MEETING FOCUS: Building partnerships and implementing principles and priorities to achieve the vision of a health system that shares data for continuous learning and improvement.

Motivating Questions: Each stakeholder workgroup in developing their stakeholder statement will consider the following:

1. Vision: Does the vision statement for a health system that shares data for continuous improvement clearly articulate the benefits of widespread data sharing and make a convincing case for addressing the outstanding cultural, regulatory, financial, and ethical barriers?
2. Barriers and priorities: Do the stakeholder statements identify the most pressing cultural, regulatory, financial, and ethical barriers preventing widespread data sharing in the U.S. as well as feasible priorities for beginning to address those barriers in the near term?
3. Resources: What resources are required to support the implementation of the key priorities and which organizations should be engaged in implementing those priorities?
4. Affecting change: How can participants work to actualize the priorities identified following the meeting discussion?

Outcomes intended: Commitments from key stakeholders to implement the principles and priorities for addressing cultural, regulatory, financial, and ethical barriers to widespread data sharing to support continuous learning and improvement in the U.S. health care system.

REPRESENTATIVE OBSERVATIONS

- The co-chairs of the steering committee presented the vision statement. Meeting participants emphasized making a distinction between health-related and health data. Some meeting participants suggested expanding the definition of health-related data used in the vision statement to include geospatial and other types of data that impact health. Others advised for more specificity since the term health-related data is broad and constantly evolving.
- While a comprehensive view of health-related data has its benefits, the granularity of the data raises issues of transparency and oversight about who gets access to what data for what purposes, and about what consumers are told about who is using the data. Prioritizing the types of data that have a significant impact on health outcomes and developing use cases is a way to narrow the focus.
- Co-chairs of the three stakeholder workgroups provided a summary of their statements. The Patient and Family workgroup emphasized the cultural and organizational barriers to data sharing. Their solutions focused on disseminating evidence about the value of data sharing, such as reducing the risk of malpractice, and the demonstrated success of organizations such as Kaiser, Geisinger, VA, and Dartmouth in doing so.
- The Patient Family Advisory Committee, a group of over 600 patient family advisors, is designing a patient portal to facilitate increased communication between patients and families and care providers.
- Getting access to research results directly impacting care is also a priority for patients. With a few exceptions, the NIH shares data from clinical trials with participants as part of a key provision in the 21st Century Cures Act that requires data sharing for all NIH funded projects.
- The Research Oversight workgroup identified the lack of shared principles around data ownership, governance, and stewardship as the primary barrier to data sharing. Solutions to addressing the barriers include assembling a task force to develop a consensus statement around a set of principles and studying the data sharing preferences of each stakeholder group.
- The Health Care Executives workgroup ranked misaligned incentives including the financial and security risks, prioritization of the financial cost associated with sharing data, and risks of harm associated with loss of competitive advantage and sensitivity, as the most significant barriers. Participants echoed the fines and fees of implementing HIPAA as a major barrier to data sharing. However, data sharing can offer a competitive advantage.
- Developing a business case is critical step to addressing the barriers.
- Concerns over the monetization of data; the cost of maintaining data repositories; differing attitudes toward data collection ownership and governance; and lack of trust emerged as common themes among the three workgroups.
- Developing an educational campaign about the benefits of data sharing; building technology and data literacy, and instituting value-based payment programs, were proposed to address these barriers. CMS has taken a step in this direction with 34% of Medicare payments being through value-based contracts. The National Vaccine Injury Compensation Program can serve as a model for building trust for data sharing.
- Along with data sharing it is equally important to have better ways to consume, visualize, and render data actionable.
- The ONC’s Notice of Proposed Rulemaking and TEFCA and CMS’s interoperability efforts aim to establish ground rules and standards for data exchange.
- The Robert Wood Johnson Foundation has a history of supporting work that promotes access to data that can be used to understand population and community health trends.

NEXT STEPS

Based on the discussion, the next steps in this initiative include:

- Use cases: Developing a series of high priority data sharing use cases that demonstrate the benefits in terms of improving patient experience/affordability.
- Business use: Creating a business case to demonstrate the value of data sharing for health care organizations.
- Stakeholder statements: Assembling and releasing the stakeholder statements in an NAM Special Publication.
- Knowledge Hub: Creating a website of ongoing data sharing initiative and resources.
### Participants

- Kristin Carman (PCORI); Joe Selby (PCORI); Erin Mackey (National Partnership for Women & Families); Peter A. Margolis (Cincinnati Children’s Hospital); Christine Bechel (X4 Health); Susan Woods (Society for Participatory Medicine); Raina Kaashal (Weill Cornell Medical College & New York Presbyterian Hospital); Sarah Greene (Health Care Systems Research Network); Russell Rothman (Vanderbilt University Medical Center); Megan Edmunds (AcademyHealth); Hilary Heineman (The Robert Wood Johnson Foundation); Michael Hodkins (AMA); Libby Hoy (Patient & Family Centered Care Partners); Kate Goodrich (CMS); Steve Gravelle (Gravely Group); Michael Lauer (NIH); Jeremy Wertheimer (Biological Engineering Ventures); Teresa Zayas-Caban (ONC); Laura Adams (X4 Health); Kevin Ban (AthenaHealth); Christopher Boone (Pfizer); Helen Brunswick (CMS); Richard Conroy (NIH); Milton Corn (NLM); Donna Cryer (The People Centered Research Foundation); Robert Emerson (BCBS of NC); Patrick Gee (PfA Network); Rachel Goldberg (AARP); Ben Green (Amazon); William Gregg (HCA Healthcare); Claudia Grossman (PCORI); John Halama (Beth Deaconess Medical Center); Kevin Haynes (HealthCore, Inc.); Mary C. Hennessy (PCORI); Adrian Hernandez (Duke University, School of Medicine); Kristen Honey (HHS); Barbara Howard (Total Child Health); Matthew Husford (UPMC); Javier Jimenez (Sanofi); Bercu Kille (Public Citizen); Susan Karsh (VHA); Gloria Kuperman (AHA); John Lantos (Children's Mercy Hospital - Kansas City); Emily Langert (Univ. of Penn. Perelman School of Medicine); Tracie Lattimore (Office of Science and Technology Policy); Danny van Leuven (Health Hats); Jenny Lanry (Research!America); Bradley Malin (VU); David Maron (VA); Kameron Matthews (VHA); John Mattison (Kaiser Permanente); Ross McKinn (AMA); Jerry Menikoff (Office for Human Research Protections); Michelle Meyer (Geisinger’s Center for Translational Bioethics and Health Care Policy); C. Daniel Mullins (University of Maryland School of Pharmacy); Adnan Muluk (Henry Ford Health System); Stacy Palmer (The Beryl Institute); Elizabeth Pike (PCORI); Casey Quinlan (Mighty Casey Media); Michael Radlitch (Epic); Susannah Rose (Cleveland Clinic); Brooke Rochevren (ACP); Sally Rodriguez (HCCI); Carla Rodriguez-Watson (FDA); Lew Sander (UHG); Sophie Shen (Johnson & Johnson); Walter Suarez (HL7); Bharat Sutariva (Cer); Mary C. Hennessey (PCORI); Adrian Hernandez (Duke University, School of Medicine).

### Clinical Effectiveness Research Innovation Collaborative

**Participating Organizations**

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**Chair**
- Mark B. McClellan (Duke University)

**Members**
- David Blumenthal (The Commonwealth Fund)
- Susan DeVore (Premier, Inc.)
- Judith Faulkner (Epic Systems)
- David Feinberg (Geisinger Health System)
- Joseph F. Fifer (Healthcare Financial Mgmt Asn)
- Patricia A. Gabow (CABG)
- Former, Denver Health
- Anil Gawande (Brigham and Women’s Hospital)
- Julie L. Gerthman (Merck & Co, Inc.)
- Brett C. James (Former, Intermountain Healthcare)
- Gary Kaplan (Virginia Mason Health System)
- Gregory F. Keenan (AstraZeneca)
- Darrell G. Kirch (AAMC)
- Peter J. Pronovost (UnitedHealthCare, Inc.)
- Michael L. unperturbed (UnitedHealthCare, Inc.)
- John J. M. unperturbed (UnitedHealthCare, Inc.)
- John W. Rowe (Former, Columbia University)
- Craig E. Samitt (Anthem, Inc.)
- Lewis G. Sandy (United Health Group, Inc.)
- Leonard D. Schaeffer (USC)
- Joe Selby (PCORI)
- Mark D. Smith (Former, CHCF)
- Jennifer Taubert (Johnson & Johnson)
- Marta Tellado (Consumers Union)
- Reed V. Tuckson (Tuckson Health Connections)
- Debra B. Whitman (AARP)
- Ex-Officio (AHRQ)
- Gopal Kharana (CDC)
- Anne Schuchat (CDC)

**Federal agencies**
- NSF
- U.S. DHHS
- Office of the Secretary
- AHRQ
- CDC
- CMS
- FDA
- NIH
- U.S. DOD
- U.S. DVA
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- U.S. DOD
- U.S. DVA

**Vision**
- Research
- Evidence
- Effectiveness
- Trials
- IT Platform
- Data Quality & Use
- Health Costs
- Value
- Complexity
- Best Care
- Patients
- Systems
- Measures
- Leadership

**The Learning Health System Series**