

Health Data Sharing to Support Better Outcomes

Building a Foundation of Stakeholder Trust

A Special Publication of the National Academy of Medicine



The Need for Effective, Efficient, Secure Data Sharing

Against the backdrop of increasing costs and unacceptable shortcomings in the nation's health and health care system, sharply demonstrated by the COVID-19 pandemic, an unprecedented opportunity exists to improve health care by effectively applying new tools and technologies to accelerate learning and evidence development. Advances in the generation and use of health-related data offer new capabilities to leverage information to address pressing questions and improve clinical decision making.

While the technical capacity to speed progress toward better health outcomes exists due to research and developments in data science, most health-related data remain siloed and data sharing, linkage, and use have not been adequately or cooperatively marshaled for care improvement. A number of ethical, regulatory, cultural, and organizational barriers hamper the growth of data sharing. While the perspectives of different stakeholder groups vary, all share the goal of improving health care and outcomes. However, these stakeholders have rarely had the opportunity to develop common solutions.

This Special Publication provides an overview of convenings including patient and family leaders, research and oversight leaders, and health care executives, in which these groups independently identified barriers and solutions and jointly brainstormed action steps for facilitating data sharing across sectors.

Barriers Identified by Patient and Family Leaders

1. Patients wanting but not being granted access to health data.
2. Insufficient appreciation among stakeholders that patients and families are key providers of patient-generated data
3. Lack of understanding among stakeholders of how patient-generated data can improve workforce efficiency, enhance data coverage and accuracy, and yield better population health outcomes
4. Financial disincentives to data sharing

Barriers Identified by Health Care Executives

1. Misaligned incentives, including financial and security risks
2. The financial costs associated with sharing data
3. Potential harms associated with the loss of competitive advantage and with the sensitivity of information

Barriers Identified by Research and Research Oversight Leaders

1. Heterogeneity in beliefs among patients, clinicians, and researchers about whether data should be freely shared
2. Lack of shared principles regarding data ownership, stewardship, governance, rights, and responsibilities
3. Uncertainty about potential uses of data and accompanying concerns about consequences arising from inappropriate or unauthorized use
4. Variability across institutions and states in their interpretation of regulations and responsibilities
5. Operational challenges, including uneven data quality, the cost to procure data, and the lag time between when data are collected and when they are available for use by researchers

Priorities for the Field

1. **Engaging in a public information campaign.** Widely disseminated public information campaign could help change attitudes and behaviors by showing people - including the general public, providers, policy makers, and health care administrators - how the use of health data could improve their health and the health of people they know. The public information campaign should also educate people about their data sharing rights and issues related to privacy and security.
2. **Making the business case.** Each stakeholder in the health care system will need to see the advantages of moving toward greater data sharing and more importantly, the patient safety risks of not sharing data. Particularly in the private sector, this will require the development of compelling business cases that clearly demonstrate the return on investment.
3. **Creating and prioritizing use cases.** These use cases should highlight the benefits of sharing data not only with patients or for research but also for AI, machine learning, performance improvement, and best practice guidelines, as well as highlight potential cost savings and analytics that drive value.
4. **Basing payment on value.** New payment models that incentivize paying for value and outcomes, rather than the volume of care could have concurrent benefits toward more seamless data sharing.
5. **Instituting supportive government policies.** These policies can establish ground rules and standards for data exchange across networks, as well as support the development of technologies and systems that promote rather than impede data sharing. They can send clear signals about how existing technologies should be used and what new technologies are needed.
6. **Building trust.** Standards of conduct can build trust, because people know what to expect.
7. **Toward a continuously learning health system.** Health data are the foundation for a continuously learning health system in which science, informatics, incentives, and culture are aligned to yield continuous improvement, innovation, and equity.

Download the publication at nam.edu/DataSharingTrust



Note: The special publication described has undergone peer review according to procedures established by the National Academy of Medicine (NAM). Publication by the NAM signifies that it is the product of a carefully considered process and is a contribution worthy of public attention, but does not constitute endorsement of conclusions and recommendations by the NAM. The views presented in this publication are those of the authors and do not represent formal consensus positions of the authors' organizations, the NAM, or the National Academies of Sciences, Engineering, and Medicine.