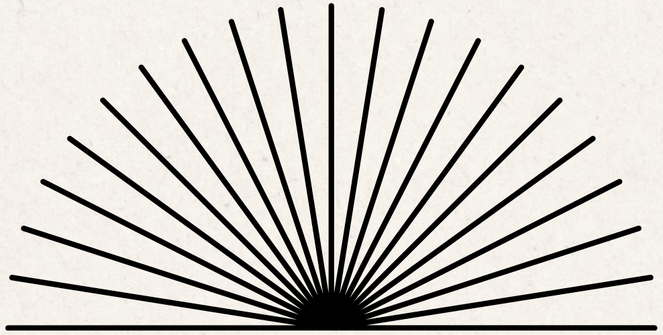
Welcome to Day 2!

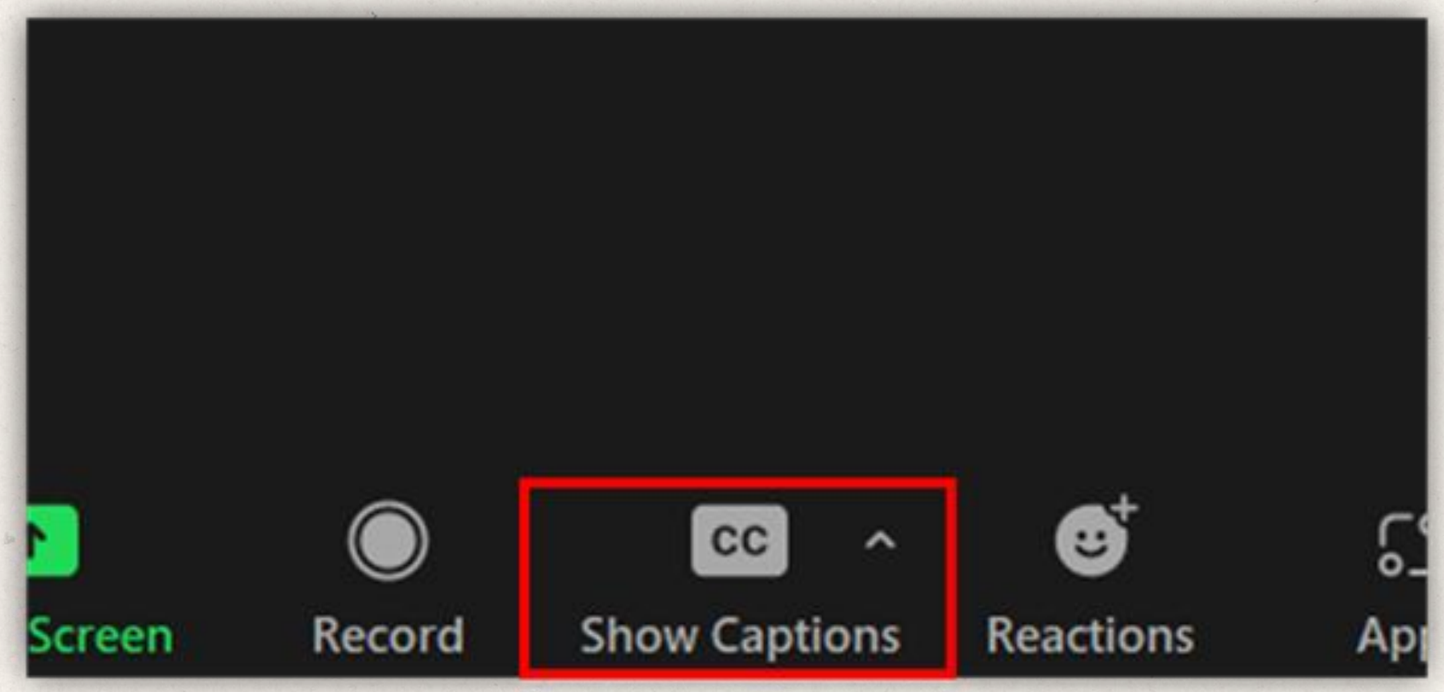


Community Agreements

1. Respect Pronouns
2. Choose to be present (silence devices)
3. Share airtime/invite participation
4. Speak your truth without blame or shame
5. Stay curious: default to inquiry over judgement
6. Own your impact & commit to repair
7. Invitation for laughter
8. Confidentiality & Permission

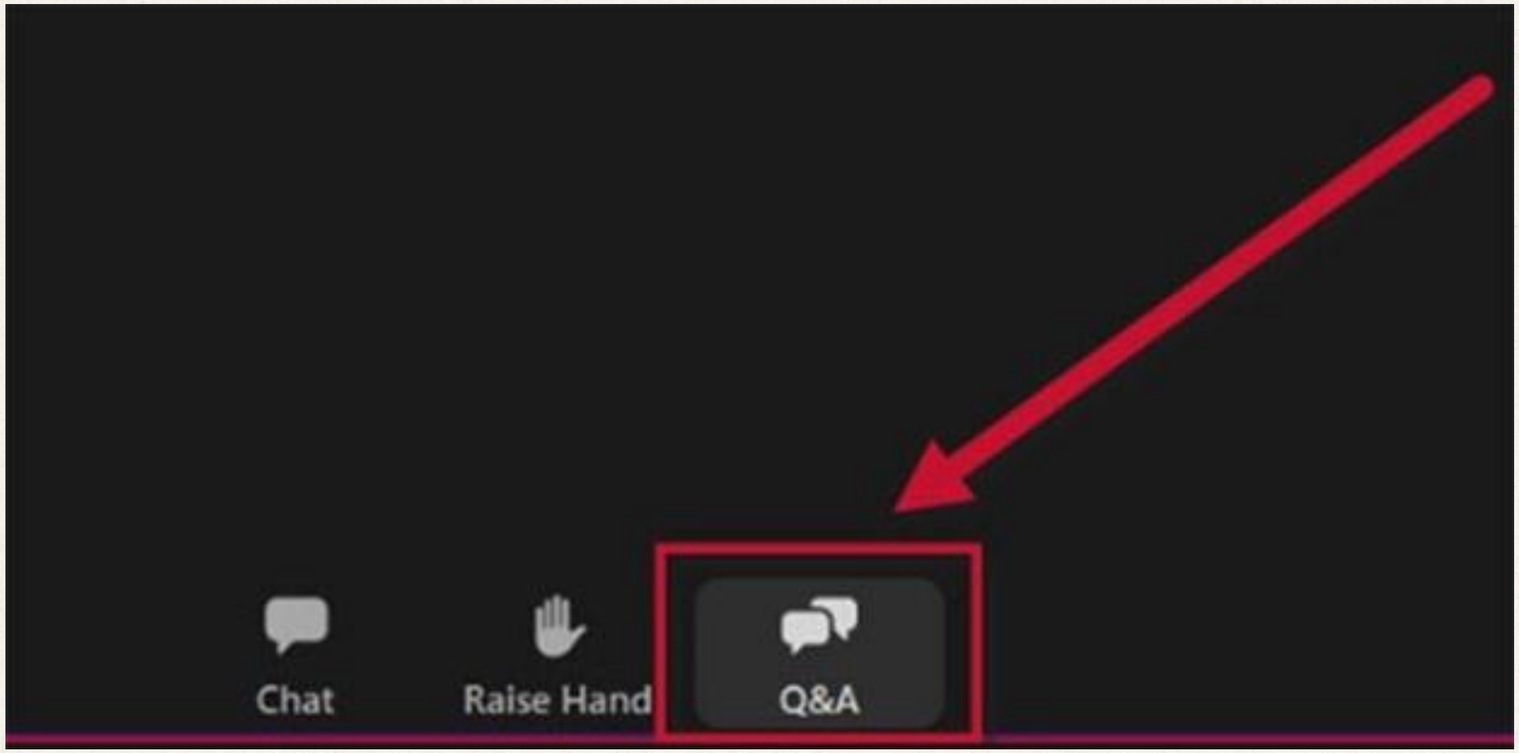
Enabling Closed Captions

Click the small up arrow next to “Show Captions” to access caption controls

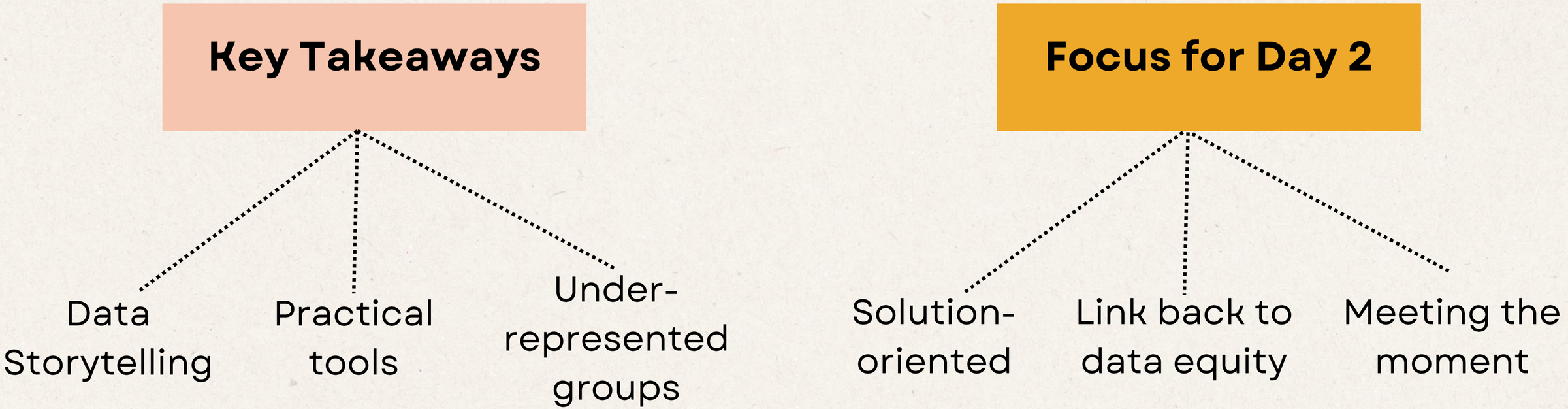


Zoom Q&A Box

Click on the Q&A icon to open up the Q&A box. Post your questions for the speakers in the box.



Day 1 Recap


Key Takeaways
Data Storytelling
Practical tools
Under-represented groups
Focus for Day 2
Solution-oriented
Link back to data equity
Meeting the moment

UNDERSTANDING THE DATA SHARING LANDSCAPE

OREGON DEPARTMENT OF Human Services

OREGON HEALTH AUTHORITY

Session Organizers

Jill Scantlan

She/Her

Data and Evaluation Advisor,
Oregon Health Authority

Matt Friesen

He/Him

READ Manager,
Oregon Department of Human Services

Session Goals

1

Build solidarity around current challenges with data sharing.

2

Bring multiple perspectives to the discussion.

3

Share best practices and solutions for common data sharing challenges.

Overview of Data Sharing Landscape

Sam Kaan

She/Her

Chief Data Officer, Oregon Department of Human Services

Steve Westberg

He/Him

Acting Data Officer, Oregon Health Authority

"Today, data science is a form of power. It has been used to expose injustice, improve health outcomes, and topple governments. But it has also been used to discriminate, police, and surveil."

Catherine D'Ignazio & Lauren F. Klein
***Data Feminism*, 2020**

Overview of Data Sharing Models

Federal Data Repositories That States Feed Into	• Social Security Administration Death Master File • Centers for Disease Control & Prevention Nat'l Vital Statistics System (NVSS) • National Notifiable Diseases Surveillance System (NNDSS) • National Crime Information Center (NCIC) • Dept of Labor Wage Records Program
State Data Repositories Accessible to Federal Government	• DOJ/FBI Sex Offender Registration and Notification Act • FBI Sex Offender Database • State motor vehicle registries and records • Commercial data brokers
State-Held Data for Hybrid Programs	• USDA SNAP and Women, Infants, & Children (WIC) programs • Supplemental nutrition and wage reporting programs

Federal-Level Data Sharing Snapshot

Requester	Data Holder	Data Type
Immigration and Customs Enforcement (ICE)	Internal Revenue Service (IRS)	Tax data
Department of Justice (DOJ), Department of Homeland Security (DHS)	Social Security Administration (SSA), U.S. Citizenship and Immigration Services (USCIS)	Citizenship status
Department of Justice (DOJ), Palantir Technologies	Department of Homeland Security (DHS), Department of Health and Human Services (HHS), Internal Revenue Service (IRS), Immigration and Customs Enforcement (ICE)	Multi-agency datasets
Department of Justice (DOJ), Department of Homeland Security (DHS)	Social Security Administration (SSA), Internal Revenue Service (IRS)	Social Security, taxpayer, and voting records
National Institutes of Health (NIH), Department of Homeland Security (DHS)	Centers for Medicare & Medicaid Services (CMS)	Medicare and autism diagnosis data

State-level data sharing snapshot

Requester	Data Holder	Data Type
United States Department of Agriculture	State Supplemental Nutrition Assistance Program (SNAP) offices	Personally identifiable information (PII), Social Security numbers, and household information
United States Department of Homeland Security	State Medicaid programs in California, Illinois, Oregon, Washington, the District of Columbia, and others	Health data and protected health information (PHI)
United States Department of Justice	State of Colorado	Voting records
United States Department of Justice	Thirty-one U.S. states	Voter registration lists
United States Department of Homeland Security and United States Immigration and Customs Enforcement	California Cash Assistance Program for Immigrants	Public benefits information and immigration status

Litigation Landscape Overview

Snapshot of Current Data Privacy Litigation (as of September 2025)

- **18** active data privacy-related lawsuits
- **10+** federal agencies sued over privacy violations
- **6** federal district courts handling privacy cases (across 5 circuits)

Ongoing Cases and Legal Actions

Area	About
Supplemental Nutrition Assistance Program (SNAP)	Multistate coalition opposing directive to share personal data.
Medicaid	States – California, Washington, and Illinois – seeking injunctions against the U.S. Department of Health and Human Services (DHHS).
Transgender Care	State challenges to anti-transgender health care executive orders.
Social Security	Supreme Court of the United States (SCOTUS) review on limits to federal access.
Internal Revenue Service (IRS)	District court denied the U.S. Department of Homeland Security (DHS) request for individual data.
U.S. Treasury Payments System	U.S. District Court for the Southern District of New York (SDNY) injunction in place; government motion to dismiss pending.

Challenges - Federal Legal Requirements

When Federal Agencies Request State Data, They Must Comply With:

- **The Privacy Act** – Publish a notice in the Federal Register before new data collection.
- **The Paperwork Reduction Act** – Justify proposed collections and invite public comment.
- **The E-Government Act** – Conduct Privacy Impact Assessments.
- **Core Constitutional Principles** – Protect individual privacy under 5th & 14th Amendments.
- **Program-Specific Enabling Statutes** – Define agency and state roles in data sharing.

Challenges - State Legal Requirements

States must comply with the following when providing access to State data:

- **State Privacy Laws** – Vary by state.
- **Program-Specific Federal & State Legal Requirements** – Define sharing and handling.
- **Sector-Specific Federal Privacy Protections** – e.g., HIPAA for health data.
- **State Contracts & Data Sharing Agreements** – Must specify information-sharing boundaries.

Case Study 1: USDA SNAP Data sharing

- **USDA Directive (May 2025)**: Required states to submit 5 years of personal SNAP data, including SSNs and addresses.
- **Legal Challenge**: Oregon and 21 other states sued, citing privacy violations and federal overreach.
- **Funding Threat**: USDA warned it may withhold admin funding from noncompliant states.
- **Court Action (Oct. 15)**: Preliminary injunction blocks USDA from cutting funding during the lawsuit; not a final ruling.

Case study 2: CMS Medicaid data sharing

- **CMS Request**: CMS requested data on Medicaid members using federally funded services, including limited PII, for a financial review.
- **OHA Submission**: OHA submitted consolidated data in Sept. 2025 for adults who used emergency Medicaid (Apr–Jun), including ID, DOB, and eligibility category based citizenship status for these members only.
- **Protecting Individuals**: No immigration status or addresses were shared; data cannot be used by ICE/DHS due to a legal injunction.

Fireside Chat

KQ 1 What are the main data sharing **challenges** State agencies face in the current landscape?

KQ2 What are some **best practices/strategies** for navigating these challenges?

Panelists

Sam Kaan

She/Her

Chief Data Officer, Oregon Department of Human Services

Steve Westberg

He/Him

Acting Data Officer, Oregon Health Authority

Jon McDaid

He/Him

Deputy Director, Office of Community Health and Engagement, Oregon Health Authority

Alma Ponce

She/Her

Senior Regional Outreach Coordinator, Oregon Health Authority

What are the main data sharing challenges State agencies face in the current landscape?

What are some best practices/ strategies for navigating these challenges?

Best Practices

Key Principle: Data Minimization: Collect, maintain, and share only the minimum necessary PII.

- ✓ Don’t mix data on federal/state beneficiaries.
- ✓ Don’t collect or retain sensitive data unnecessarily.
- ✓ Protect privacy under state law.
- ✓ Review existing data-sharing agreements and vendors.
- ✓ Limit access and transfers of personally identifiable information (PII).

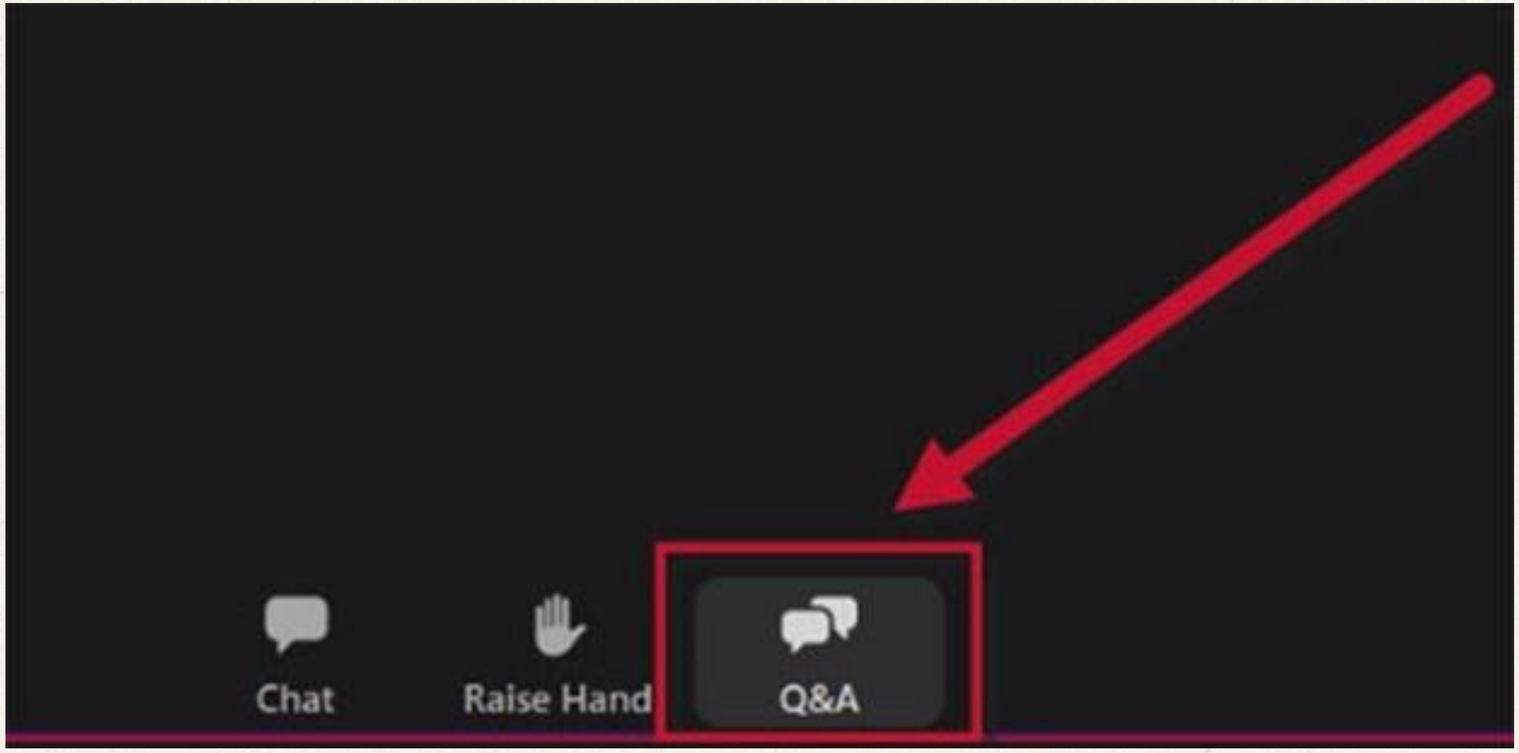
Best Practices Cont.

1. **Centering communities in decision making around data**
- Co-create data collection tools
- Strengthen capacity along the way

2. **Put more intention into data use**
- Be clear on how data will be used and hold ourselves accountable to that

Zoom Q&A Icon

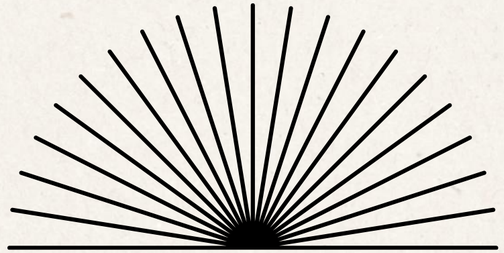
Click on the Q&A icon to open up the Q&A box. Post your questions for the speakers in the box.



BREAK

Q&A with Our Panelists

What's Up Next at the 2025 Data Equity Summit



Session 3:
Data Governance Practices Supporting Equity

Beginning at 1:00PM PT