Connecting for Better Health Meeting

January 9, 2025
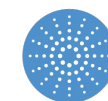
About The Coalition & Policy Priorities

Our Vision: Every Californian and their care teams have the information and insights they need to make care seamless, high quality and affordable

Establish DxF Governance and Accountability

Engage in DxF policy development and provide critical feedback to state legislative and regulatory leadership to realize the full promise of AB 133.

Identify Dedicated and Sustained Funding Streams

Support continued and coordinated funding for health and social services data sharing and encourage state agencies to actively seek federal match and/or other funding sources when and where appropriate.

Strengthen Social Services Data Sharing

Improve cross-sector data sharing through the development of priority use cases and policy advancements that support consent management, standards alignment, and capacity building for social services data sharing.
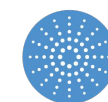
Advance High-Quality and Actionable Data Sharing

Support focused efforts that enhance the completeness, accuracy, and timeliness of data sharing to transform data usability and drive better outcomes.
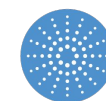
Agenda

No.	Item	Minutes
1	Welcome and Introductions	5 minutes
2	Introduction: Digital Medicine Society (DiMe) DATAcc Project	5 minutes
3	Federal Data Exchange Updates	20 minutes
4	California Data Exchange Updates	15 minutes
5	Introduce 2025 California State Legislation Tracking	5 minutes
6	C4BH Annual Dinner and 2025 Day at the Capitol & 2025 DxF Summit	5 minutes
7	News, Events and Announcements	5 minutes

Connecting for Better Health
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Digital Medicine Society (DiMe) DATAcc Project Introduction

Sarah Valentine

Partnerships Lead

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Federal Data Exchange Updates

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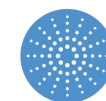
ASTP Update: HTI-2 and HTI-3 Final Rules

To implement select provisions from the HTI-2 proposed rule, ASTP released two final rules: *Health Data, Technology, and Interoperability: Trusted Exchange Framework and Common Agreement* **(HTI-2)** and *Health Data, Technology, and Interoperability: Protecting Care Access* **(HTI-3)**.

HTI-2 Highlights

- The TEFCA Manner Exception for information blocking
- Strengthens TEFCA reliability, privacy, security and trust

HTI-3 Highlights

- The new Protecting Care Access Exception in information blocking for reproductive health care privacy
- Revises Privacy Exception and Infeasibility Exception for information blocking

2024 End-of-Year Federal Health IT Policy Updates

Jen DeAngelis, Director, Federal Policy and Advocacy

January 9, 2025

Reps. DeGette and Bucshon Release Cures 2.1 White Paper

BACKGROUND: In June, Reps. DeGette (D-CO) and Bucshon (R-IN) issued a Request for Information on next steps for the 21st Century Cures Initiative. After reviewing 300 stakeholder responses, on December 24, they released a white paper detailing a menu of policy ideas and next steps for a Cures 2.1 legislative package

- **WHAT:** The white paper covers a wide array of topics including: improving clinical trials, improving the use of health information technology, expanding the use of real-world evidence, and improving Medicare coverage policies for novel technologies, among other topics.

- In the section titled, "Information Sharing and Evidence Gathering", the following concepts were included:

  - **Medial Record Maintenance and Exchange:** (1) address the challenge of patient matching; (2) update national health IT policies around patient safety; (3) encourage data sharing by setting clear expectations for data exchange participants while maintaining a secure environment; (4) expand how EHRs incorporate novel types of patient information (e.g. data from remote patient monitoring equipment); and (5) improve public input and ASTP/ONC oversight of TEFCA.

  - **Secondary Clinical Data Use:** (1) connect EHRs and research tools to allow for greater use of clinical data –i.e., real-world data – in evidence generation; (2) establish a nationwide network or repository of clinical data to make real-world evidence studies simpler to conduct and support development of a synthetic registry for nearly any intervention (they envision many potential uses for this "nationwide health data utility").

Cures 2.1 White Paper, Cont'd

- Additional concepts in the "Information Sharing and Evidence Gathering" section:
  - **Adoption of Certified EHR Technology:** Updating the criteria or requiring the issuance of guidance for rural development grants and loan programs to explicitly permit such funds to be used to purchase CEHRT.

- **OUTLOOK:** Uncertain, particularly in the near term. Rep. Bucshon's retirement and Republicans' prioritization of reconciliation and other policy priorities will slow down this effort, particularly in 2025. It awaits to be seen if another Republican wants to step into this project. In addition, there is no complementary Cures 2.1 exercise under way in the Senate.
  - More likely that this effort gains momentum in 2027, after the midterm election.
  - They are accepting input on an ongoing basis at cures.rfi@mail.house.gov.

House Bipartisan Task Force on Artificial Intelligence Releases Report

BACKGROUND: The House AI Task Force launched in February 2024 led by Reps. Jay Obernolte (CA-23) and Ted Lieu (CA-36) to "explore how Congress can help America be a leader in AI innovation and to study guardrails to protect against potential threats" from AI technology. The Task Force's final report was released on December 17, following the release of a "roadmap" for AI policy from the Bipartisan Senate AI Working Group this past May.

- **WHAT:** The Task Force report details guiding principles, key findings, and 89 recommendations across 15 sectors – including health – while assessing national security risks and applications.

- **GUIDING PRINCIPLES:** identify AI issue novelty, promote AI innovation, protect against AI risks, empower government with AI, use a sector-specific regulatory framework, take an incremental approach, and keep humans at the center of AI policy.

- **HEALTH CARE RECOMMENDATIONS:**
  - Encourage practices needed to ensure AI in health care is safe, transparent, and effective.
    - Develop high-quality data access mechanisms that ensure the protection of patient data, such as creating data commons, using incentives to encourage sharing of high-quality data.
    - Congress should monitor use of predictive technologies to approve or deny care and coverage.

House AI Task Force, Cont'd

- **ADDITIONAL HEALTH CARE RECOMMENDATIONS:**
  - Maintain support for health care-related AI research, particularly through the National Institutes of Health.
  - Create incentives and guidance for risk management of AI technologies
    - Develop standardized testing and voluntary guidelines for evaluating AI technologies and promotes interoperability and data quality.
    - Depts. Of Commerce and HHS could collaborate with stakeholders to develop best practices (such as standards for data and algorithms) to facilitate the development and use of AI technologies.
    - Critical area for improved guidance or regulation is industry post-market surveillance and self-validation to ensure AI technologies are continually and sufficiently monitored for safety and reliability.
  - Develop standards for liability related to AI issues.
    - Limited guidance on legal and ethical frameworks for determining who bears responsibility when AI models produce incorrect diagnoses or may harmful diagnostic recommendations.
    - Congress should review and update liability laws to ensure patients are protected.
  - Update payment mechanisms to reimburse the use of AI in health care.
    - Congress should look at new Medicare reimbursement policies that recognize the value of AI-related medical technologies.
- **OUTLOOK**: The incoming Trump Administration's approach to AI policy is not clear but expect an industry-friendly approach and limited interest in establishing new regulations; likely will move away from President Biden's October 2023 Executive Order on AI. Congress is not likely to move significant AI-related legislation except for (potentially) the national security and research spaces.

HHS Office of Civil Rights Releases Proposed Updates to HIPAA Security Rule

If finalized, this Proposed Rule would be the first update to the HIPAA Security Rule since 2013. The goals of the rule are to improve cybersecurity protections in health care and ensure "regulated entities" (i.e., health plans, health care clearing houses, most health providers, and their business associates) are better equipped to secure electron Protected Health Information (ePHI).

JUSTIFICATION:

- Inconsistent adherence to and slow adoption of the HIPAA Security Rule's standards and implementation specifications, particularly concerning risk analysis and management;

- Reliance on outdated systems and insufficient investments in security infrastructure; and

- Misinterpretations of and confusion surrounding the HIPAA Security Rule's flexibilities.

IN GENERAL:

- The Proposed Rule is not a "light touch" and would impose significant new costs on regulated entities. It would strengthen and clarify almost every standard of the existing HIPPA Security Rule (and establish new standards); establish more prescriptive timeframes for regulated entities to take action; and enhance contractual and documentation requirements

HIPAA Security Proposed Rule, Cont'd

SELECT PROPOSALS:

- Technology Asset Inventory & Network Map: Would require regulated entities to develop and annually review a technology asset inventory and network map to track movement of ePHI within and outside their systems, including connections with business associates and offshore entities. The inventory would document all technology assets, including hardware, software, and systems that handle or impact ePHI.

- Risk analysis: Would strength existing risk analysis requirements by requiring regulated entities to conduct them at least annually and by proposing eight implementation specifications associated with such analysis, including: documenting security measures, assessing business associate agreements, evaluating risks posed by threats and vulnerabilities, among others.

- Business Associate Contracts & Other Arrangements: Would require regulated entities to (1) get written assurances from BAs that they will safeguard ePHI; and (2) verify that BAs have deployed necessary technical safeguards. Verification would include a written analysis of the BA's information systems and must be conducted annually by an individual with cybersecurity expertise.

- Contingency Plans: Would require regulated entities to establish written contingency plans detailing how to respond to events and restore operations. Such plans must include procedures for accurate data backups and a plan to recovery critical systems within 72 hours of an incident.

HIPAA Security Proposed Rule Cont'd

SELECT PROPOSALS

- Encryption and Decryption: Would require regulated entities to implement encryption for ePHI at rest and in transit, except in specific cases where encryption is infeasible or when the ePHI is transmitted per an individual's request.

- Authentication: Would require regulated entities to deploy technical controls that verify the authenticity of a person or asset seeking access to ePHI and electronic systems, including the required implementation of multi-factor authentication.

OUTLOOK: Unclear if the Proposed Rule will face modification, delay, or be rejected by the incoming Trump Administration. Enhancing cybersecurity protocols in health care has bipartisan support (per S. 5390 and S. 5218), so this Proposed Rule may be more likely to survive in some form BUT the administrative burdens and costs it would impose on regulated entities may lead the Trump Administration to rethink the proposed approach. **HHS OCR estimates that first-year compliance costs could reach $9 billion, with ongoing annual costs of approximately $6 billion.**

NEXT STEPS: Public comments are due by March 7.

Questions

California Data Exchange Updates

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C4BH Response to CDII Centralized Roster RFI

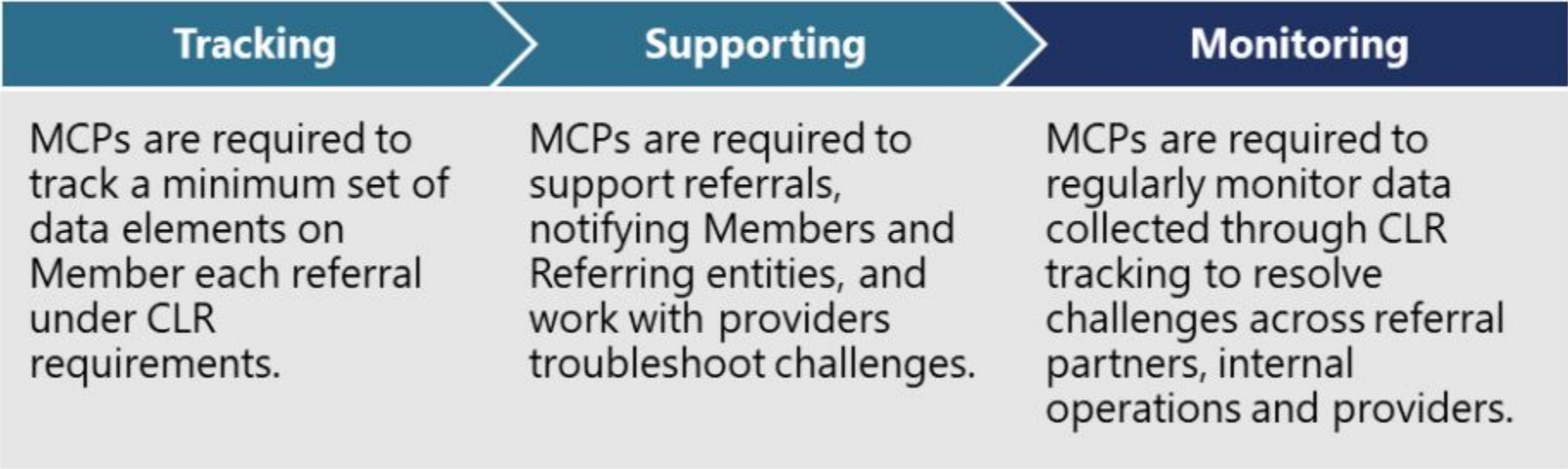## C4BH Response Highlights (Due January 10 - *Access the RFI*)

1. **Yes, a centralized roster service is vital and necessary for DxF Participants to effectively request notifications, determine where to route notifications, and query networks for patient information.** The roster must be a service that is dynamic to reduce provider burden and maintained to ensure its relevance and usefulness. It should be viewed as a collective asset for public and private organizations and leverage existing patient matching infrastructure maintained by the state, such as California's All-Payer Claims Database, the DHCS PHM Service, and CDPH registries.

2. **Patient matching capabilities must be included.** There is utility and merit in a statewide person index that serves as a Record Locator Service and is developed in parallel with consent management registries. The index should build upon all medical record numbers and their associated providers and health plans.

3. **Investments in a centralized roster service should develop a scalable reference model rather than a pilot.**

4. **Advancing DxF governance is essential, and investing in governance for a centralized roster service and overarching digital identities strategy.** We recommend that all DxF Participants should be required to contribute to the development of a statewide person index, and recognize there should be a clear distinction with optional use for participating organizations.

5. **Privacy and Security in the service is crucial**. In addition to strong governance for the centralized roster service, maintaining provenance and trust.
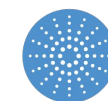
DHCS Update: Closed-Loop Referral Implementation Guidance Finalized

- The CLR guidance details requirements for Medi-Cal Managed Care Plans (MCPs) to collect data and track referral status as well as resolve issues to address referral challenges

- MCPs are required to implement CLR requirements by **July 1, 2025 for ECM and Community Supports referrals**

- CLR requirements for MCPs are organized around the DHCS CLR Framework:

Tracking	Supporting	Monitoring
MCPs are required to track a minimum set of data elements on Member each referral under CLR requirements.	MCPs are required to support referrals, notifying Members and Referring entities, and work with providers troubleshoot challenges.	MCPs are required to regularly monitor data collected through CLR tracking to resolve challenges across referral partners, internal operations and providers.

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C4BH Response to DHCS Data Sharing Authorization Guidance (DSAG) Toolkits

General Highlights

- Call for clarification around decision points for toolkit actors to determine if they are subject to HIPAA, including the "ECM health care provider" assumption
- Recommendation to crosswalk with State Health Information Guidance (SHIG) and and our Consent-To-Share White Paper for guidance on federal and state laws impacting consent, especially for foster youth/guardians, schools, and WIC agencies
- Addition of intermediaries as toolkit actors

Medi-Cal Housing Supports Services Toolkit Highlights

- **General:** Expand focus of toolkit to individuals at-risk of homelessness, include new transitional rent services
- **Laws and Regulations:** Increase connectivity between HMIS and QHIOs under the DxF
- **Scenarios:** Expand scenarios to reflect other "front doors" for service referrals other than MCPs

Reentry Initiative Toolkit Highlights

- **General:** Reflect Correctional Facility relationships with Sheriff's Offices and subcontractors and HIPAA considerations, gear the toolkit examples towards reentry initiative
- **Laws and Regulations:** Consider privacy and security requirements for Correctional Facilities from the Department of Justice
- **Scenarios:** Add a youth/guardian scenario, clarify behavioral health link examples

C4BH Response to ACF Development of Interoperability Standards for Human Service Programs RFI
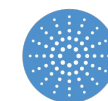
Background

The HHS Administration for Children and Families (ACF) seeks information on the most effective approaches, technical standards, and technological tools that currently or could promote interoperability between health and human services.

Highlights From Our Response

- Call out for clear interoperability standards that will guide meaningful exchange across diverse organizations engaging in data sharing across California.
- C4BH DxF Community Sandbox serves as a critical service for organizations to simulate testing for organizations to readily identify, test, and validate data sharing strategies. Lessons learned from the Community Sandbox can be shared among peers, intermediaries, policy makers, and regulators.
  - Specifically, the visualization tools aid users to create sub-networks of their data sharing partners and better understand existing data sharing patterns.

Access C4BH's Response

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California State Legislation Tracking

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2025 California Legislative Calendar

January 10

Governor's Budget Bill submitted

February 21

Deadline for bills to be introduced

June 6

Deadline for Senate and Assembly to pass bills introduced in their respective houses

June 15

Deadline for budget bill to be passed

August 18

Legislature reconvenes after summer recess

August 29

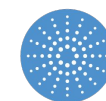Deadline for fiscal committees to hear and report bills to the floor

Sept 12

Deadline for each house to pass bills

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California Legislation Tracking

No./Author	Summary	Recent Developments
AB 4 (Arambula)	Removes the requirement to apply for federal waiver for persons unable to obtain coverage through Covered CA because of their immigration status. By January 2027 the legislature will need to administer a program to allow persons otherwise not able to obtain coverage by reason of immigration status to enroll in health insurance coverage in a manner as substantially similar to other Californians as feasible, consistent with federal guidance and given existing federal law and rules.	Introduced on December 2, 2024
AB 45 (Bauer-Kahan)	Prohibits geofencing an entity that provides in-person health care services and health care providers from releasing medical research information in relation to an individual seeking or obtaining an abortion in response to a subpoena or request for information based on another state's laws that interfere with an individual's rights under the Reproductive Privacy Act.	Introduced on December 2, 2024.
AB 67 (Bauer-Kahan)	Authorizes the Attorney General to investigate persons that have potentially engaged in an act or practice of violating the Reproductive Privacy Act and if proven guilty, impose a civil penalty not exceeding $25,000.	Introduced on December 4, 2024.
AB 91 (Harabedian)	Requires state and local agencies that collect demographic data to use separate categories and tabulations for major Middle Eastern or North African groups starting in 2026.	Introduced on January 6, 2025
SB 11 (Ashby)	Defines what synthetic content is, require the Judicial Council to review the impact of AI in court proceedings, and requires any person that sells or provides access to AI technology that is designated to create synthetic content to provide a consumer warning that misuse of the technology may result in civil or criminal liability for the user.	Introduced on December 2, 2024
SB 53 (Wiener)	This bill would declare the intent of the Legislature to enact legislation that would establish safeguards for the development of AI frontier models and that would build state capacity for the use of AI.	Introduced on January 7, 2025

C4BH 2025 Annual Dinner and Day at the Capitol

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Impact & Engagement

CONNECTING FOR BETTER HEALTH
ANNUAL DINNER + DAY AT THE CAPITOL

03·19·2025 · Sacramento, CA

REGISTER

Join us for a transformative day and evening to celebrate the coalition's impactful work and drive meaningful change together

2025 Day at the Capitol
California State Capitol

Interested in participating? Let us know!

Open to all coalition partners, the day will begin by meeting with state legislators and state agency representatives to advocate for advancing data sharing across California

First Annual Dinner
Tsakopoulos Library Galleria

Reserve your seat or table!

Following meetings, all coalition partners are invited to an uplifting evening of recognition and celebration featuring a network reception and dinner

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2025 Annual California DxF Summit:

The Road to Whole-Person Care

March 20TH

Tsakopoulos Library Gallery

828 I St, Sacramento, CA 95814

(logos: Data Exchange Framework, CalHHS, Center for Data Insights and Innovation)

Join CDII for the 2025 Annual California DxF Summit for a full day of engaging panels, fireside conversations, and networking!

Request a Ticket!

Space for this event is limited, and we are committed to ensuring balanced representation from all invited organizations. As such, we may limit the number of participants from any single organization. Please note that registering for the event does not guarantee a confirmed spot.

News, Events and Announcements

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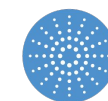# What We're Reading – Check Out C4BH's Newsletter!

CMS Approves of California's BH-CONNECT 1115 Waiver

CMS approved of California's section 1115 waiver - Behavioral Health Community-Based Organized Networks of Equitable Care and Treatment (BH-CONNECT). The approved waiver will build off existing initiatives in California to expand and strengthen community-based behavioral health care to better support Medi-Cal members with significant behavioral health needs. In particular, BH-CONNECT will offer transitional rent assistance, workforce investments, community transition in-reach services, and create a Health IT Plan leveraging the DxF to meet serious mental illness goals. Read More

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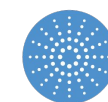Advancing data sharing to improve the health of all Californians

Upcoming Webinars & Events

- **January 22, 11-12PM PT:** Civitas FHIR Deep Dive Webinar Series: Gravity FHIR Accelerator Webinar | [Register here](#)

- **January 27, 12:30-1:30PM PT:** C4BH January Office Hours | [Register here](#)

- **February 3-4:** Insure the Uninsured Project (ITUP) Annual Conference | Sacramento, CA| [Register here](#)

- **February 6, 10-11AM PT:** DHCS All Comer Webinar on Closed-Loop Referral Implementation Guidance | [Register here](#)

- **February 16-19:** ViVE 2025 Conference | Nashville, TN | [Register here](#)

- **February 26-27:** California Primary Care Association (CPCA) Quality & Technology Conference | San Ramon, CA | [Register here](#)

- **March 19:** C4BH Day at the Capitol & Annual Dinner | Sacramento, CA | [Register here](#)

- **March 20:** 2025 Annual California DxF Summit | Sacramento, CA | [Register here](#)

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Appendix

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C4BH Storytelling Continues - Reach Out!

DATA SHARING TO ASSIST CARE MANAGERS

Anwar Zoueihid
Vice President Long Term Services & Supports,
Partners in Care Foundation

DATA SHARING TO PROVIDE LIFE-SAVING NUTRITION

Michelle Kuppich
Executive Director
California Food is Medicine Coalition

SAVING LIVES WITH INFORMED EMERGENCY CARE

Jonathon Feit
Jonathon Feit, Co-Founder & CEO,
Beyond Lucid Technologies

Jonathon's Vision
To transform pre-hospital care systems through enhanced data sharing, eliminating inefficiencies and ensuring seamless, effective emergency medical services.

EMPOWERING HEALTH WITH INTEGRATED SOCIAL AND HEALTH CARE DATA

Bill York
President & CEO,
211 San Diego

Bill's Vision
My vision is an integrated system of social and health care data that empowers decision-making so individuals can build and sustain healthy lives.

CENTERING COMMUNITY CARE

Scott Perryman
Battalion Chief, Paramedic, PA-C,
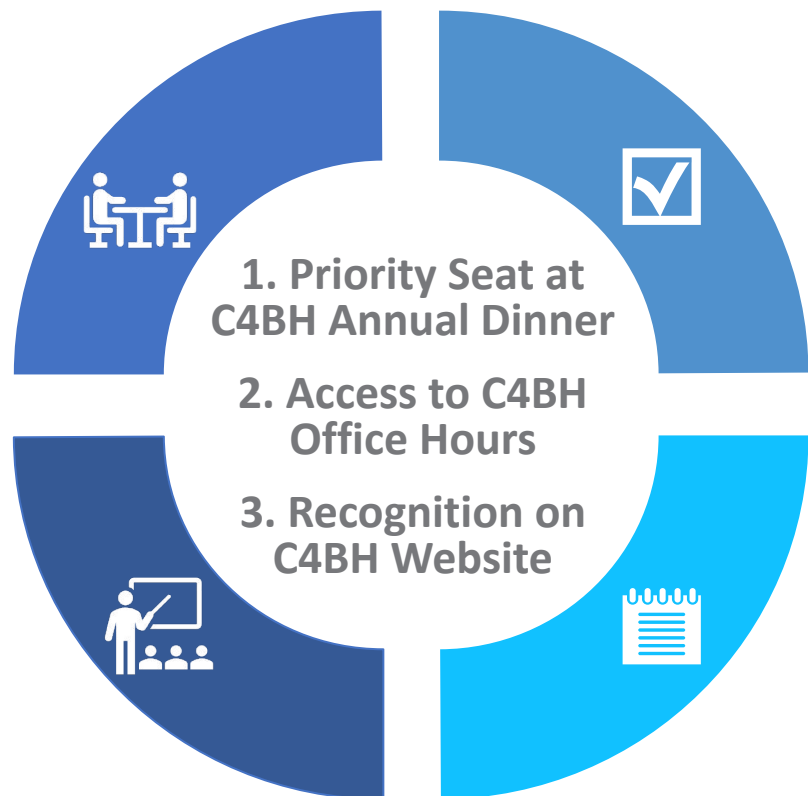Sacramento Metropolitan Fire District

Scott's Vision
My vision is for Sacramento's Mobile Integrated Health (MIH) to use data sharing to optimize coordinated care for better community health and well-being.

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Call for C4BH Supporters

Join C4BH as a Supporter
$500 contribution

Supporter Benefits

1. Priority Seat at C4BH Annual Dinner

2. Access to C4BH Office Hours

3. Recognition on C4BH Website

Why Become a Supporter?

- **Impact:** Be on the Leading Edge of Policy and Research

- **Impact:** Contribute to California's Meaningful Transformation

- **Opportunity:** Network with Industry Leaders over Shared Mission

- **Recognition:** Showcase Your Commitment to Health Improvement

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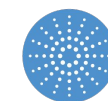
Now Live: DxF Community Sandbox Platform

Find and Filter DxF Participants in your Region
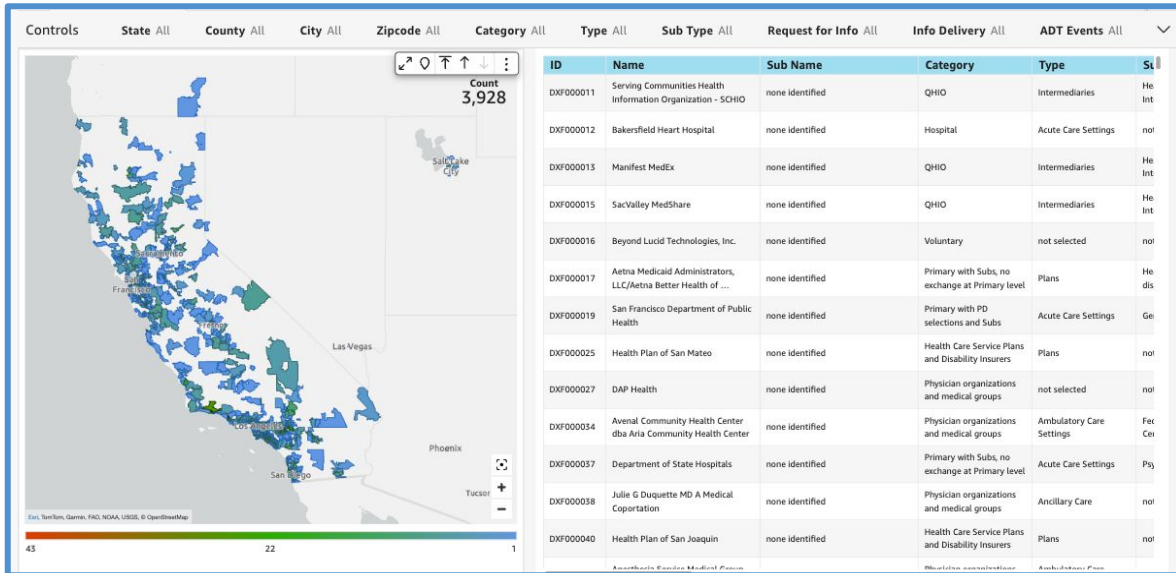

Access the Sandbox Platform

The Sandbox enables DxF Participants to

- **Use visualization tools** to identify neighboring organizations and learn how they are sharing data

- **Explore available use cases** to further your organization's data sharing practices - with more coming soon!

- **Simulate data exchange and test use cases** with organizations that have onboarded to the Sandbox

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Available Technical Assistance

Level of DxF Readiness	C4BH Supports	What it is	Outputs
1 Planning	DxF Bootcamp	Half day education of what the DxF is, overview of Policies and Procedures, and help with identifying priority use cases	Develop a DxF Roadmap and Identify Priority Use Cases
2 Assessment	DxF Community Design Studio	6-8 weekly sprints to design real-world community use cases	Technical and Functional data exchange workflows, test data and reports
3 Ready to Connect!	DxF Community Sandbox	Real-world testing environment for DxF priority use cases	Test and Validate Use Case to Establish Workflows

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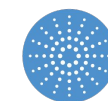
C4BH Annual Sponsor Tiers

Annual Sponsor Tiers *See next slide for exclusive sponsor benefits*	Platinum $100,000+	Gold $50,000	Silver $25,000	Supporters $500
End-of-Year Dinner	Table of 8-10 seats with recognition	4 seats with recognition	2 seats with recognition	Priority Invitation
Add Logo to Website and Sign-On Letters with Opt-Out Approach	✓	✓	✓	✓
Access to Office Hours	✓	✓	✓	✓
Advisory Group Representatives	1+	1	1	
Access to DxF Sandbox Community Studio	Priority Access	✓	✓	
Access to DxF Bootcamps	Priority Access	✓		
First Right to Engage in New C4BH Projects	✓			
White-Labeled DxF Implementation Toolkit	✓			

Do Your Priorities Differ From The Annual Sponsor Tiers? Reach Out To Us!

Additional Sponsor Opportunities Available For Our Annual Dinner