



Office of the National Coordinator
for Health Information Technology

ONC Social Determinants of Health (SDOH) Information Exchange Learning Forum

Values, Principles & Privacy

2:00 - 3:30 pm ET

Tuesday, March 28th, 2023



Agenda

- Welcome
- Background on SDOH Information Exchange
- Overview of SDOH Information Exchange Foundational Element: Values & Principles
- Spotlight: DASH
- Overview of SDOH Information Exchange Foundational Element: Legal
- Spotlight: OCHIN
- Questions and Discussion
- Learning Forum Series and Small Group Opportunities
- Closing



Welcome

Please chat in your name, role and organization.



Meley Gebresellassie
ONC



Mark Knee
ONC



Sam Meklir
ONC



Morris Landau
ONC



Jillian Annunziata
EMI Advisors



Sara Behal
EMI Advisors



Kristina Celentano
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Evelyn Gallego
EMI Advisors





Background on SDOH Information Exchange

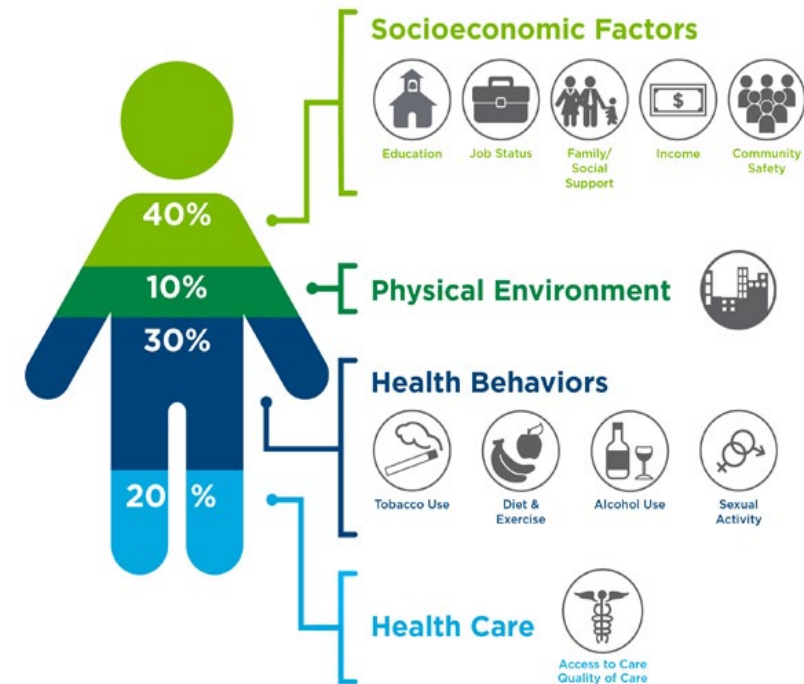
Why are social needs important?

Unmet social needs negatively impact health outcomes.

- **Food insecurity** correlates to higher levels of diabetes, hypertension, and heart failure.
- **Housing instability** factors into lower treatment adherence.
- **Transportation barriers** result in missed appointments, delayed care, and lower medication compliance.

Addressing social needs is a primary approach to achieve health equity.

What Goes Into Your Health?



Source: Institute for Clinical Systems Improvement, Going Beyond Clinical Walls: Solving Complex Problems (October 2014)

The Bridgespan Group

SDOH and HHS Healthy People 2030

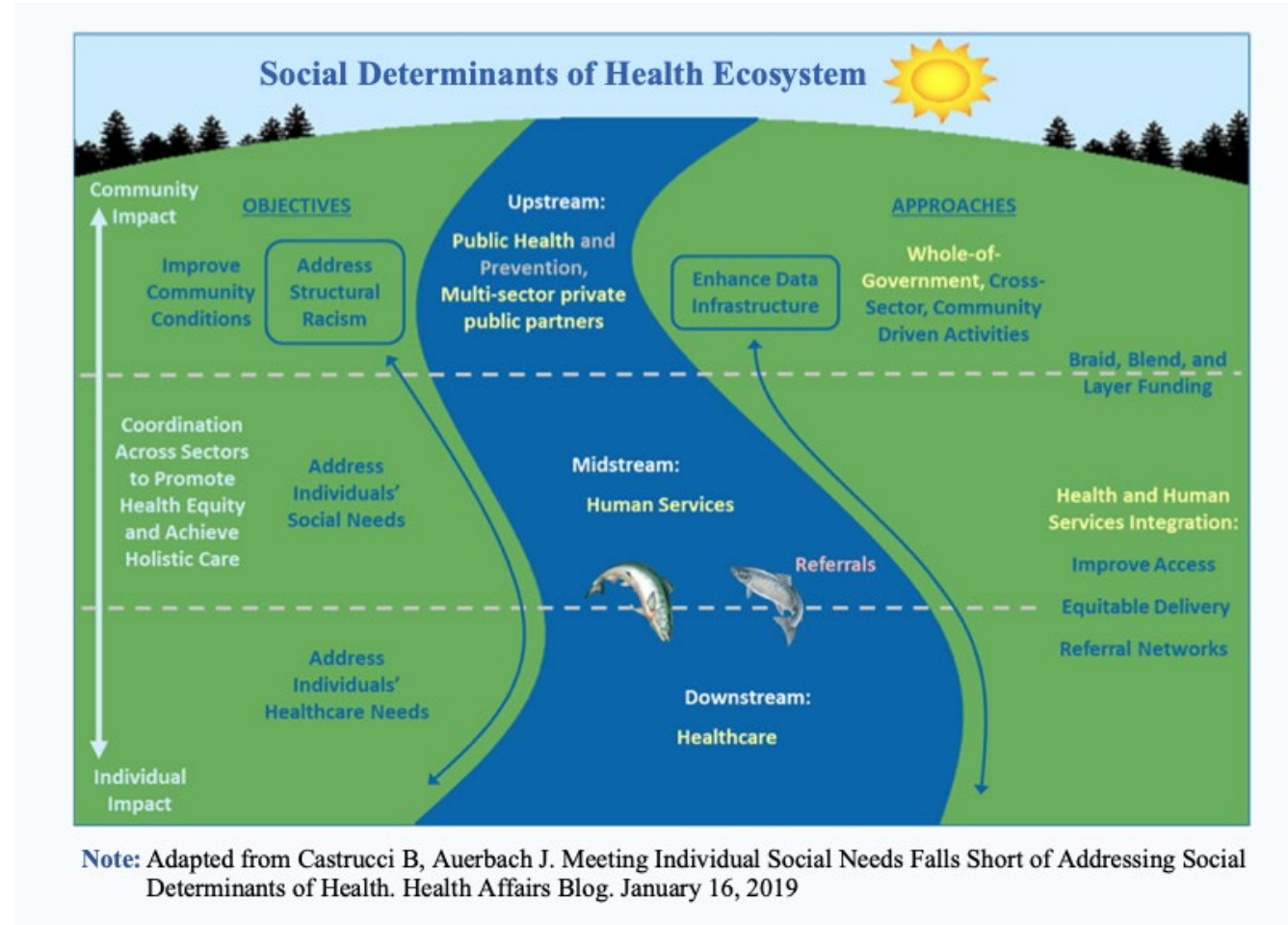
Social Determinants of Health



- Healthy People 2030 sets data-driven national objectives to improve health and well-being over the next decade and was released by HHS on August 18, 2020.
- One of Healthy People 2030's 5 overarching goals is specifically related to SDOH: "Create social, physical, and economic environments that promote attaining the full potential for health and well-being for all."

HHS SDOH Action Plan

- **Goal 1:** Build a robust and interconnected data infrastructure to support care coordination and evidence-based policymaking.
- **Goal 2:** Improve access to and affordability of equitably delivered health care services, and support partnerships between health care and human service providers, as well as, build connections with community partners to address social needs.
- **Goal 3:** Adopt whole-of-government approaches, support public-private partnerships, and leverage community engagement to address SDOH and enhance population health and well-being.

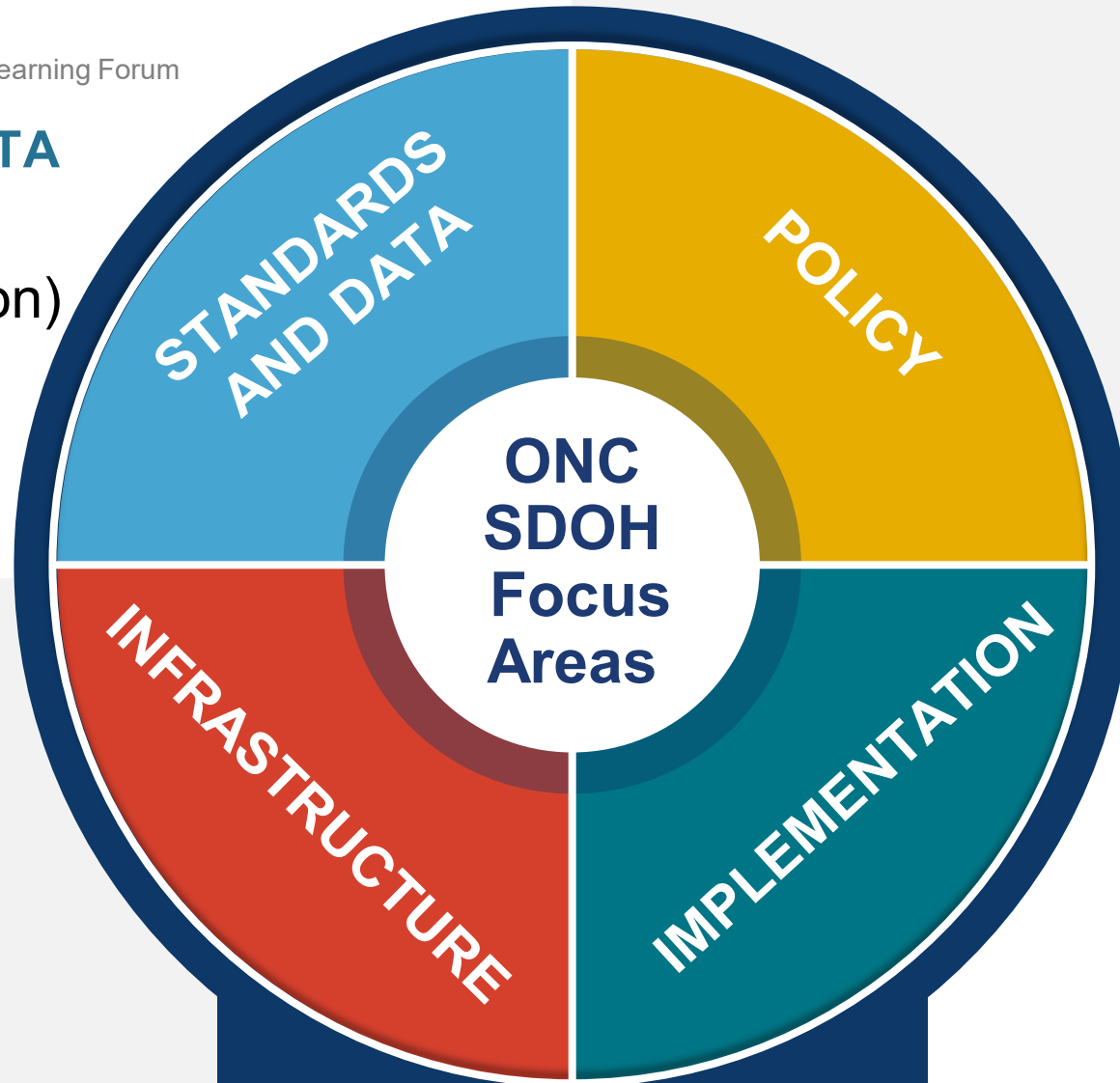


STANDARDS AND DATA

(Advance Standards
Development Adoption)

INFRASTRUCTURE

(SDOH
Information
Exchange/
Interoperable
Referrals, HIE,
State, & Local)



POLICY

(Emerging Policy
Challenges &
Opportunities)

IMPLEMENTATION

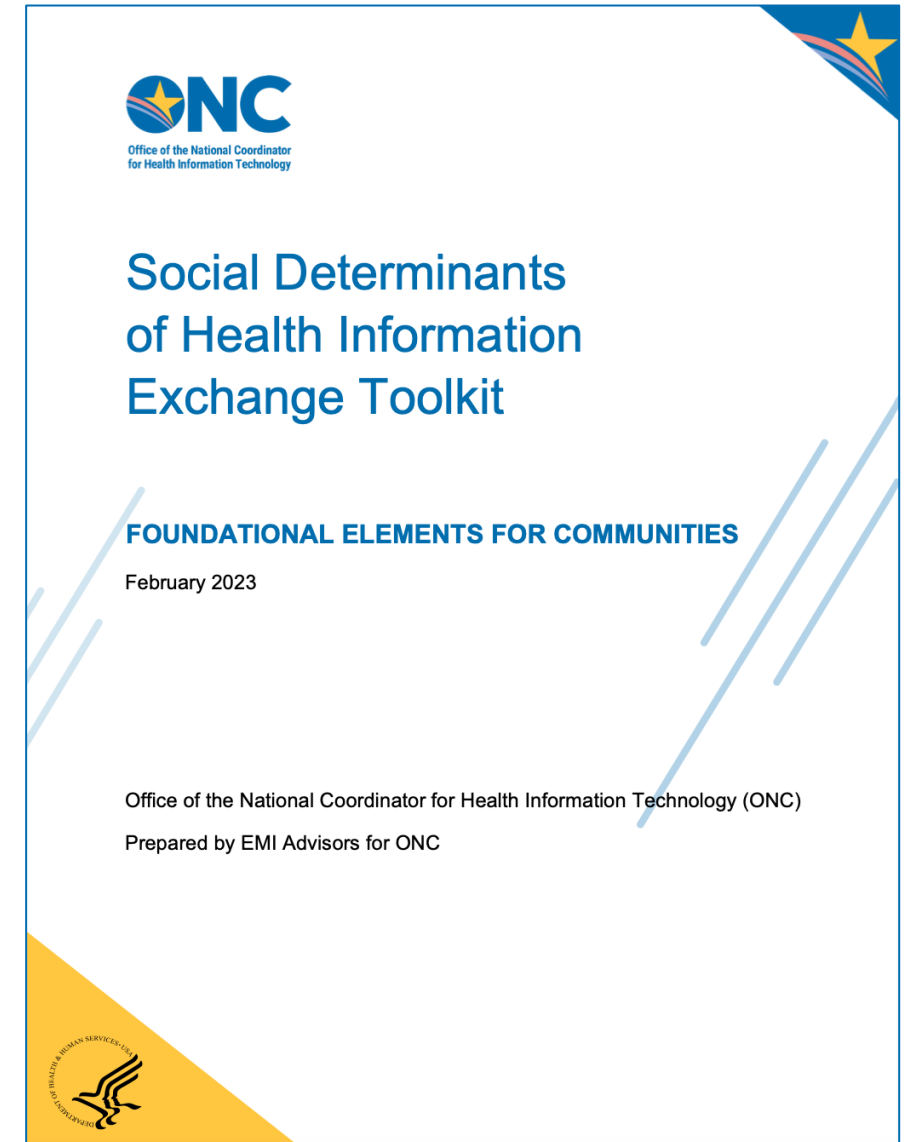
(Integration,
Innovation, and Health
IT Tools)


Collect, Access, Exchange, Use

ONC SDOH Information Exchange Toolkit publication

Developed by ONC with support from EMI Advisors and a panel of technical experts convened in 2020.

- Provides information on the SDOH information exchange landscape to stakeholders of all experience levels.
- Identifies approaches to advance SDOH information exchange goals through the 'foundational elements' framework.
- Provides examples of common challenges and promising approaches.
- Shares guiding questions and resources to support implementers.
- Available here: [Social Determinants of Health \(SDOH\) Information Exchange Toolkit](#)





Overview of SDOH Information Exchange Foundational Element: Values and Principles



Social Determinants of Health Information Exchange Foundational Elements





Foundational element: values and principles

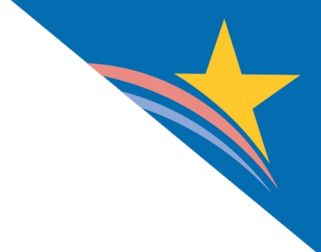
Standards for establishing a framework for action, including ethical decision-making in pursuit of health equity.

- Ethical and equitable principles focused on accountability to and fairness in actions and outcomes for the community. For example:
 - Transparency
 - Accountability
 - Inclusiveness
 - Cultural responsiveness
- Emphasis on anticipating and mitigating risks, monitoring unintended consequences, and taking action to prevent, reduce and repair possible harms.
- Ongoing collaborative engagement with community and other interested stakeholders in each phase of an initiative's lifecycle to promote equity and prevent harm.



Questions to consider

- How will the initiative address the interests of different types of stakeholders in such a way that prioritizes the interests of people in need and their communities?
- What are the most common concerns shared by community stakeholders, and how will those concerns be equitably addressed through a governance process?
- What are the ethical principles and values that your initiative commits to uphold and reflect in the approach to data and IT?
- What is your community's approach to preventing harm to communities and individuals in the course of the initiative? Ensuring alignment with ethical and equitable principles? Assessing gaps and addressing them?



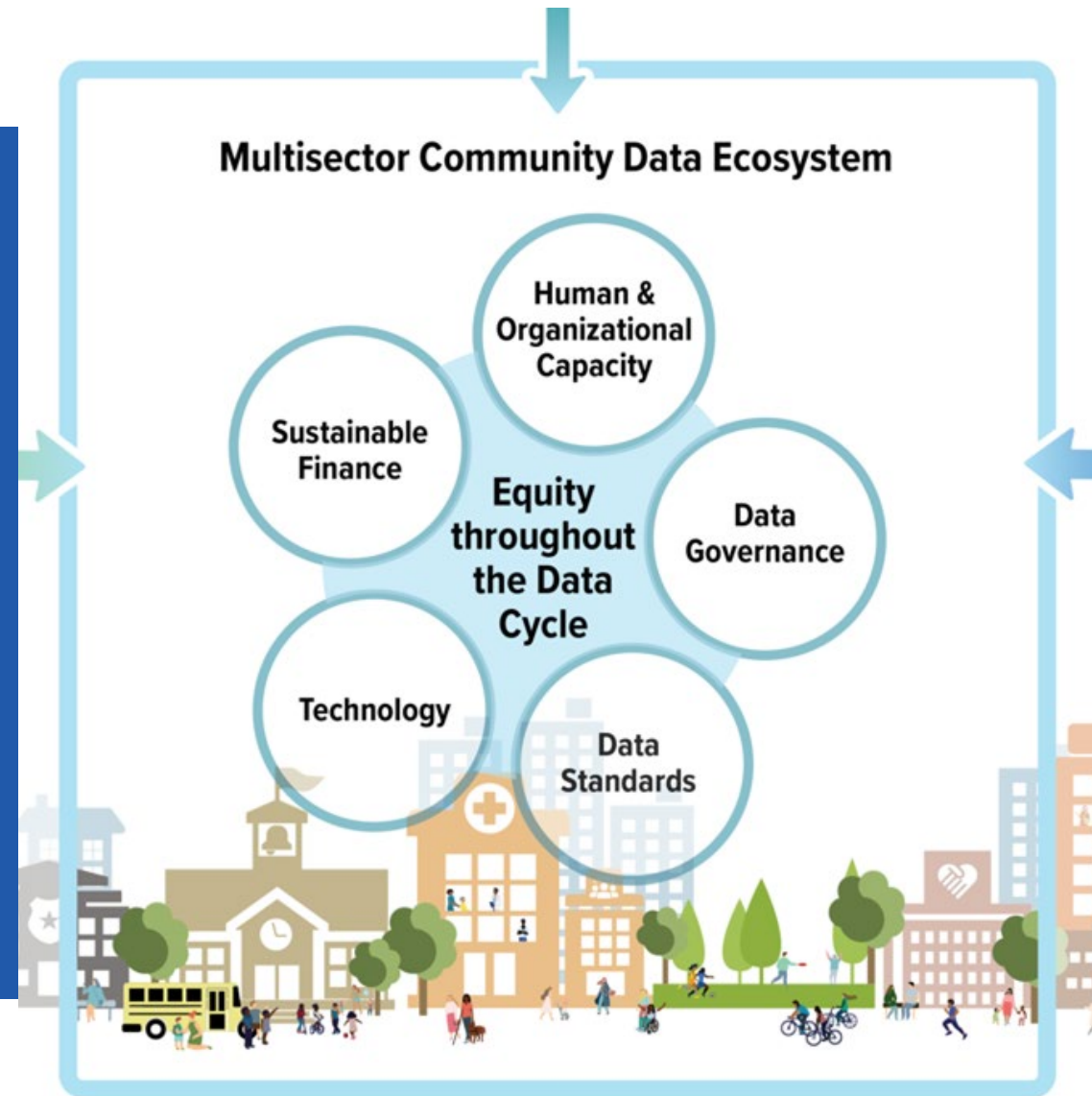
Spotlight: DASH

March 28, 2023

Promoting Equitable Data Ecosystems for Advancing Community Health

ONC SDOH Learning Forum

Melissa Moorehead, Program Manager



Purpose

Build local data sharing capacity to collaboratively promote community health equity and well-being efforts across healthcare, public health, and community-based services.

Data Across Sectors for Health (DASH)

- DASH is co-led by the Illinois Public Health Institute and the Michigan Public Health Institute. The two institutes make up the DASH Program Office (PO), which is funded by the Robert Wood Johnson Foundation.
- DASH started in February 2015 – current award through fall 2025.

Funding Programs (in more than 500 communities)

First “OG” Grantees

10 awardees

18-24 months, \$200K

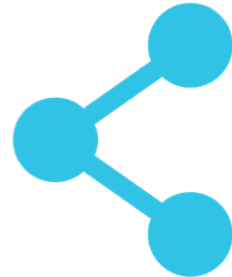


CIC-START & CIC-COHORT

~6 months, \$25K

40 CIC-START

8 CIC-COHORT



Mentorship

10 months

6-8 Mentors (~\$25K),
100+ Mentees (\$5-10K)



Learning in Action and Policy Partnerships (LAPP)

9-12 months
12 Awardees
(\$80-100K)

Asset-Based Community Development (ABCD)

Cohort

~6 months,
\$20+K
10 awardees



The Peer-to-Peer Network

DASH is a founder and co-leader of *All In: Data for Community Health*

ALL IN 



Current Partners:



BUILD
Health
Challenge



Data Across
Sectors for
Health



Network for
Public Health
Law



New Jersey
Health
Initiatives



Public Health
National
Center for
Innovations



Population
Health
Innovation
Lab



Pew Charitable
Trusts
Health Impact
Project

Past Partners: Community Health Peer Learning Program, Connecting Communities and Care

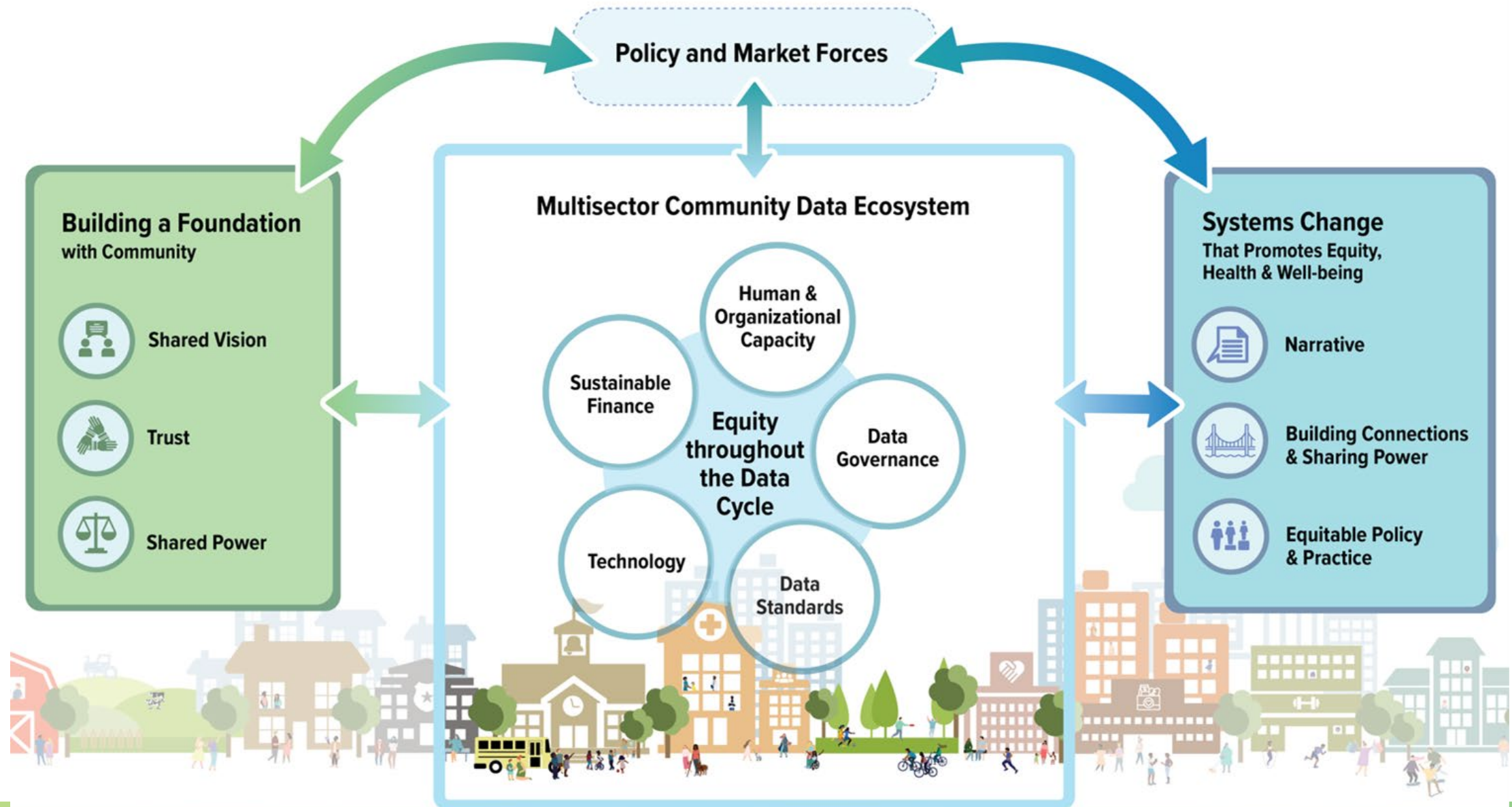
ALL IN 

DATA FOR
COMMUNITY
HEALTH

DASH supports community-based data ecosystems

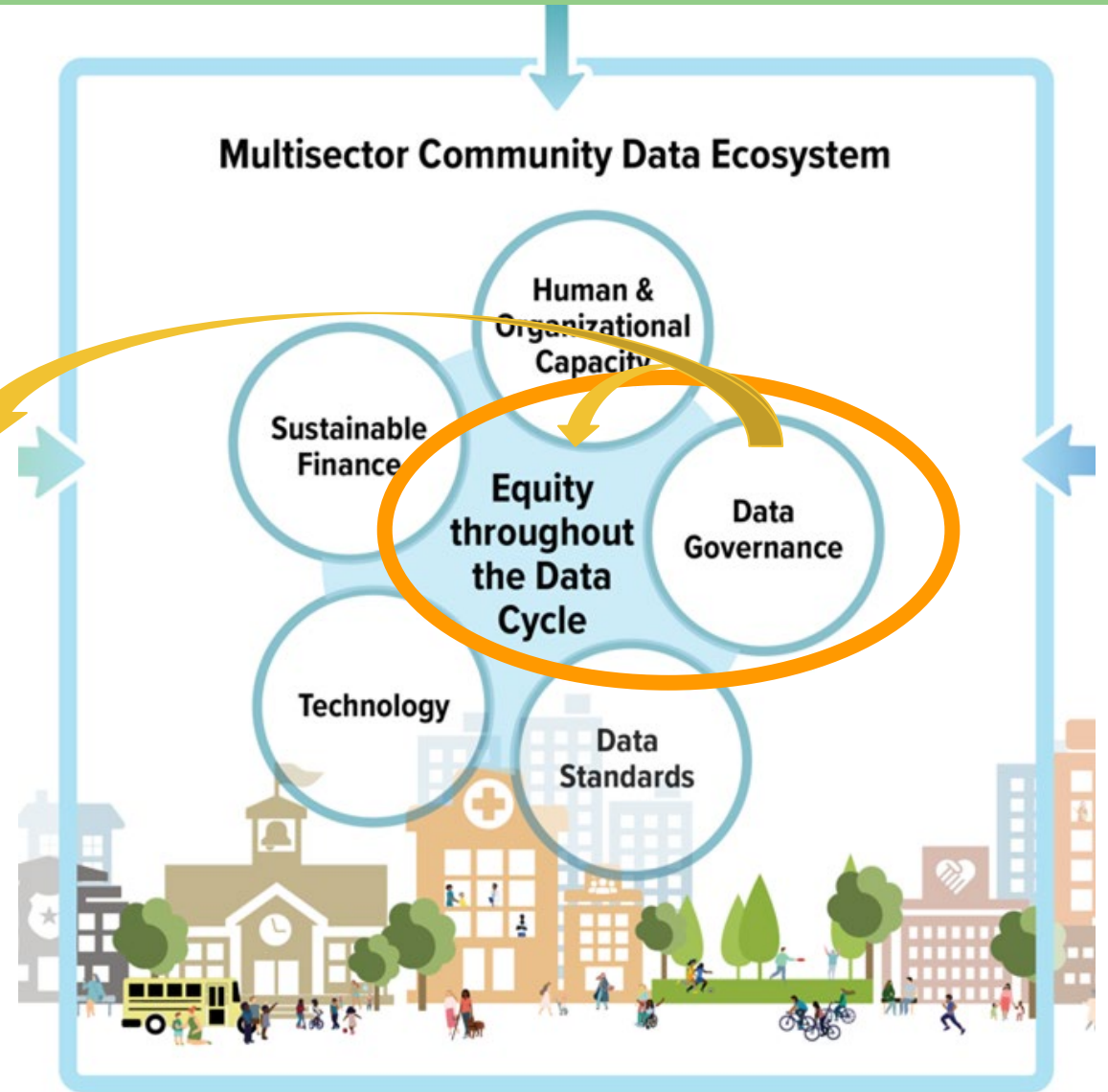


Diverse Sectors



Community Data Ecosystems

Community data ecosystems are made up of the what, the who, and the how that enables sharing data and collaboration within a community.

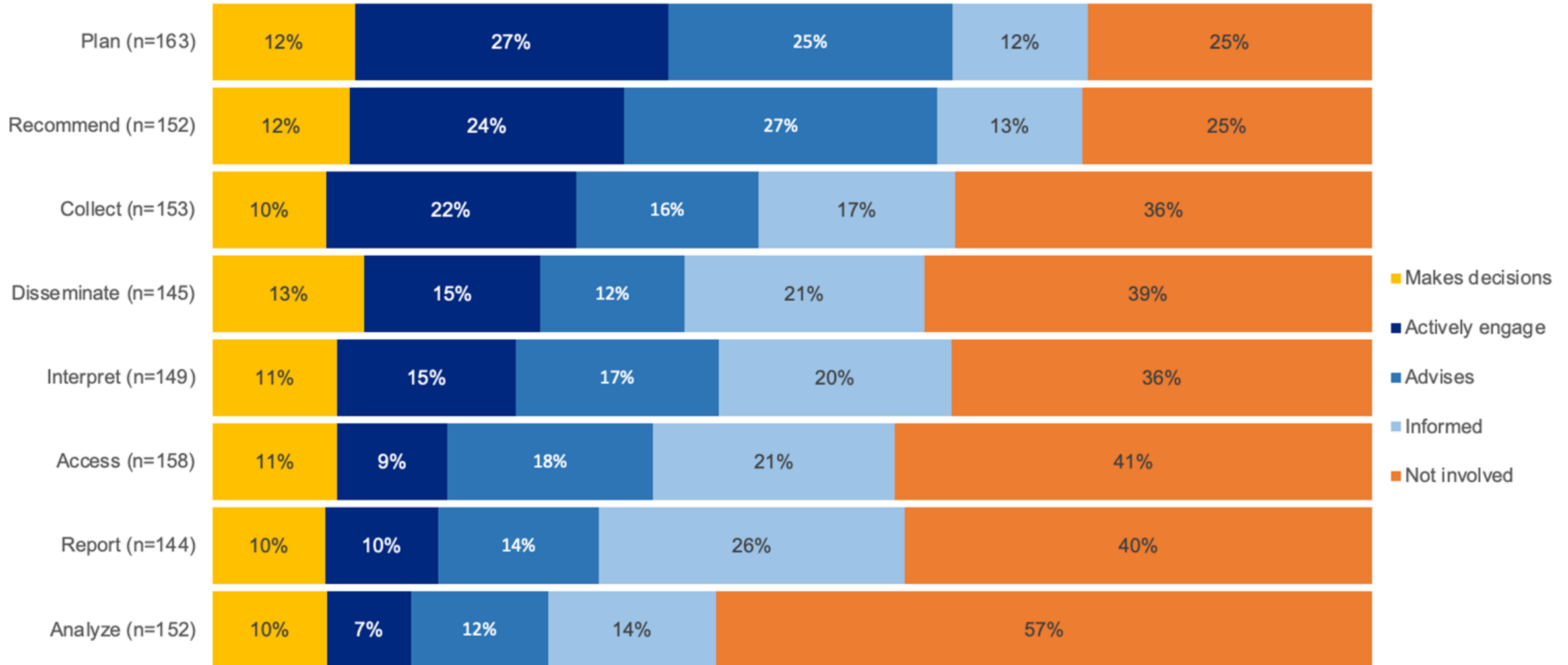


Data is a community asset



Asset-based approach to creating community data ecosystems suggests that community leadership might be a key to sustainability and equity.

Insufficient Involvement of PwLE in Data Sharing



Practices to Center Equity

Assess how risks of data sharing could vary by identity group

Potential risks include:

- Reinforcing negative narratives
- Harming individuals
- Replicating structural racism

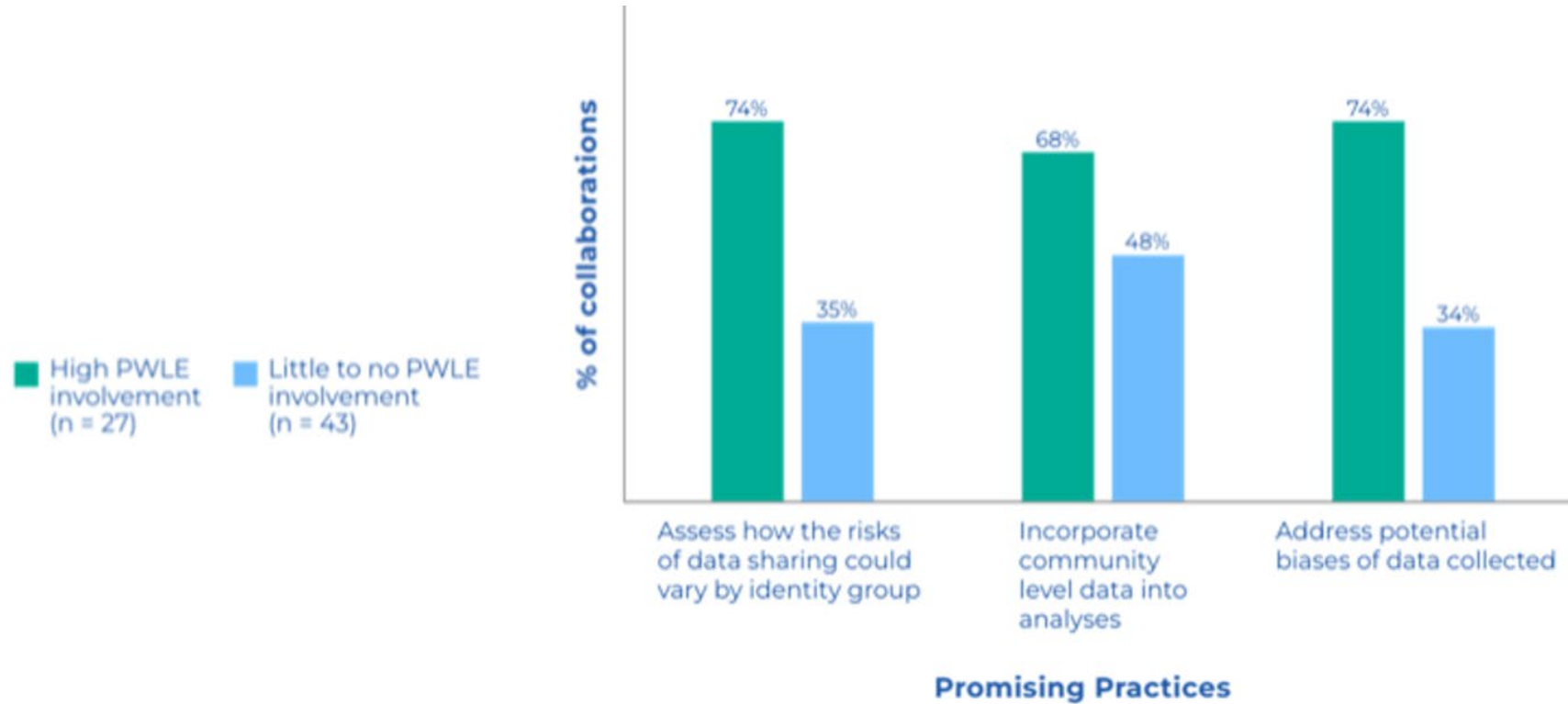
Incorporate community level data into analyses

- Social determinants are conditions in the environments ... that affect a wide range of outcomes
- Structural indicators (rather than individual) train the eye towards policy/program change

Address potential biases of data collected

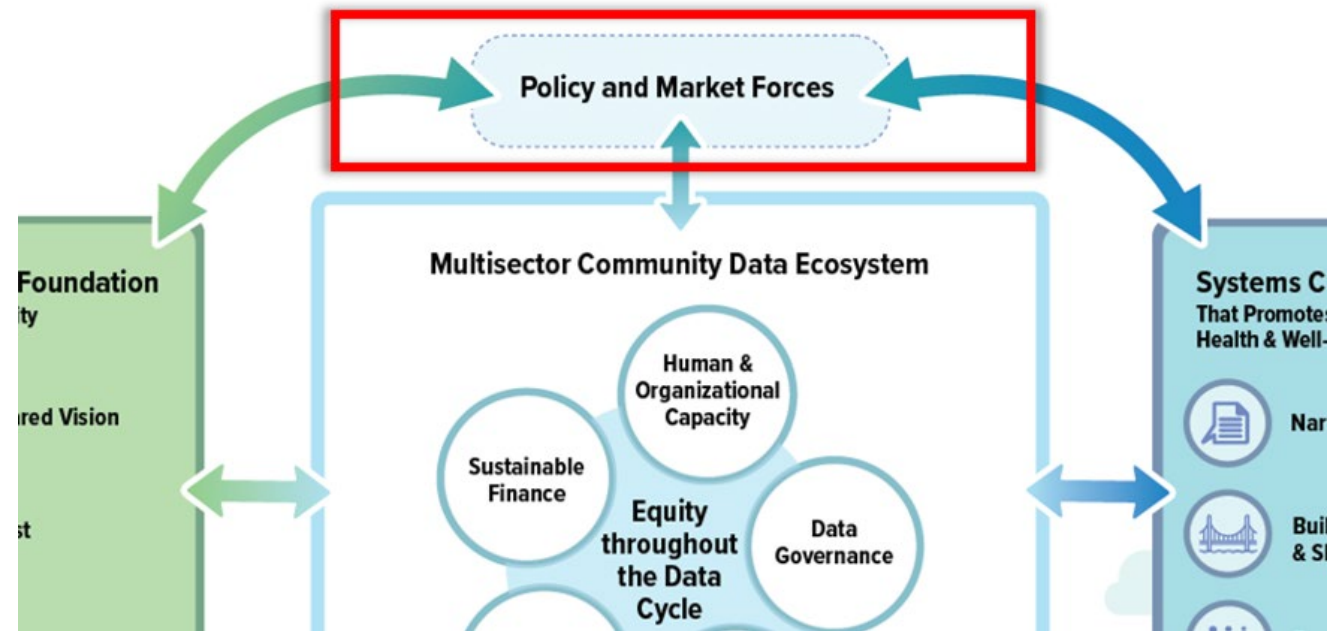
- How might over- or under-representation in data be caused and drive biased interpretation
- Balance risk and protective factors – avoid deficit-based approach

Higher engagement of PwLE led to better equity practices



Policy & Market Forces

- Actors in community data ecosystems are operating in markets that exert powerful forces on competition and collaboration
- State, Federal, and local government policy impacts data ecosystems (and vice versa)



Examples

Learning and Action in Policies and Partnership (LAPP)
Funding opportunity in collaboration with CHCS

[A Community-Centered Approach to Data Sharing and Policy Change: Lessons for Advancing Health Equity - Center for Health Care Strategies \(chcs.org\)](#)



Led All In Affinity Group

Foundation of their work: For some use cases, government must step in to ensure equitable access to accurate community information

Next Steps for DASH

- An incubator that supports community-level data-sharing work through direct funding and technical assistance to build capacity at the implementation level to directly inform policymakers
- National partnerships that accelerate development and adoption of sustained, equitable practices and policy around data sharing
- Synthesize and equitably share out community learnings to spread best practices and inform equitable community data ecosystems.

Thank You!

DASHCONNECT.ORG

MPHI.ORG

IPHIONLINE.ORG

ALLINDATA.ORG

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Questions and Discussion



Overview of SDOH Information Exchange Foundational Element: Legal



Foundational element: legal

Establishing the legal framework, along with rights and obligations, to support data use and sharing in compliance with federal, state, local, and tribal laws.

Legal considerations for SDOH information exchange include activities, either required by law, policy, and/or contract, to establish a framework of:

- Processes and operations (e.g., liability, indemnity, and insurance)
- Data use and rights (e.g., consent model, privacy rights)

Privacy takeaways

- HHS Notice of Proposed Rulemaking in 2022 to modify the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule to support individuals' engagement in their health care, remove barriers to coordinated care, and decrease regulatory burdens on the health care industry, while continuing to protect individuals' health information privacy interests.
 - [Fact Sheet on Proposed Modifications to the HIPAA Privacy Rule to Empower Individuals, Improve Coordinated Care, and Reduce Regulatory Burdens.](#)
- The U.S. Department of Education and HHS OCR released updated joint [guidance](#) in December 2019 addressing the application of the Family Educational Rights and Privacy Act (FERPA) and the HIPAA Privacy Rule to records maintained on students.
- Comprehensive Consumer Data Privacy Laws have been enacted in 5 states-California, Colorado, Connecticut, Utah, and Virginia.



Questions to consider

- What entities are subject to specific legal obligations?
- What federal, state, local, and tribal laws are applicable to the initiative?
- What are your organization's role-based permissions for service providers and individuals to access and use data? Where can you get guidance on legal provisions for your organization's policies?
- Are your organization's consent policies and practices clearly stated and made widely available? Were the individuals, service providers, and other relevant stakeholders engaged in the development and periodic review and revisions of these policies?
- Are the policies and practices of the SDOH information exchange initiative covered by the HIPAA rules, FERPA, and other applicable laws and policies, including individual consent policies and restrictions?



Spotlight: OCHIN

SDOH Information Exchange Values, Principles and Privacy

Jennifer Stoll, Executive Vice President

March 28, 2023

OCHIN

A driving force for health equity

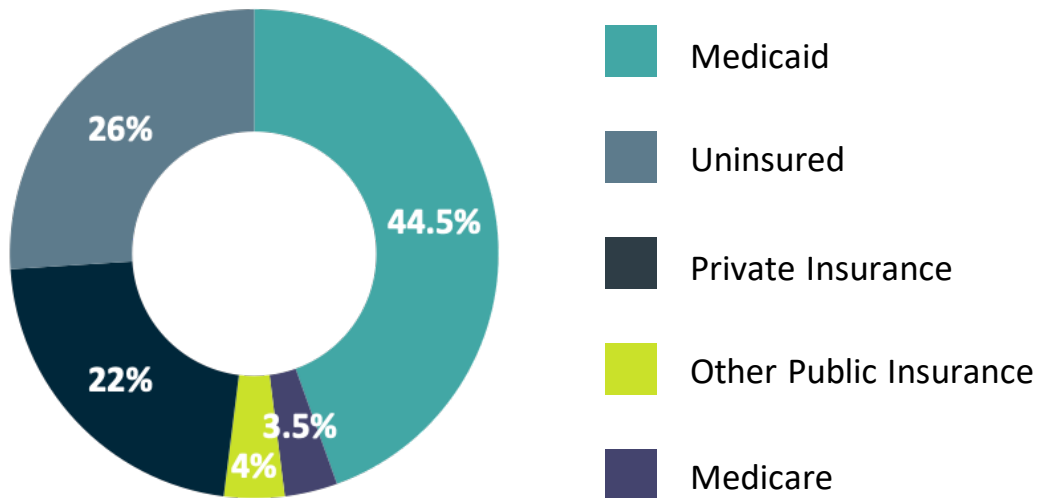
The OCHIN Network Supports

6M+ Active Patients

66% Female | 19% Children

42% At or Below Federal Poverty Level

Payer Mix



From Underserved Communities

Nearly 1 out of 2 network patients are on **Medicaid**, and 1/4 are **uninsured**

2+ out of 5 network patients identify as **people of color** (BIPOC)

3 out of 5 network patients have **chronic conditions***

Nearly 1 out of 3 network patients are **Hispanic/Latinx** (of any race)

Nearly 1 out of 3 network patients are best served in a **language other than English***

1+ out of 3 network patients screened would **benefit from social support***

**Includes OCHIN Epic patients only*

Why Focus on Social Drivers of Health?



Patient Care - provide users with point of care **context about patients' lives** and situations and the opportunity to work upstream to affect health as our members have some of the most medically and socially complex patients



Population Health Management – provide **targeted subpopulations with interventions** and services that will improve overall health of patients served



Public Health – mitigating harm to **vulnerable populations as demonstrated by COVID-19 it was critical to identifying housing and transportation insecure patients**



Payment and Delivery Models – **cover services** to address social drivers of health and **account for cost** in clinical context associated with social drivers of health in order to achieve sustainable and equitable care.



Research – assessing implementation to optimize improved outcomes and population health through an equity lens

See NASEM (2019): Integrating Social Care into the Delivery of Health Care: Moving Upstream to Improve the Nation's Health
<https://nap.nationalacademies.org/read/25467/chapter/4>

OCHIN Integrated SDOH Documented Screening & Referrals Leading the Nation Among Providers in Underserved Communities

1.8 Million SDOH Screenings

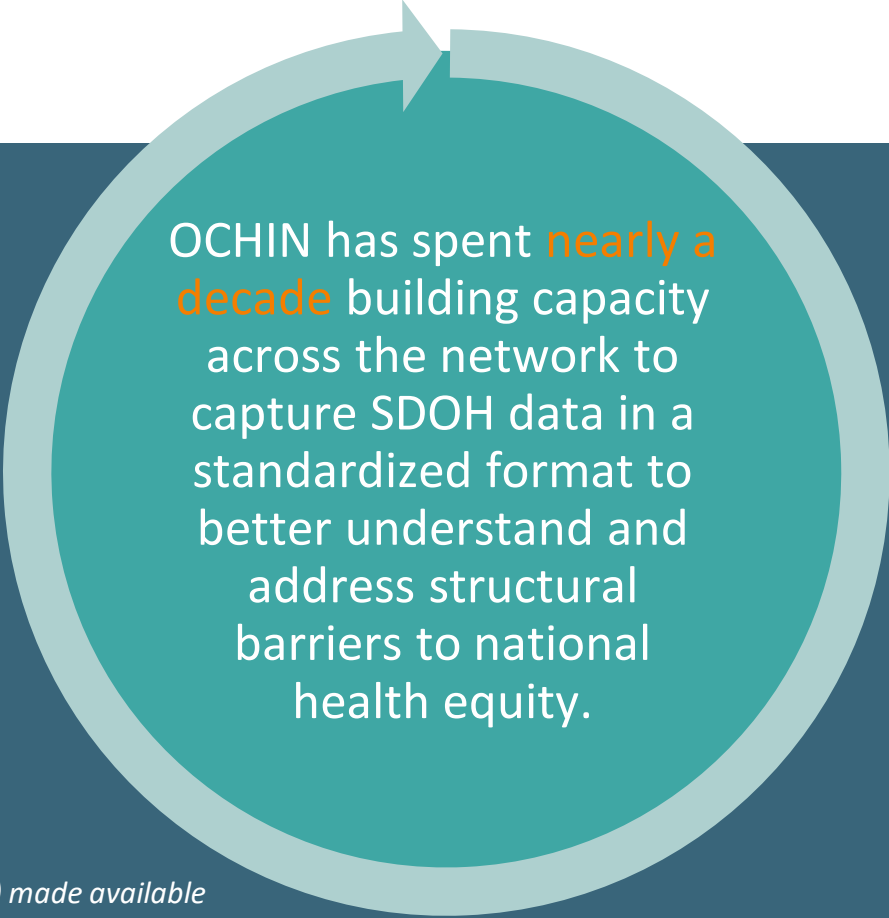
completed across the OCHIN network enhancing care for more than 920,000 unique patients

1 in 3 patients screened
had at least one social need*

Over 6,000 OCHIN Epic-integrated
community service referrals

125,000 screenings have been
conducted via telehealth

Growing patient dataset to
advance disparities research

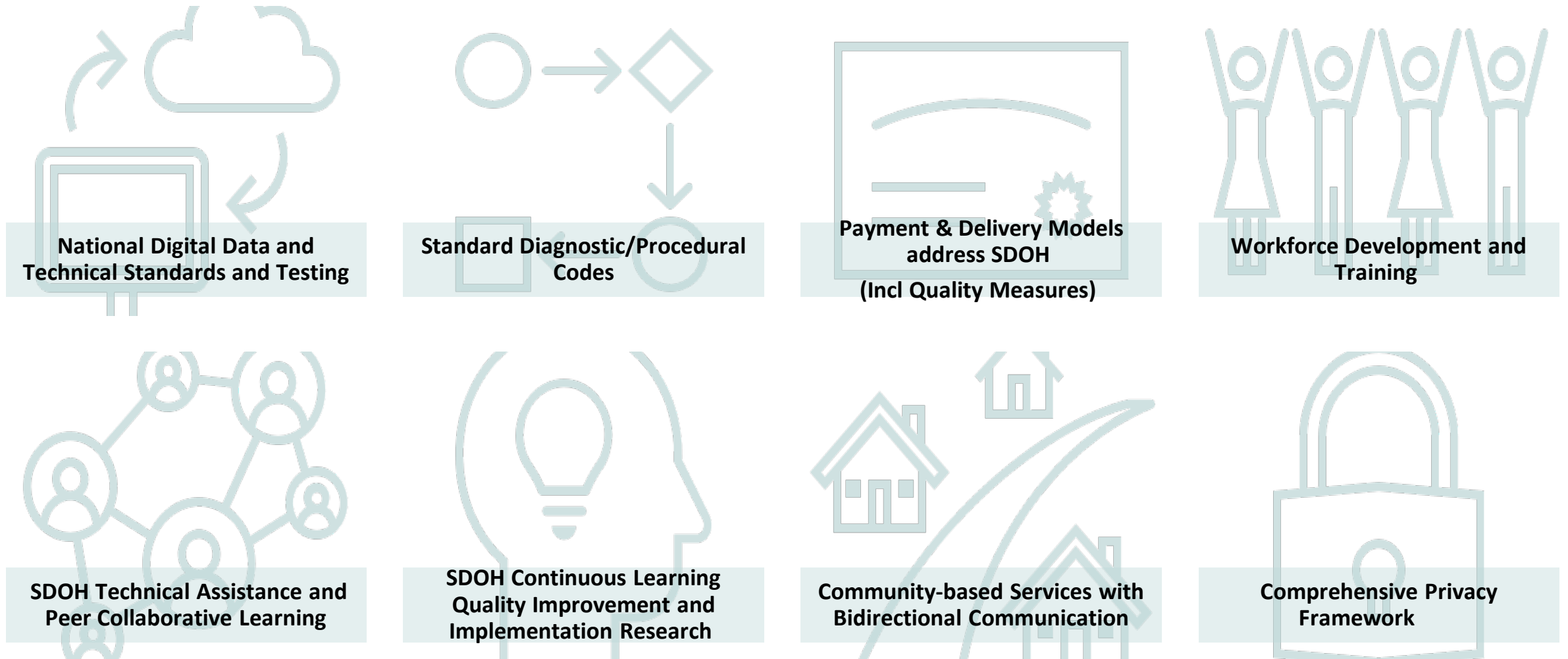


OCHIN has spent **nearly a decade** building capacity across the network to capture SDOH data in a standardized format to better understand and address structural barriers to national health equity.

**Social needs determined by defined SDOH screening categories (shortened PRAPARE instrument) made available via OCHIN Epic, such as food, income, housing, education, or transportation assistance.*

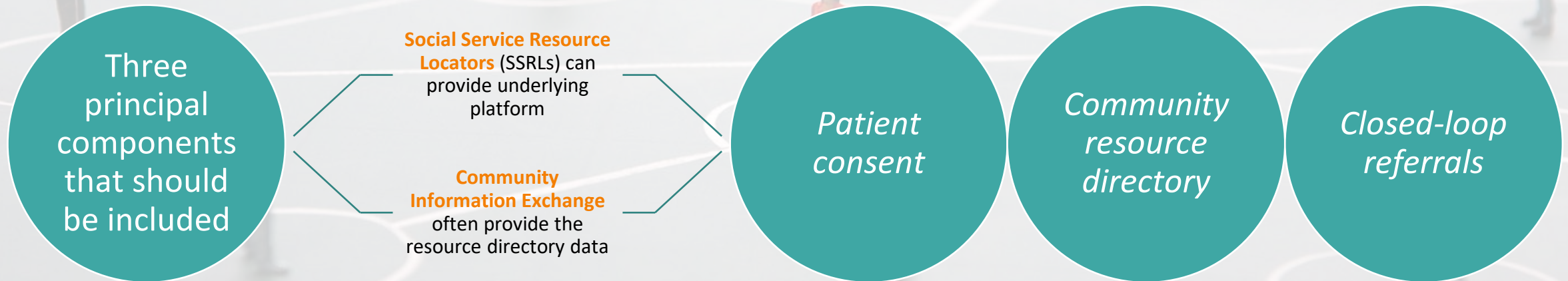
OCHIN Comprehensive SDOH Approach

Support for Patients and Community-Based Providers



What are we learning?

Data Sharing Across Sectors Foundational Requirements from Provider's Perspective – HIPAA as the Established Framework



TECHNICAL CHALLENGES:

Data Exchange has been fraught with legal and operational challenges

- Varied models for patient consent to data sharing
- Disparate regulatory/legal frameworks
- Differing approaches, workflows, code sets, and standards
- Gap in resources/technological capability

Challenges

Partnering

Community Based Organization Partnership

Lack of sustainable resources and money to consistently exchange information

Capacity, capability, and infrastructure are widely varied

Staffing and skill sets are varied in community-based organizations

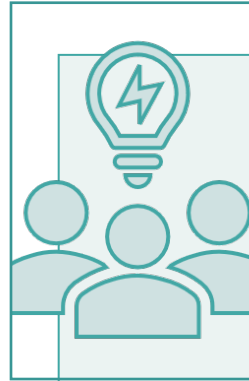
Privacy concerns may result in **trust issues** because there is not a national framework for data governance for CBOs

Too many or too few...

Where is Information Generated Patient Consent Considerations

Proliferation of Data Standards Governing Patient Consent

- States creating standards for consent
- Organizations at local, region, and state level are developing standards for consent
- Organizations with national footprint are also creating differing standards of consent



Both SSRLs and CIEs can have different models for obtaining patient consent to share data – for example

- Some use a **single patient authorization and consent** to enable sharing with any organization that is part of the same network and has signed the appropriate agreements
- Some require **patient authorization and consent for each** sharing of information to any of the participants on its network



Organizations may require their own authorization process and documentation on top of the SSRL/CIE consent process.

State Privacy Laws Creating Patchwork of Complexity



One patient, same data, same ultimate purpose yet different legal framework depending on where data generated

Active State Consumer Privacy Bills

New Hampshire
New Jersey
New York
Oklahoma
Oregon
Rhode Island
Tennessee
Texas
Vermont
Washington

Enacted Consumer Privacy Laws

CA Consumer Privacy Act and Privacy Rights Act
VA Consumer Data Protection Act
UT Consumer Privacy Act
CO Privacy Act
CT Personal Data Privacy and Online Monitoring Act

New Type of Bill – Social Care Information

California Bill on Social Care and Data Privacy (AB 1011)

The bill would prohibit a participating organization of a close-loop referral system (CLRS) from adding to or accessing from a CLRS an individual's personally identifiable information or "social care information" unless the individual provides consent, or if the individual was referred to the participating organization for care.

Policy Recommendations

Drive National Alignment

Drive Adoption of National Digital Data and Technical Standards

- Drive uptake of US Core Data for Interoperability version 2 and version 3

Comprehensive HIPAA Federal Privacy Law

- Extend HIPAA protection to all consumer health information
- Avoid acceleration of state privacy law fragmentation

Thank You

Jennifer Stoll, Executive Vice President
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OCHIN

A driving force for health equity

www.ochin.org





Questions and Discussion



Learning Forum Series and Small Group Opportunities

Feedback

You may enter into the chat your thoughts on these two questions:

- How useful did you find today's ONC SDOH Information Exchange Learning Forum webinar on Values, Principles and Privacy?
- What other content or information would be useful for you in your efforts?

Other feedback or suggestions?

Email: oncsdohlearningforum@hhs.gov



Webinar series schedule

DESCRIPTION	Meeting Date/Time (EST)	Registration Link
Phase I Webinars		
Introduction to SDOH Information Exchange and the Learning Forum	March 2022	View past meeting materials and recordings here
Vision, Purpose, and Community Engagement	April 2022	
Governance	May 2022	
Technical Infrastructure and Interoperability	June 2022	
Policy and Funding	July 2022	
Phase II Webinars		
Community-level Governance	Thur, February 23,12-1:30pm	View past meeting materials and recordings here
Values, Principles, and Privacy	Tue, March 28, 2-3:30pm	View past meeting materials and recordings here
Implementation, Measurement, and Evaluation	Tue, May 23, 1-2:30pm	Register here
SDOH Information Exchange Learning Forum Summary	Thur, June 29, 12-1:30pm	Register here



Small group opportunity: April 12th

Join us on April 12th at 1pm ET to engage a small group conversation on the topic of governance.

- Groups of approximately 10-15 individuals across a diverse set of stakeholder groups.
- Paired with a facilitator and subject matter experts who will guide and support learning and engagement.
- Discussion questions and focus areas will be collaboratively developed.
- Topics will align with the Learning Forum webinar series.

To express interest in small group participation, please email oncsdohlearningforum@hhs.gov for more information on how to join.



Office of the National Coordinator
for Health Information Technology

THANK YOU!



Office of the National Coordinator
for Health Information Technology

Contact ONC

ONCSDOHLearningForum@hhs.gov



Phone: 202-690-7151



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<https://www.healthit.gov/form/healthit-feedback-form>



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