in April 2023. 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 5 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.
- Met with Oregon state privacy officials to provide information and lessons learned related to California's oversight and compliance program.

Oversight Related Activities:

- Conducted compliance reviews focused on Patient Rights for six state organizations.
- The goals of CDII's Policy and Compliance Oversight Program are to:
 - Create a collaborative culture of compliance for state departments.
 - Keep Californians' health information safe.
 - Provide technical assistance and leadership on California's HIPAA compliance.

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 2023, the oversight team also:

- Revised the CDII Policy Compliance Oversight Program to create a more user-friendly experience for state organization stakeholders.
- Performed monthly monitoring of 11 state covered entities and business associate organizations' Corrective Action Plans (CAPs).
- Created a 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 self-help tools for stakeholders to utilize when determining whether their compliance program is compliant with current federal and state laws.
- Followed up on reported breach incidents of state entities subject to CDII oversight.

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 DMHC. CDII supports the data analysis and production of three annual online [Health Care Quality Report Cards](#) about health plans and medical groups. These Report Cards are designed for consumers to ensure they 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 to reflect current data availability,

which regularly changes based on the latest medical standards and health care system collection targets.

- Conducting multiple levels of quality assurance reviews to ensure the reliability of the ratings.
- 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, 2023, 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 2023 provided quality and patient experience ratings for the 16 largest Health Maintenance Organization and Patient Provider Organizations plans in California, with over 60 composite star ratings and individual measure scores on different health care topics. The Medical Group – Commercial Report Card released in Spring 2023 provided quality, patient experience, and cost ratings for nearly 200 medical groups that serve Californians in commercial health plans. This Report Card shows over 30 individual measure scores and composite star ratings, which combine measures into topic ratings and overall ratings. The Medical Group - Medicare Report Card, released in May 2023, provided quality ratings for 167 medical groups that serve Californians in Medicare Advantage plans, with 25 composite star ratings and 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 5 to 7 million consumer contacts each year for various health care issues. An eighth consumer assistance center is expected to be included in the next publication, with the addition of data reported by DHCS about its new Medi-Cal Rx service center. The four departments report data using standardized complaint data categories established by CDII.

The [Annual Health Care Complaint Data Report](#) to the Legislature, released in August 2023, addressed nearly 35,000 health care complaints closed by state consumer assistance programs in 2021. The state consumer assistance programs from the four departments reported 5,763,069 total consumer inquiries and complaints about health care issues in 2021. In 2023, CDII collected and analyzed more than 34,000 records of complaints closed in 2022, as well as other information about the state consumer assistance program activities, which will be addressed in the next report publication.

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 2023, CDII conducted consumer testing to inform the development of associated Report Card displays and ensure the information will be meaningful to consumers.

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). As such, the IRB is required to review human subjects research involving funding, staff, or subjects under the custodial control (such as state hospital patients) of CalHHS departments. Under the Information Practices Act, CPHS is also required to review and approve all research-related requests for data that can be linked to an individual that is held by any state department. 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. CPHS staff support the operations of the committee.

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 projects that have any contact with human subjects and may also discuss data-only projects.

CPHS accomplishments in 2023 include updating the CPHS Policies and Procedures handbook to clarify when studies fall under the Common Rule or IPA regulations, including an updated "CPHS Review Pathway Decision Tree". These revisions provide additional clarity to researchers into the review process. 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. Finally, CPHS recruited three new committee members.

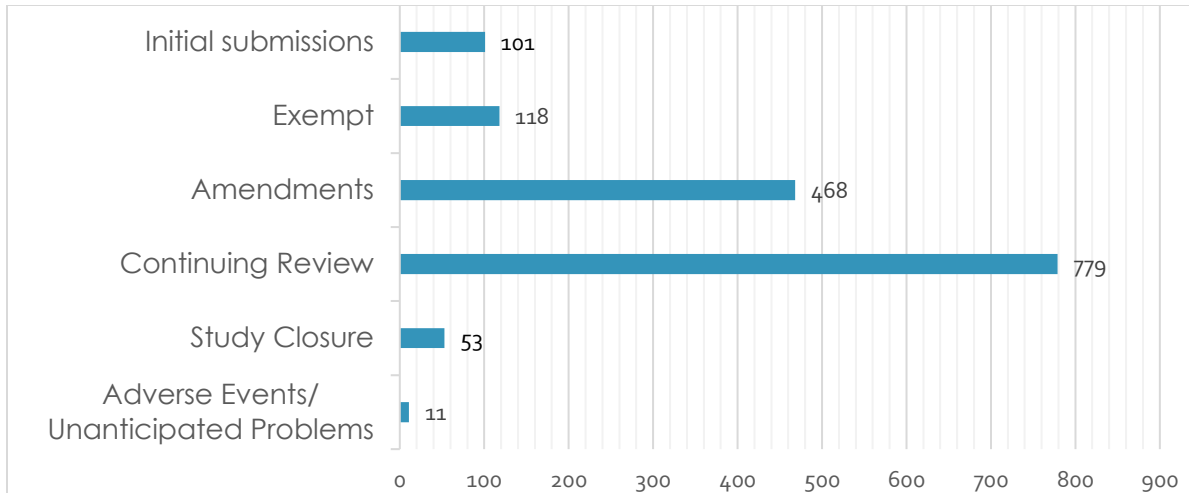
2023 CPHS Project Breakdown:

Over the course of 2023, CPHS worked on 1,530 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:** 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.
- **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 may accept the report and corrective action or request additional corrective action.
- **Study Closure:** Once a study is ended, a final report must be submitted to CPHS.

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



Data Expo

CDII coordinated and produced the annual California Health and Human Services Agency (CalHHS) Data Expo on August 8, 2023. 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, and Office of Technology and Solutions Integration (OTSI) Director, Adam Dondro. The 2023 Data Expo was a live, three-hour hybrid event comprising of a live stream to an on-line audience of over 900 attendees and watch room parties in State buildings. The theme for 2023 was Storytelling Through Data, a topic chosen to highlight one of CalHHS' strategic priorities of providing whole-person care. Storytelling through data is the art of presenting data with a contextual narrative and effective visuals.

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.

This year's keynote speaker was CalHHS Secretary, Dr. Mark Ghaly, who reminded event attendees of CalHHS guiding principles of being person-centered, equity-focused, and data-driven.

The 2023 Data Expo featured a diverse set of panelists including Ross Lallian, Chief of Research, Department of Aging; Melissa Stafford Jones, Director of the Children and Youth Behavioral Health Initiative, CalHHS; Michael Valle, Deputy Director and Chief Information Officer, Department of Health Care Access and Information; Dr. Linette Scott, MD, MPH, Deputy Director and Chief Data Officer, Department of Health Care Services; Ryan Gillette, Deputy Director and Chief Data Officer, Department of Social Services; Marcela Ruiz, Director of Office of Equity, Department of Social Services;

Aparna Ramesh, Chief of Research and Data Insights, Department of Social Services; Dan Torres, Chief Equity Officer, CalHHS; Christine Blake, IT Manager, Center for Data Insights and Innovation; Mary Ann Bates, Executive Director, California Cradle-to-Career Data System; and Dr. Rohan Radhakrishna, Deputy Director of the Office of Health Equity, California Department of Public Health. Through the four thought-provoking panel discussions, panelists shared their departments' collaborative and innovative efforts in telling California's story through data, data-sharing, and turning data into policy and equity efforts.

To ensure that all CalHHS departments and offices were represented in the event, a new segment, "Department Spotlight – All The Work That We Do" was created. CDII produced five videos to highlight the good work of departments and offices not represented on the panels. The participating departments included the Department of State Hospitals (DSH), Department of Managed Health Care (DMHC), Department of Developmental Services (DDS), the Office of Youth and Restoration, and the Office of the Surgeon General. Representatives from these departments and offices joined the event and engaged with attendees in the event's chat room.

The Data Expo fosters a data community by creating a virtual atmosphere to involve our attendees in two-way discussions instead of merely sharing information one way. Attendees were treated to engaging discussions with panelists and the opportunity to participate in Q&A sessions, polls, and ice-breaker questions.

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 34%. Also, attendance of the Data Expo has grown by 27%. Of the 1,200 people who registered for the 2023 event, 932 people from 17 CalHHS departments and offices attended the live streamed event. Those who did not attend had the opportunity to watch the event through on-demand videos located on CDII's YouTube channel. Results from an exit poll provided to attendees showed that 91% of respondents rated the 2023 Data Expo as good to excellent, with 44% 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 2023 Data Expo, visit CDII's Data Expo webpage at <https://www.cdii.ca.gov/data-expo>.

Plans for the 2024 Data Expo are already well underway, with a proposal to expand participation and engagement by featuring in-person networking events.

Conclusion

CDI 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.

2023 was another monumental year for CDII, full of growth and workstream innovation. Into the future, and throughout 2024, 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