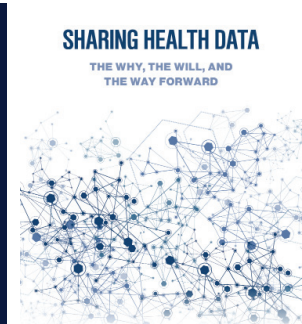# Sharing Health Data

The Why, the Will, and the Way Forward

A Special Publication of the National Academy of Medicine

Sharing health data and information across stakeholder groups is central to building an effective, efficient, and equitable health system. As data and information are increasingly combined, they offer new insights to guide action and change the course of individual and population health. However, barriers such as disagreements about data ownership and misaligned incentives often impede the potential of health data sharing to advance research or practice. The 2020 NAM Special Publication *Health Data Sharing to Support Better Outcomes: Building a Foundation of Stakeholder Trust* identified several cultural, operational, financial, and ethical barriers meriting concerted attention (shown below), and prioritized several action steps that could be accomplished in a one-to-three year time horizon.

Barriers Identified by Stakeholders that Impede Sharing Health Data

(adapted from *Health Data Sharing to Support Better Outcomes: Building a Foundation of Stakeholder Trust*)

Patients & Families
- Difficulty **accessing** their own data
- Feeling **valued** as partners in generating and applying health data
- Insufficient understanding of how to **use** patient-generated data more effectively
- Risks and other embedded **disincentives** to patients sharing data

Health Care Executives
- Potential financial and security **risks** of sharing health data
- Lack of a compelling **business case** to motivate data sharing
- Concerns about a loss of **competitive** advantage if data are shared

Researchers
- **Uncertainties** about whether and in what circumstances data should be shared
- **No shared principles** related to data ownership, stewardship, and governance
- Concerns about future use of collected data, including **third party use**
- Embedded **disincentives** related to cost, quality, and availability of health data

A number of data collaborations and facilitative policy and regulatory changes have emerged of late, propelling health data sharing throughout the ecosystem. Many of these changes arose in response to the urgency of COVID-19. Yet in spite of these evolving attitudes toward data sharing and the ubiquity of data-sharing partnerships, barriers and uncertainties persist which have been magnified throughout the course of the pandemic.

Serving as a companion to the 2020 *Health Data Sharing* Special Publication, this new publication features 11 data sharing exemplars to provide context and practical implementation guidance for overcoming barriers. Lessons and insights harvested from those in the vanguard can dispel myths and reservations that impede sharing of health data with stakeholders and encourage innovative approaches to make progress in the current environment.

Health data are not being used to their fullest potential—this is true for both research and care improvement—with consequential implications for society as a whole. However, the 11 exemplars described in this publication illuminate the possibilities for improving care, patient experience, and research when sharing health data among different stakeholders. Many interviewees for this report were motivated by the moral imperative of using health data more fully and effectively. Others were spurred to act in response to catastrophic occurrences, including the COVID-19 pandemic. All exemplars applied their data sharing efforts in service to a large-scale issue in health care, ranging from patient safety to control of health care costs, to maximizing investments in biomedical research. Accordingly, several key messages and themes emerged from this work.

- **Trust,** and more importantly, trustworthy behaviors, are the foundation for a successful data sharing effort. Trust must be earned and nurtured, and this entails being transparent and forthright about how health data will and will not be shared.
- Concentrated and sustained **engagement of diverse patients, families, and communities** is essential as health data-sharing efforts are initiated and implemented, and can help organizations overcome resistance to data sharing.
- As health data sharing efforts are being developed, articulating a clear and compelling **value proposition** for each partner/stakeholder is imperative. Recognizing that the value proposition may differ by stakeholder is a key corollary.
- With respect to organizational buy-in, two beneficial strategies were cited by the interviewed exemplars. First, **engage executive leadership,** as well as influential internal champions at the outset and throughout the data sharing effort. Second, ensure that the **data sharing endeavor has visibility and input** from across all parts of an organization, including health IT, legal/regulatory, and operations to get widespread buy-in and surface the full realm of considerations as early in the process as possible.
- Continued efforts to **modernize and harmonize data sharing policies and regulations** will benefit the entire health care ecosystem, especially considering how traditional ideas of what constitutes "health data" continue to evolve. Related modernization of and investments in the infrastructure that underpins data exchange can also help accelerate progress.
- Revisit the pillars of Big Data, which has often been characterized by a set of "V's", including volume, variety, velocity, veracity, and value. A beneficial concept of Big Data specific to health data sharing would include four A's: health data that are **accessible, affordable, analyzable, and actionable** by all stakeholders—such a framework could galvanize public trust, forge better outcomes, and yield meaningful progress toward an equitable learning health system.

Download the publication at nam.edu/SharingHealthData

NATIONAL ACADEMY OF MEDICINE