

Building the Foundation: A Roadmap to Data Modernization for Emerging Public Health Efforts

Agenda

- Who We Are
- Modernization Group Overview
- Challenges & Lessons Learned
- Best Practices

Disclaimer

Funding for this project was made possible (in part) by the Centers for Disease Control and Prevention.

The views expressed in written conference materials or publications and by speakers and moderators do not necessarily reflect the official policies of the Department of Health and Human Services, nor does the mention of trade names, commercial practices, or organizations imply endorsement by the U.S. Government.

Objectives

- Identify key steps for early implementation of data modernization efforts.
- Discuss the technical, legal, and governance aspects critical to initiating and sustaining data-sharing and integration efforts.

Who We Are

AISP helps state and local governments collaborate and responsibly use data to improve lives.



PARTICIPATORY LEARNING



PROCESS ORIENTATION



ASSET FRAMING



INTERROGATE NARRATIVES

Our Commitments

Our Network of Integrated Data Systems

IDS Landscape AISP Network

The map that follows highlights a range of data sharing and integration efforts with different goals and roles in the diverse landscape.



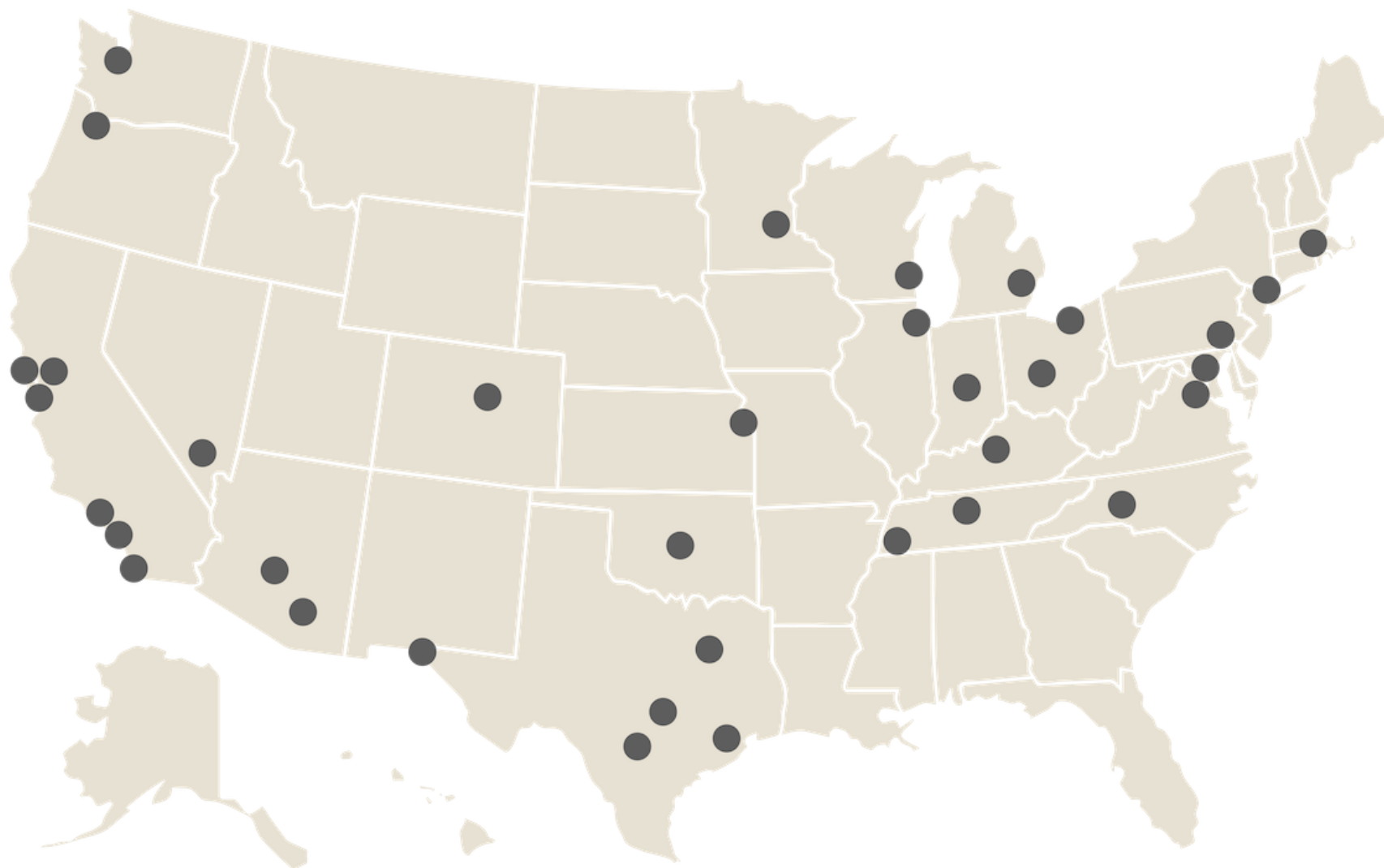
The map demonstrates the increasing breadth and depth of data efforts nationwide. It is by no means a comprehensive accounting, nor is it intended to imply any judgment regarding the quality or maturity of sites included or omitted.

- ★ Statewide
- ◆ Local
- ★ ◆ Network Sites



35 member jurisdictions

More than 61 million, or 1 in 5, Americans served



Austin
Baltimore City
Boston
Charlotte (Mecklenburg Co)
Chicago
Cleveland
Columbus
Dallas (Co)
Denver
Detroit
El Paso
Houston
Indianapolis (Marion Co)
Kansas City
Las Vegas (Southern NV Health Dist)
Long Beach
Los Angeles (Co)
Louisville
Memphis (Shelby Co)
Milwaukee
Minneapolis
Nashville
New York City
Oakland (Alameda Co)
Oklahoma City (OKC-Co)
Philadelphia
Phoenix (Maricopa Co)
Portland (Multnomah Co)
San Antonio
San Diego (Co)
San Francisco
San Jose (Santa Clara Co)
Seattle (Seattle-King Co)
Tucson (Pima Co)
Washington, D.C.

Data Modernization Workgroup

BCHC Data Modernization Work Group

- Engaging data strategy leads
- Facilitating peer learning & support
- Identifying collaborative project opportunities
- Connecting & aligning with partners



Focus Areas

1. Create **standards and mandates** for data exchange, including defining the **minimum infrastructure** needed at STLTs to support the future state of data exchange.
2. **Develop governance** to clarify roles and responsibilities to enhance coordination, communication, and decision making.
3. Develop **legal standard clarification** on data use, sharing, and dissemination to facilitate data exchange.

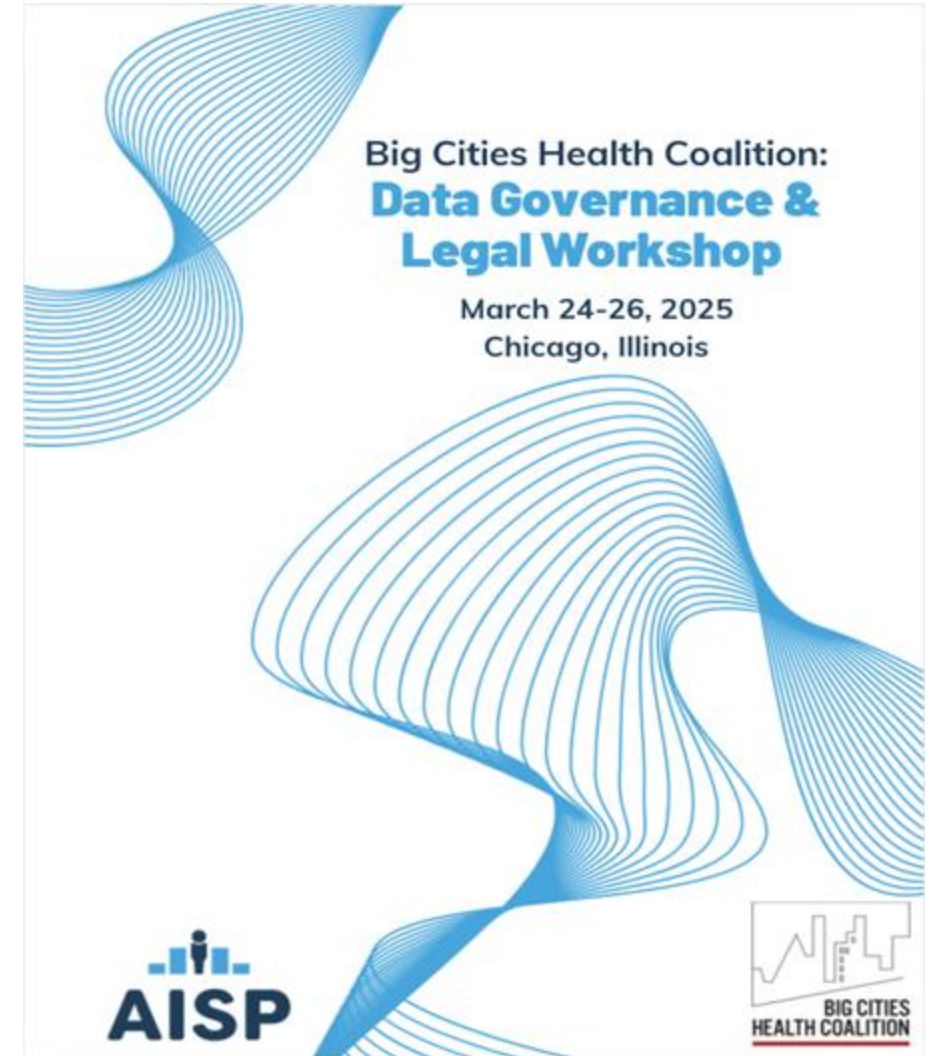


Targeted Support with Data Governance & Legal Frameworks

Participants included 24 DMI leads and 12 legal counsel across 18 cities.

Cities represented:

Baltimore, Boston, Charlotte-Mecklenburg County, Chicago, Columbus, Dallas, Houston, Indianapolis/Marion County, Las Vegas, Long Beach, Los Angeles County, NYC, Philly, Phoenix/Maricopa County, San Jose/Santa Clara County, Seattle-King County, Tucson Pima County, Washington D.C.



Themes & Lessons Learned

How would you describe your current data governance?



How would you describe your aspirational data governance?



Common DMI challenges

Relationships: Relationship barriers between departments—turf, trust, time

Legal barriers: Real or perceived legal barriers- fear & uncertainty around web of state and federal privacy laws; lack of interaction with legal and DMI leads

Technical/logistical challenges: inflexible legacy systems, common fields in different datasets defined differently, not always a unique identifier to match with, lack of data documentation

Capacity & resource limitations: Insufficient staffing, inconsistent funding, lack of institutional buy-in

Participant feedback

32 responses (20 DMI Leads & 8 Legal Reps)

“All of it was helpful, interesting, and informative”

The majority of respondents (20) said that the most valuable part of the convening was **spending time with peers in the same roles**

- 3 specifically called out having guided conversations with colleagues

Legal sessions were highly rated

- Appetite for **more connections between legal reps and DMI leads**
- Appetite for **more peer opportunities for the legal reps to connect**

“Sharing successes, failures, and resources with one another.”

Participants are looking forward to diving deeper on a variety of topics, including: **governance charters** and making the case for **governance, data stewardship recruitment, tools for data asset inventory**, and **all things legal**.

“The mix of content, discussion, and reflection time was really a great balance”

Lessons Learned

- Wide variation in size and organizational structure of departments and maturity of DMI efforts
- A key challenge with modernization efforts is data governance and legal
- People need resources, templates and opportunities to engage with peers facing similar challenges
- Need for continued relationship development between DMI leads and legal

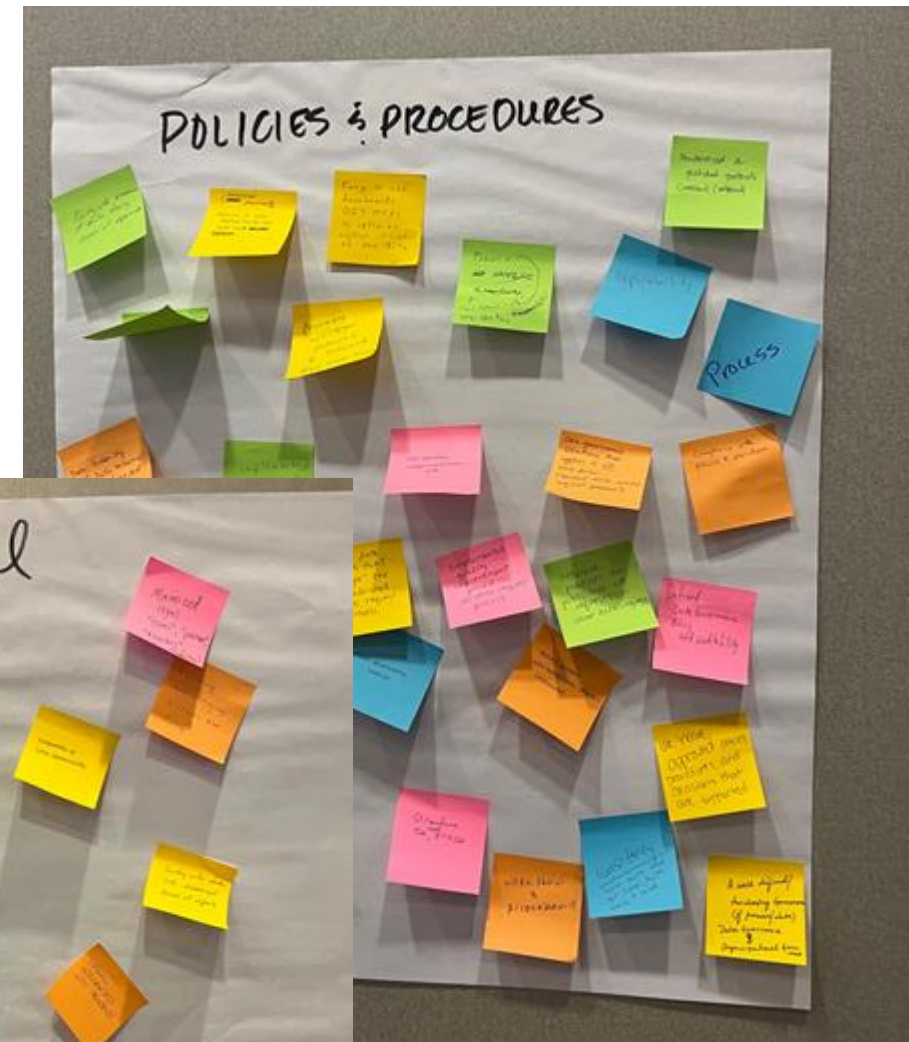


Best Practices

What does success look like?

Common themes

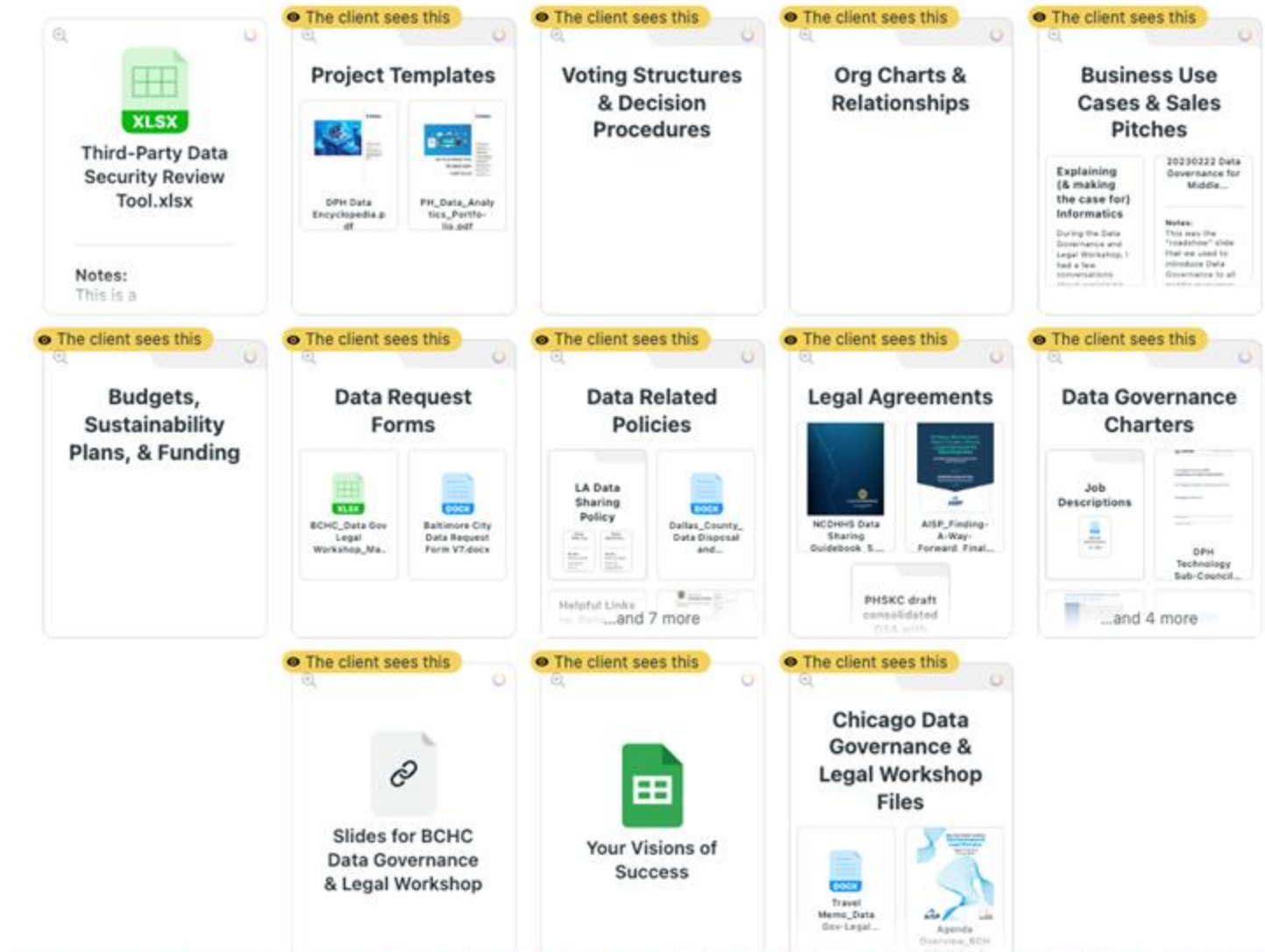
- Policies & procedures
- Legal clarity
- Collaboration
- Buy-in & leadership
- Tech modernization
- Timely access for partners
- Transparency
- Communication
- Program improvements
- Data quality (& metadata)



Activities/concepts we introduced to help get there

- Governance elevator pitches
- Finding your “org chart twin”
- Defining key roles (data owner, data steward, data custodian)
- Creating a high value data asset inventory
- Using a documentation checklist
- Deciding which data governance structures you need
- Mapping decisions that have been made vs. decisions that need to be made
- Conducting an inventory of legal agreements
- Evaluating risk vs. benefit of data uses
- Balancing risk of disclosure with utility of data

Shared Resources



Questions?

Please take this survey to evaluate conference sessions.



THANK YOU