DIGITAL FRONTIERS IN PUBLIC HEALTH

INSIGHTS AND RECOMMENDATIONS

January 31, 2023

HARVARD T.H. CHAN
SCHOOL OF PUBLIC HEALTH

Ellison Institute

Panelists, breakout room moderators, and hosts (left to right)

Joshua Sharfstein, MD; T.J. Lane, MPH; Monica Bharel, MD, MPH; Gabriel Seidman, DrPH (back row); Ivor Braden Horn, MD, MPH; David Brailer, MD, PhD; Anne Zink, MD, FACEP; David Feinberg, MD; David Agus, MD; Lisa Bari, MBA, MPH; Barbara Ferrer, PhD, MPH, MEd; Anthony Iton, MD, JD, MPH; Claudia Williams, MS (front row); Trishan Panch, MD, MPH; Michelle A. Williams, ScD; Julie L. Gerberding, MD, MPH

OPENING REMARKS | KEY TAKEAWAYS

Speaker: Dr. Gabriel Seidman

- Patients deserve access to health data that empowers them to manage their medications, their labs, and their care. Health care leaders need a system that gives them the right data at the right time to make decisions that will save lives.
- Unfortunately, we don't have that system in the United States. Patients still experience delays in care and errors due to missing health data. Leaders are still missing systems that can integrate public health, clinical, and social determinants data to inform public health and population health.
- There are many important initiatives underway to address this issue, including CDC's Data Modernization Initiative, the Trusted Exchange Framework & Common Agreement (TEFCA), and the PREVENT Pandemics Act.
- However, across the states and territories, fragmented regulations, insufficient infrastructure, and gaps in funding and workforce still pose obstacles to progress.
- Leaders need to keep attention on this issue and build sustained political will to improve our nation's health data ecosystem.

A frontier can be an exciting place to break new ground or a place where you encounter unforeseen hurdles. What's next on the digital frontier? Where will we break new ground and where will we get stuck?

— Gabriel Seidman
Director of Policy, Ellison Institute

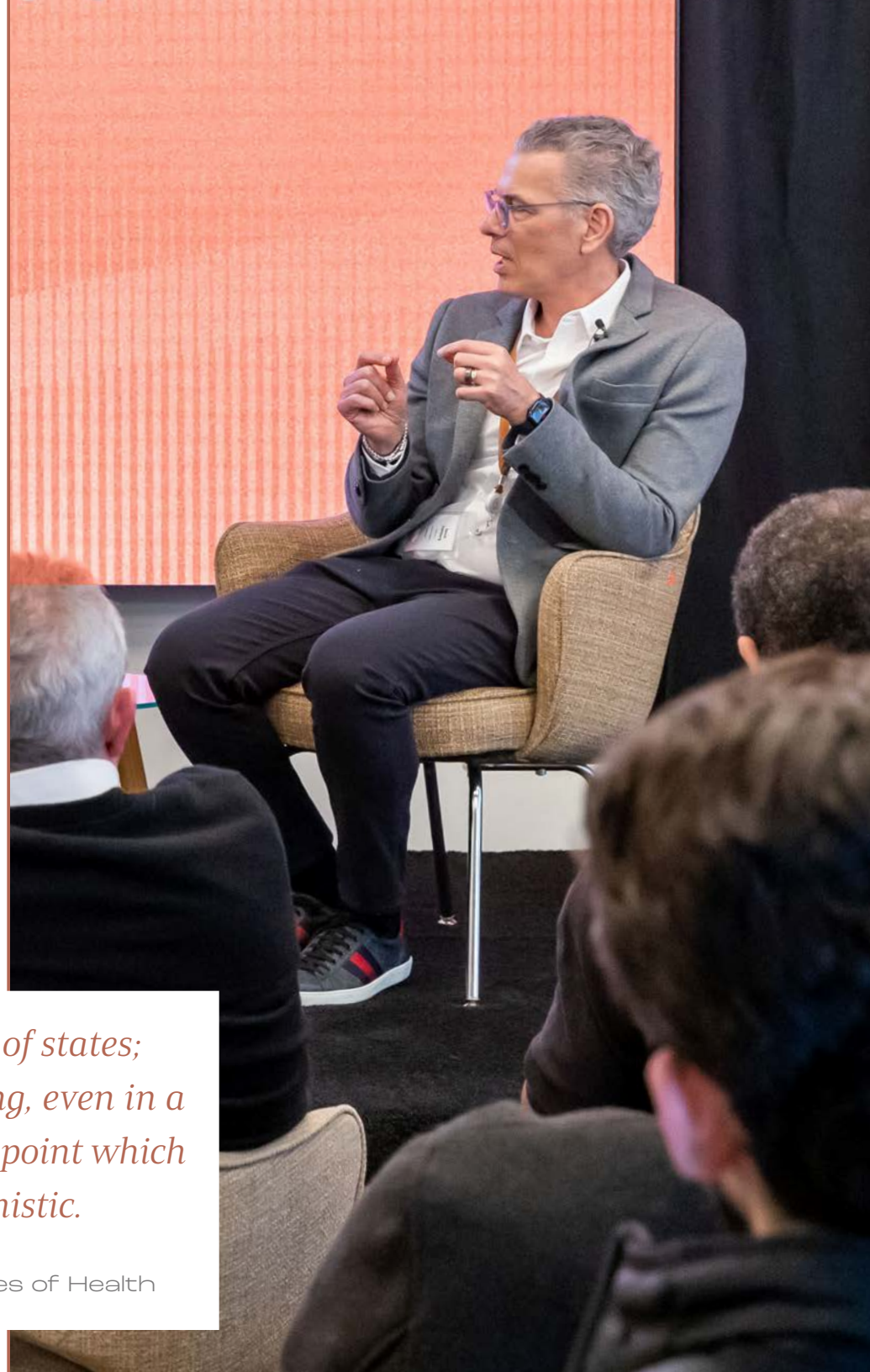
PANEL DISCUSSIONS | KEY TAKEAWAYS

Architecture for health data at the federal level

Moderator: Dean Michelle A. Williams

Panelists: David Brailer, David Feinberg, and Julie L. Gerberding

- Our current system is deeply dysfunctional: There are still challenges to interoperability; health departments still often use faxes to share information; the CDC faces barriers to mandate data reporting, even in a public health emergency.
- State public agencies are often very reluctant or slow to share data with the federal government.
- In the U.S., investments in data sharing and integration have mostly focused on primary uses such as clinical care. But data sharing and integration has enormous potential for secondary uses: Disease surveillance, population health management, and the use of real-world evidence to shape prevention and treatment recommendations.
- Public distrust and political polarization have made this an especially difficult time for federal agencies to advance health data initiatives.
- Culture change of any kind is hard. Culture change in government is exponentially harder.



We have a big challenge here in being a federation of states; there is still no authority to mandate data reporting, even in a public health emergency... And that's a major choke point which hasn't been overcome. So it's hard for me to be optimistic.

— Julie Gerberding
CEO, Foundation for the National Institutes of Health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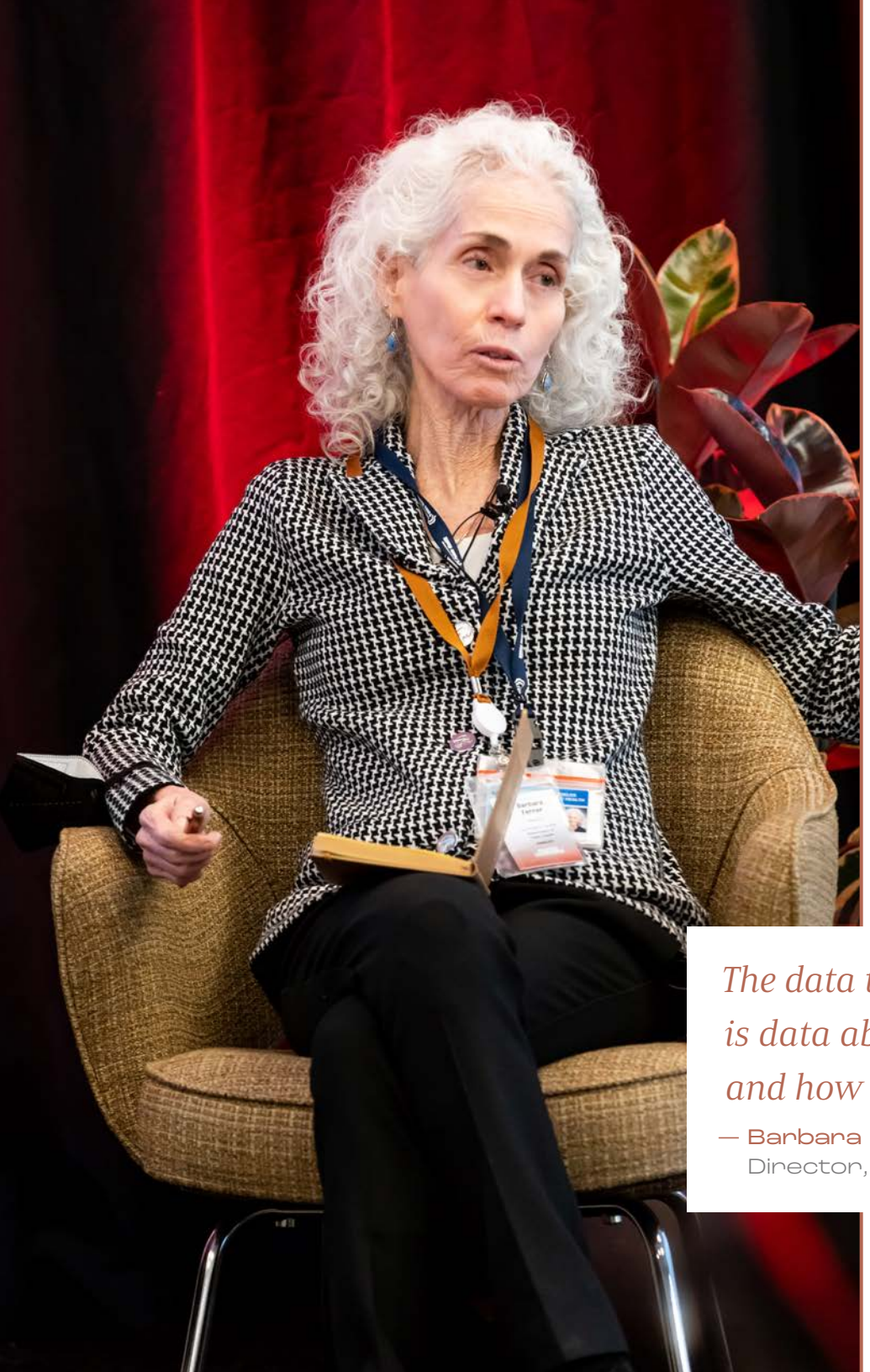

Architecture for health data at the state and local level

Moderator: Dr. David Agus

Panelists: Barbara Ferrer, Anthony Iton, Claudia Williams, and Josh Sharfstein

- To protect public health, it's critical to integrate clinical data, social determinants data, and public health data in the same system.
- These data have many use cases—everything from mapping slip-and-fall cases to fixing public health hazards like uneven sidewalks to addressing chronic truancy in schools.
- While de-identified data are useful, providers and public health officials also need access to personal data so they can connect individuals to the services and supports they need.
- One promising model is for statewide health information exchanges to act like public utilities, with strong governance, buy-in from all hospital systems, and a reliable funding stream.
- Federal funding for local data modernization is paltry. Speakers noted that Los Angeles County expects just $8 million over five years to upgrade its infrastructure (which serves a population of 10 million people).

The data that we really need to [gain trust] in our communities is data about how people feel, and what they think they need, and how can we be helpful?

— Barbara Ferrer
Director, L.A. County Department of Public Health


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BREAKOUT SESSIONS | KEY TAKEAWAYS

Harnessing patient data for public health goals

- States and territories have much of the authority to collect and use health data, but each jurisdiction has different regulations.
- Participants called for a transparent overview of each state's legal and regulatory landscape—a roadmap to help states strengthen their data ecosystems and align with federal standards.
- Participants also noted challenges around (perceived) ambiguity about data sharing regulations, a reluctance to share data across state agencies, and limited workforce capacity to analyze and leverage data.
- Leadership that will support all states and territories, including funding and training, is critical.

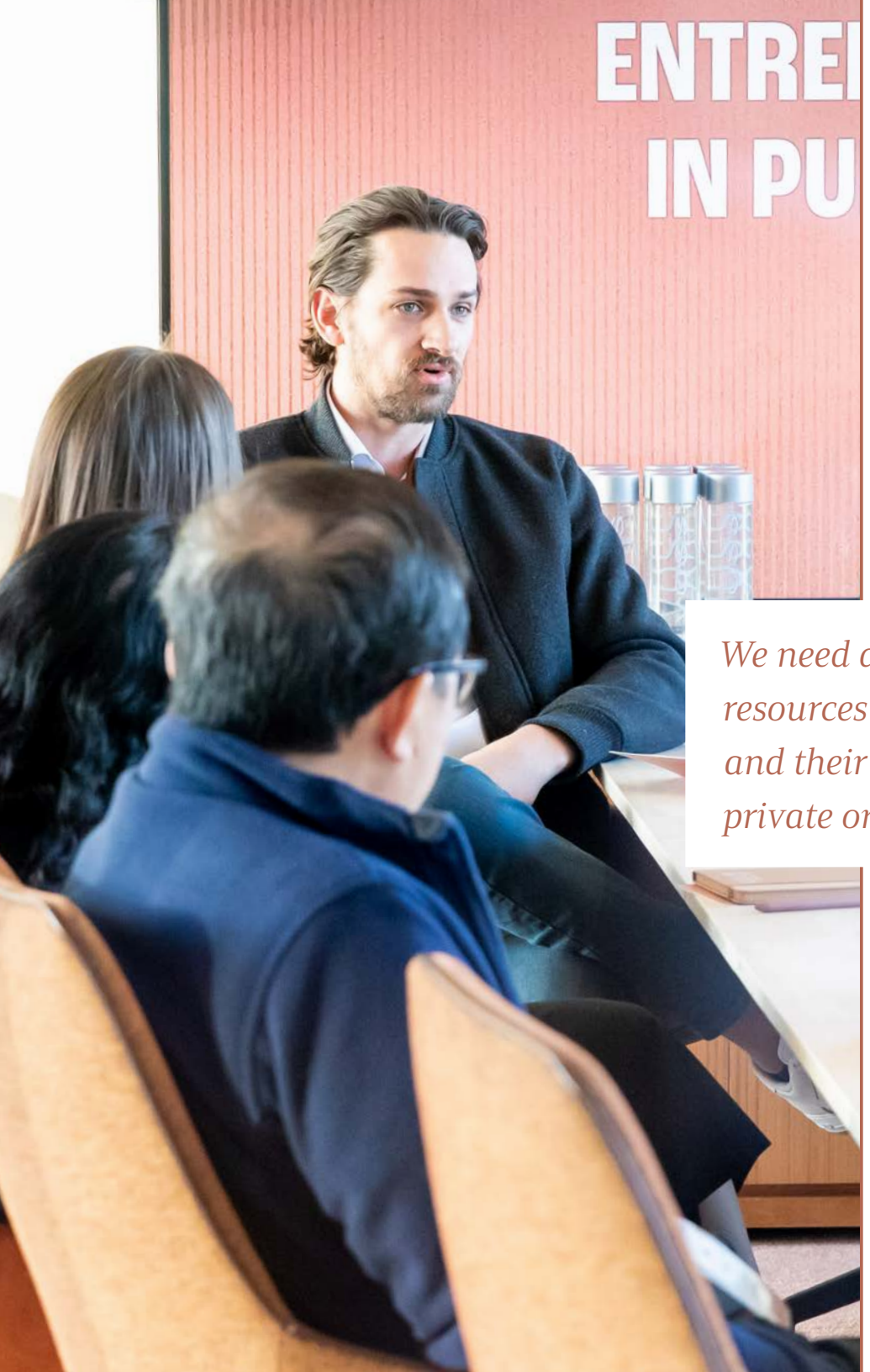
We need to understand legislation in each state... a clear documentation of wins and losses and how you got there. It would be useful to have a playbook with key insights and outcomes.

Developing best practices for data sharing, security, and governance

- Regulations and infrastructure vary across jurisdictions, states, and the federal government, so we don't have a unified national data ecosystem.
- HIPAA authorizes disclosure of protected health information for public health purposes, so, as a rule of thumb, federal privacy laws should not be the greatest barrier to data sharing.
- States that use "opt-out" consent for sharing health data, rather than "opt-in" consent, typically have a stronger track record with sharing health data effectively for public health purposes.
- Participants noted successful examples from a number of states, including Maryland, California, and Vermont.

Building successful public-private-academic partnerships

- Building partnerships that improve health outcomes requires trust and leadership.
- Strong leadership can establish legal frameworks and systems to enable secure data sharing that protects patient privacy.
- Leaders can also establish incentives that benefit each partner, such as giving academics the ability to publish research using shared data
- Participants noted examples of successful public-private-academic partnerships to share data to improve public health from across the country, including in Massachusetts, California, and at the federal government level.



Nurturing entrepreneurship in public health

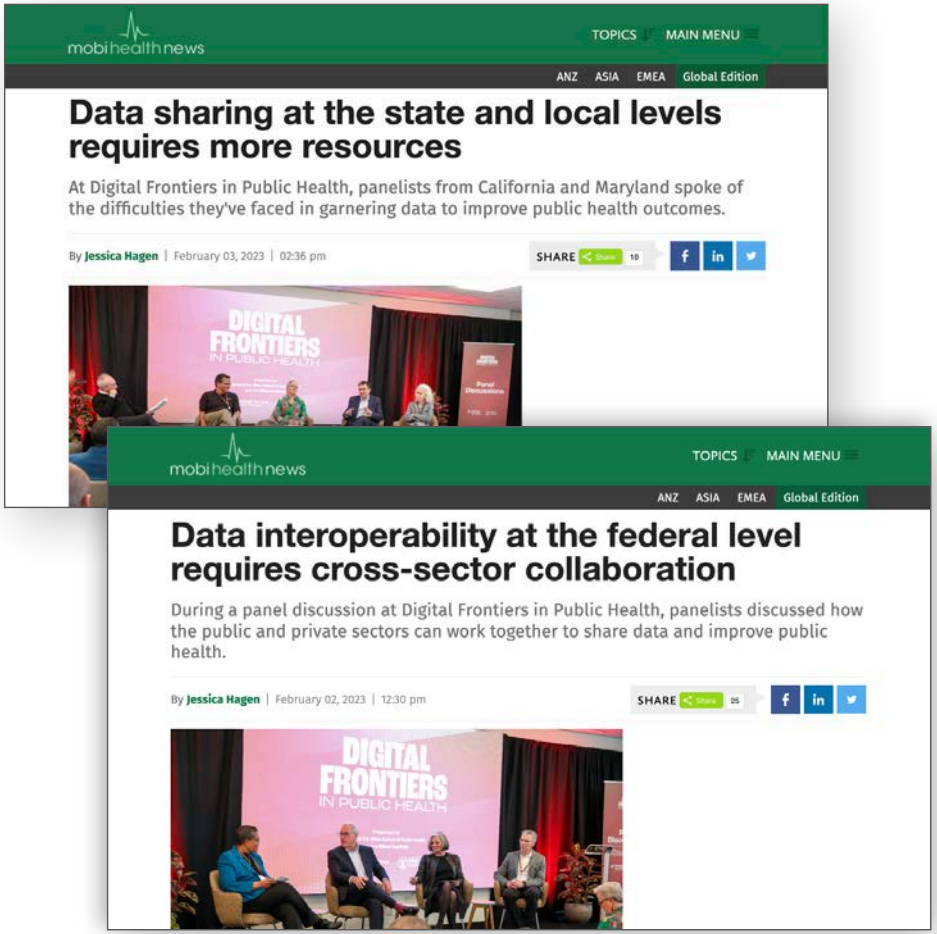
- Governments have a critical role in nurturing innovation to tackle public health challenges.
- Incentives could include scientific grants, market guarantees for innovators, and competitions.
- Participants noted the importance of bringing in the community to help develop solutions; the people being served must help define the problem and pressure test solutions.
- It is important for each sector to recognize where their strengths are, and where they need to rely on one another for expertise.

We need a governance structure that determines how we share resources and technologies. A governance layer protects people and their health data and is the body that oversees which private organizations become involved.

Leveraging technology to advance health equity

- Health data is irrelevant without context, such as social determinants.
- We need to tell stories with our data, explaining why it matters and what changes it should spur.
- Participants noted that “public health is a public good,” and any new technology that seeks to improve health and wellness must have a mechanism to support those who may be left behind.

MEDIA COVERAGE

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