



Building Trust in Health Science Through Community Partnership & Lived Experience

Learning and Leading: *Together Virtual Roundtable*
September 17, 2025



Building Trust in Health Science Roundtable: Learning & Leading - Together



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Shaneah Taylor, NAM Acting Director of Programs

Agenda

2:00pm- 2:10pm ET	Welcome & Framing
2:10pm-2:30pm ET	Overview & Framework Introduction
2:30pm- 2:50pm ET	Framework & Structure
2:50pm-3:15pm ET	Interactive Breakouts
3:15pm- 3:25pm ET	Reconvening & Reflection
3:25pm-3:30pm ET	Closing

National Academies of Sciences, Engineering, and Medicine (NASEM)

- Provides objective, evidence-based advice on science, technology, and health
- Composed of three academies: NAS (Sciences), NAE (Engineering), NAM (Medicine)

Health for everyone,
everywhere.



National Academy of Medicine (NAM)

- Founded in 1970 as the Institute of Medicine; renamed NAM in 2015
- Mission: Advance science, improve health, and promote equity
- Focuses on health policy, biomedical research, workforce well-being, and global health
- Advances health for all through cross-sector partnerships, evidence-based research, and public partnerships and engagements

The Action Collaborative: Mission

Strengthening public trust in health science by fostering genuine community partnerships, promoting transparency in research practices, and amplifying lived experiences. The Collaborative aims to bridge the gap between scientific institutions and the communities they serve, ensuring that health science is inclusive, responsive, and rooted in trust.

The Action Collaborative: Vision

To establish a strategic infrastructure that builds and sustains public trust in health science—advancing health and well-being for all through inclusive partnerships, operational excellence, and evidence-based collaboration.

Health Science Defined

An interdisciplinary field that applies principles from biology, chemistry, psychology, sociology, and public health to understand, improve, and sustain human health. It encompasses both the study of disease and wellness, and the development of interventions, technologies, and systems that promote physical, mental, and social well-being.

Definition and Reality

The definition of health science is both descriptive (*understanding health patterns and causes*) and prescriptive (*developing solutions to improve health outcomes*).

The Reality

- ***HOW* are communities truly experiencing health science—and *WHY* do those experiences often lead to mistrust?**
- **How is health science showing up in people's lives and why do those encounters frequently fall short of building trust?**

Why Trust in Health Science Matters

- **Enables Public Adoption of Evidence-Based Solutions-** Without trust, even the most effective interventions fail to reach those who need them
- **Protects Against Misinformation-** A trusted scientific voice is a critical defense in an age of disinformation and skepticism
- **Accelerates Crisis Response-** In moments of public health emergency, trust drives swift, coordinated action
- **Fuels Innovation with Accountability-** Trust allows science to evolve boldly—while staying grounded in ethical responsibility
- **Strengthens Health Equity-** Trust ensures traditionally excluded communities engage with and benefit from scientific advancements
- **Transforms Science into Public Good-** When trusted, health science becomes not just knowledge, but a shared tool for well-being

From Engagement to Partnership: From Transaction to Transformation

Community Engagement

- Often one-directional: informing, consulting, or soliciting feedback
- Short-term or project-based involvement
- Community may be invited to react, not co-create

Community Partnership

- Built on mutual trust, shared power, and long-term collaboration
- Communities are co-designers, decision-makers, and evaluators
- Requires transparency, accountability, and sustained investment

Co-Creation

- **Definition:** A collaborative process where communities and institutions work together from the start to define problems, shape priorities, and imagine solutions.

In This Collaborative:

- Community members help define what trust looks like
- Lived experience guides the framing of health science challenges
- Equity is built into the foundation—not added later
- Institutions listen, adapt, and share power

Co-Development

- Definition: A joint effort to build, refine, and implement specific tools, policies, or interventions based on shared priorities.

In This Collaborative:

- Communities and experts co-design messaging, data tools, and engagement strategies
- Feedback loops ensure solutions evolve with community input
- Products reflect both scientific rigor and cultural relevance
- Trust is reinforced through transparency and responsiveness

Co-Creation vs. Co-Development in the Collaborative

Co-creation builds the blueprint. Co-development builds the structure. Trust is built when both are done together—with communities at the center.

Lived Experience

- Firsthand knowledge gained through direct life events inclusive of oral history
- Distinct from academic theory or secondhand observation
- Rooted in personal, emotional, and social realities

The Power of Lived Experience: The Expertise That Data Alone Can't Capture

- **Lived experience reveals the human impact of systems, policies, and research**
- **It brings context, nuance, and emotional truth to health science**
- **Elevating lived experience ensures relevance, equity, and trust**
- **It challenges assumptions and reshapes priorities from the ground up**



Honoring Origins, Let's Dig!

- Originated in phenomenology (late 19th–early 20th century)
- Introduced by Wilhelm Dilthey to distinguish subjective experience from scientific analysis.
- Expanded by Edmund Husserl and Martin Heidegger
- Popularized by Simone de Beauvoir in feminist and existential thought

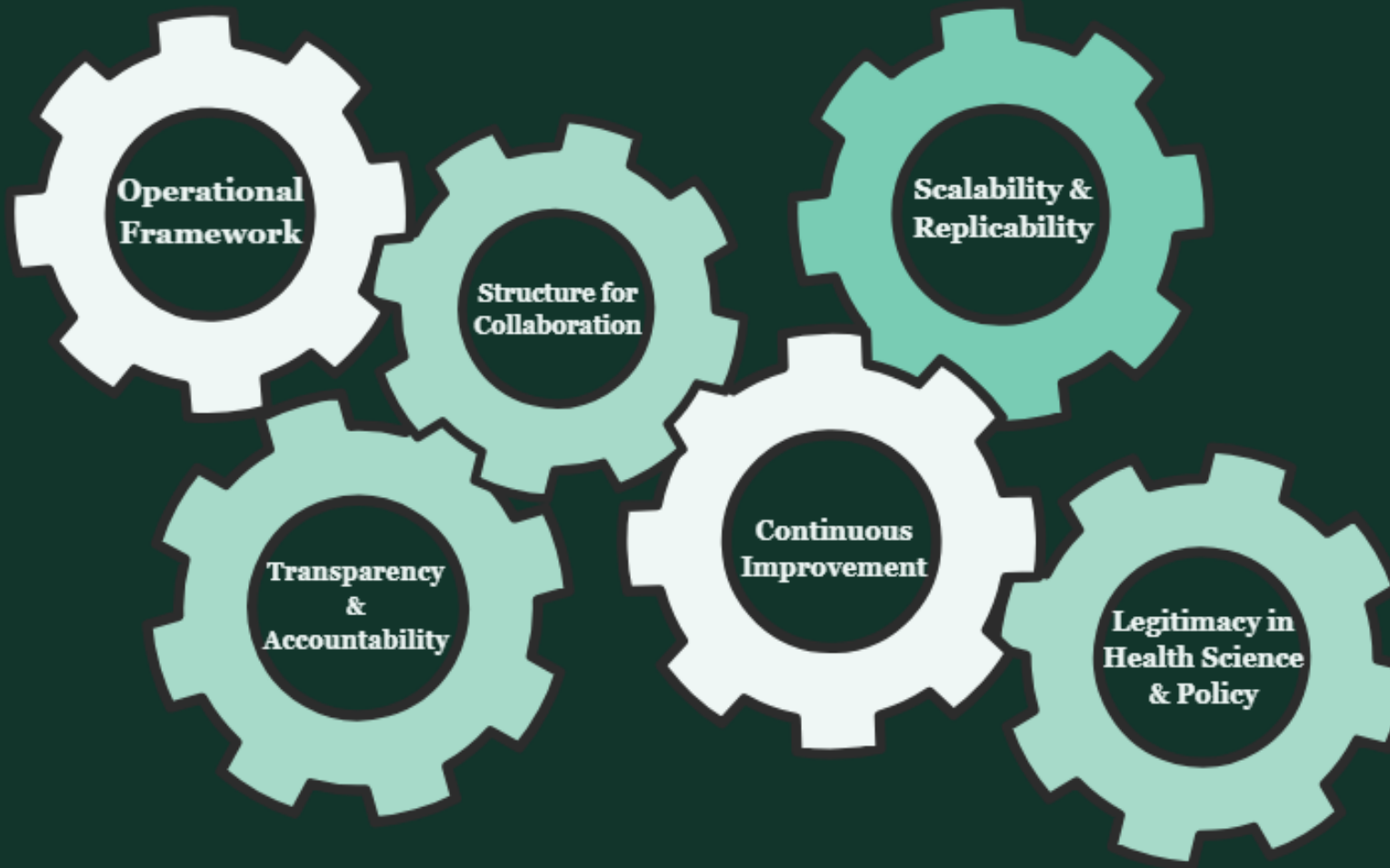
Everyday Meaning

- **“I know because I’ve lived it!!”**
- **Affirms personal stories and oral history as valuable and instructive**
- **Builds agency and trust in decision-making**
- **Shifts power from institutions to individuals and communities**

Why Lived Experience Matters in Health Science

- Valid form of knowledge especially in public health
- Reveals the real-world impact of systems and policies
- Challenges traditional hierarchies of expertise and values other ways of knowing
- Encourages co-creation and co-development of solutions with communities

Framework: The Engine of Systems Change: Collective Impact and Results Based Accountability



An operational framework- Existing resources aren't just vetted and successful planning tools. They are and can be the backbone of coordinated action

Structure for Collaboration- It aligns diverse stakeholders around shared goals, roles, and metrics, preventing fragmentation and duplication

Scalability & Replicability- A well-defined framework allows successful models to be adapted across different communities and contexts

Transparency & Accountability:- Builds trust by making progress visible and measurable—communities can see what's working and why

Continuous Improvement- Specific frameworks support feedback loops, enabling real-time learning and refinement of strategies

Legitimacy in Health Science & Policy:- In global health and research, structured approaches signal rigor, and readiness for institutional adoption and systemic replication

Collective Impact Core Principles:

- **Common Agenda**
 - Shared vision for change
 - Jointly defined goals and priorities
- **Shared Measurement Systems**
 - Consistent metrics across partners
 - Tracks progress and informs strategy
- **Mutually Reinforcing Activities**
 - Coordinated efforts across sectors
 - Each partner contributes through their strengths
- **Continuous Communication**
 - Builds trust and shared understanding
 - Promotes transparency and alignment
- **Backbone Support Organization**
 - Dedicated team to coordinate and manage the initiative
 - Provides strategic guidance, facilitation, and data support

Results Based Accountability (RBA)

Is structured around two key levels—population accountability and performance accountability.



Population Accountability refers to the well-being of entire populations (e.g., all children in a city, all residents in a region).



We are accountable to:

The public: citizens, families, and communities whose lives we aim to improve.

Policymakers and elected officials: who allocate resources and set priorities.

Cross-sector partners: including schools, health systems, nonprofits, and businesses that share responsibility for outcomes.



Results Based Accountability (RBA)

Performance Accountability: focuses on the effectiveness of programs and services delivered by organizations.



We are accountable to:

Customers or service recipients: those directly impacted by the program.

Funders and grantmakers: who expect measurable results for their investment.

Internal leadership and staff: who must ensure quality and efficiency

Oversight bodies: such as boards, auditors, or regulatory agencies.



Results Based Accountability Asks Three Core Questions: Turn the Curve

- How much did we do?
- How well did we do it?
- Is anyone better off?

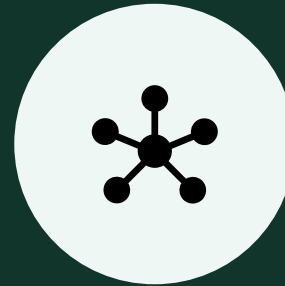
Elevating What Works: Trusted Methods for Trust-Building in Health Science

- **Field-tested and widely adopted across sectors**
- **Translate complexity into actionable steps**
- **Center accountability and measurable outcomes**
- **Bridge research with real-world application**
- **Avoid reinventing the wheel by leveraging existing models**

Data Driven Integrated Impact



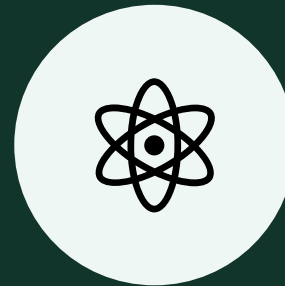
Operational
Framework



Relationship Based
Strategy



Community
Partnership and Lived
Experience



Scientific Rigor



NATIONAL ACADEMY OF MEDICINE

Pillar One: Operational Framework

- Anchored in Collective Impact and Results-Based Accountability (RBA)
- Provides structure for cross-sector collaboration
- Aligns partners around shared goals
- Enables scalable, repeatable implementation
- Supports data-driven decision-making and continuous improvement



Pillar Two: Relationship-Based Strategy

- Builds trust through authentic partnership
- Centers empathy and long-term commitment
- Encourages inclusive dialogue, co-creation & co-development
- Strengthens cross-sector collaboration
- Promotes equity by elevating traditionally excluded voices and those most affected



Pillar Three: Community Partnership & Lived Experience

- Centers equity and relevance
- Elevates lived experience as expertise
- Builds trust through shared ownership
- Improves responsiveness to community needs and voices
- Addresses historical exclusion
- Strengthens the collaborative's legitimacy



Pillar Four: Scientific Rigor

- Ensures validity and reliability
- Builds institutional credibility
- Supports ethical accountability
- Drives innovation and continuous learning
- Strengthens global health impact



Integrated Impact

- *Operational Framework* provides structure
- *Relationship-Based Strategy* builds trust
- *Community Partnership* ensures relevance and equity
- *Scientific Rigor* delivers trusted practice and evidence-based, validated knowledge



Rationale for a Multi-Source Selection Strategy for Action Collaborative Membership

To build a credible and impactful Action Collaborative, we must draw from three interconnected sources:

- **Existing and emerging partnerships** offer trust, continuity, and operational readiness. Noting that each relationship maybe different.
- **Scientific experts** bring domain-specific knowledge essential for evidence-based solutions.
- **Community Health Needs Assessments (CHNAs)** surface lived experience, local priorities, and equity gaps.

This triangulated approach ensures that the collaborative is:

- **Rooted in reality** — guided by what communities say they need, not what outsiders assume.
- **Scientifically sound** — informed by rigorous, cross-disciplinary expertise.
- **Ethically grounded** — avoiding parachute science by elevating community voice, co-ownership and partnerships over time.

Collaborative Goals: A Summary

- **Consistently centering lived experience**
- **Ensuring scientific rigor and ethical integrity**
- **Strengthening cross-sector collaboration**
- **Scaling infrastructure for systems change**
- **Promoting inclusive, flat leadership and co-creation**
- **Communicating transparently, effectively and bi-directionally**
- **Driving measurable, community-shaped outcomes**

Cross-Matrixed Role Categories & Selection Criteria

Role Category	Selection Criteria	Strategic Contribution
Community & Lived Experts	Trusted locally; experienced in advocacy, storytelling, frontline work, oral history	Ground the work in lived realities; ensure relevance and equity
Subject Matter Experts	Expertise in each category of health science and other relevant industries	Translate evidence into strategy; uphold rigor and ethical standards
Institutional Partners	Capacity to implement systems change, share resources, co-create policy	Drive policy alignment; scale infrastructure; sustain long-term impact
Collaborative Builders	Skilled in facilitation, trauma-informed leadership, cross-sector partnerships	Foster trust and cohesion; ensure equity-centered process
Research & Evaluation Leads	Committed to inclusive metrics, qualitative/quantitative insight, ethical frameworks	Measure progress meaningfully; ensure accountability and learning
Implementers & Innovators	Ability to pilot programs, mobilize infrastructure, scale community solutions	Turn ideas into action; adapt and replicate successful models
Public Relations & Marketing	Skilled in strategic messaging, audience engagement, media relations	Build public trust; amplify impact; ensure transparency and accessibility
Ethics Experts	Deep understanding of research ethics, cultural humility, and community safeguards	Protect integrity; guide responsible decision-making and implementation

Why “Building Trust in Health Science Through Community Partnership and Lived Experience” Is a Call to Action

- **Partnership:** We commit to long-term, power-sharing relationships—not one-time engagement
- **Co-Creation:** Communities help define the problems, shape the priorities, and imagine the solutions
- **Co-Development:** We build tools, policies, and systems together—grounded in both evidence and lived experience
- **Intentionality:** The title reflects a deliberate shift from institutional control to community-centered leadership. Not just words
- **Action-Oriented:** This is not symbolic—it’s a commitment to measurable change, rooted in equity and trust



Key Aspirations

- **Build measurable trust in health science** through transparency, accountability, and shared outcomes
- **Advance health equity** by centering community voices and lived experience in decision-making
- **Strengthen cross-sector collaboration** using proven frameworks like Collective Impact and RBA
- **Translate scientific knowledge into real-world impact** that communities can see, feel, and shape
- **Establish scalable infrastructure** for systems change that can be replicated across geographies and disciplines
- **Promote inclusive leadership** by elevating community partners as co-creators, not just stakeholders
- **Ensure scientific rigor and ethical integrity** in all aspects of research, implementation, and communication
- **Position health science as a trusted public good**, responsive to societal needs and grounded in shared values

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*Elisabeth Solomon, Research Assistant of Building Trust
in Health Science Action Collaborative*

Our Starting Point...



We Want to Hear from You –Mentimeter Activity

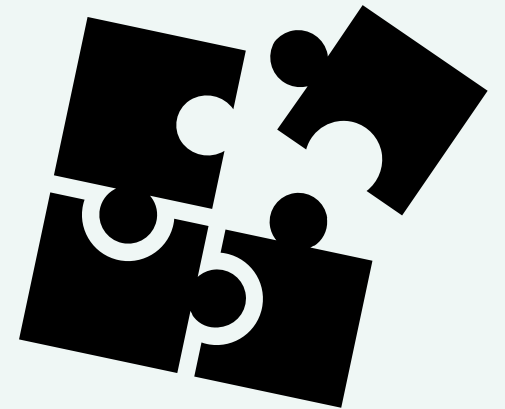
- Action Collaborative Framework & Structure
- Navigate to [mentimeter.com](https://www.mentimeter.com)
- Enter the code **2396 5890**
OR
- Scan our QR Code 



Time to Discuss- Breakout Sessions

Breakout Themes

- Trust in Health Science
- Factors that Influence or Limit Trust
- Community Engagement & Partnership
- Transparency & Communication
- Representation
- Building the Collaborative
- Breaking and Rebuilding Trust



Reconvening & Reflection

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Jill Sonke, US Cultural Policy Fellow



Arts & Culture

Why they are important in this collaborative

Your poem...

Honoring your words, perspectives, and lived experiences

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Thank you!

Connect with us!

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