THE PATH TO A VIRTUAL HEALTH DATA TRUST AS A CORE UTILITY FOR THE COMMON GOOD
TRANSFORMING CONTINUOUS LEARNING AND IMPROVEMENT IN HEALTH CARE
An NAM Strategic Initiative

Activity: Engage key experts and stakeholder leaders in a comprehensive multi-sector strategy assessment initiative aimed at ensuring that health and health care data are: focused on the most important issues, timely, secure, reliable, consistent, comparable, and seamlessly used as a basic resource for continuous learning and improvement in health and health care.

Compelling vision: *Revolutionize care quality and safety, the pace of care improvement, and the knowledge base for discovery and care innovation.* This will be accomplished by ensuring that, while localized in operation, the data framework and infrastructure for progress in health and health care is designed, developed, and governed as a secure, reliable, and accessible resource—a virtual health data trust—for continuous learning and improvement.

Issue: Currently, health and health care data are prolifically generated, marginally used, of limited reliability, and only awkwardly shared. Potential data uses include application in shaping personal health choices; patient-clinician decisions; effectiveness assessment; care targeting; care safety and quality improvement; care guideline development; research; and human and financial resource allocations. Reliable, consistent, and readily accessible data are essential for health and health care that continuously improves and innovates, for individuals and for society. Potential data sources include data generated personally by individuals, actively and passively, through monitoring devices and other reports; use of medical devices in clinical settings; testing through assessment of blood, tissue, imaging; recorded notes of clinicians; service and payment claims; academic and commercial research; employer health plans and programs; and public agencies providing social, environmental, criminal justice, other health-impacting services. Despite the potential, true data-driven care and innovation currently falls far short of the possible. Health data stewardship is currently fragmented and conflicted with respect to individual and societal interests, lacking clarity on multiple issues—e.g. ownership, oversight, access, sharing, curation, application, release, protection, and improvement. Accordingly, distorting factors include poor targeting, unsystematic capture, incompatible systems, misplaced incentives, uncertainties in ownership, concern about confidentiality, very limited sharing, opaque data governance policies, methodological limitations, and lack of a clear funding model for health data integration and use. The ironic consequence: the more data points measured in isolation, the more likely is our attention to be drawn away from overall system performance.

Approach: Specify provisional conceptualization of prominent health data ecosystem elements: 1) data ownership and control; 2) identity protection protocols; 3) data integrity/reliability; 4) core common data elements; 5) coding cross-walk protocols; 6) platform integration; 7) data access/sharing protocols; 8) data curation and analysis; 9) artificial intelligence and machine learning; 10) results release protocols; and 11) cybersecurity. Assemble a steering committee comprised of leadership from key stakeholder sectors (e.g. health care organizations, patients, clinicians, payers, vendors, researchers) to prioritize, guide, and advise on collaborative activities to advance progress on key issues from these domains. Establish Working Groups to identify common operating principles and explore facilitative strategies related to progress on a) *data ownership and control*; b) *identity protection protocols*; c) *data access/sharing protocols*; and d) *AI/machine learning* progress. Each working group will identify priority unresolved issues, related ongoing initiatives, collaborative opportunities, stakeholder roles, governance and resources, strategic priorities, and possible facilitative projects.

Deliverable(s): A series of NAM discussion papers co-authored by participants in each Working Group, describing in detail the pathways to progress on the targeted priorities, with an overview piece on the integrative and governance steps necessary to foster development of the virtual health data trust envisioned.

Working group participants: Senior leadership from: patients & families, clinicians, health care systems, clinical research, information technology, cybersecurity, employers, payers, regulators.

Related NAM work: *Integrating Research and Practice: Health System Leaders Working Toward High-Value Care (2014); Observational Studies in a Learning Health System (2013); Large Simple Trials and Knowledge Generation in the Learning Health System (2013); Digital Data Improvement Priorities for Continuous Improvement in Health and Health Care (2012); Best Care at Lower Cost (2012); Digital Infrastructure for a Learning Health System (2011); Clinical Data as a Basic Staple for Health Learning (2011); Learning What Works (2011); The Learning Health Care System (2007)*

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HEALTH DATA AS A CORE UTILITY: PROTOCOL ELEMENTS

Virtual Health Data Trust

- Data ownership & control
- Identity protection protocol
- Data integrity & reliability
- Core data elements
- Coding cross-walk protocols
- Platform integration
- Data access & transfer protocols
- Data curation & analysis
- Machine learning
- Results release protocol
- Cybersecurity