

Ethicists propose harnessing participant engagement to address trustworthiness in medical data sharing

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In order to advance and ultimately achieve precision medicine in healthcare, the National Academies has suggested that genomic and other health-related data must be shared through a medical "information commons." Released online today in a special issue of the *Journal of Law, Medicine & Ethics*, scientists and ethicists look to address and propose solutions to many of the questions that surround the development and operation of such a resource.

"This collection of papers is a robust report of the major findings and state of the field of ethics and policy as it concerns genomic and related health information collection and sharing. The goal of this special edition is to report empirical findings and recommendations for governance of a medical information commons. A key component addresses [public concerns](#) about trustworthiness," said Dr. Amy McGuire, director of the Center for Medical Ethics and Health Policy at Baylor College of Medicine and guest editor of the special issue.

The driving purpose behind a medical information commons is enhancing understanding of disease and normal biology, and informing researchers and clinicians in a learning health system. A medical information commons assembles molecular, environmental and health records or outcomes data that are linked to individuals and made widely available for research, clinical and public health purposes.

One of the primary findings from the collection of papers is that, for a medical information commons to be successful, the participants must be central to the vision and must feel as though their feedback is important

and valuable to the process.

"Socially, we are struggling with trusting [big data](#) and the institutions behind the collection and sharing processes. Another key finding from this research is that we need to focus on building an infrastructure that creates this trust organically," said Dr. Mary Majumder, associate professor in the Center for Medical Ethics and Health Policy at Baylor and another guest editor of the special issue.

In addition to contributions from ethicists and scientists at Baylor, an external advisory council comprised of a diverse group of stakeholders, including patient advocates and representatives from the technology sector, healthcare systems, [government agencies](#) and academia, was assembled to develop recommendations for a framework that will build trust and is participant-centered.

"Despite the fact that everyone was coming from a [different perspective](#), we were all pretty unanimous in the overall vision and direction of a medical information commons," McGuire said.

The collection of 11 papers covers a range of topics regarding sharing data, including features of the current landscape for sharing genomic and related data, the role of participants, data ownership and protection, trustworthiness, and the role of a medical information commons in supporting learning healthcare systems.

"The traditional idea of a medical [information](#) commons was a single database with set guidelines on how it shares data and who can contribute to and access those data," McGuire said. "However, our findings suggest a different model is emerging—one that is made up of numerous health-related databases or resources that would benefit from the wide-spread adoption of sophisticated, yet flexible, principles."

More information: Robert Cook-Deegan et al. Introduction: Sharing Data in a Medical Information Commons, *The Journal of Law, Medicine & Ethics* (2019). [DOI: 10.1177/1073110519840479](https://doi.org/10.1177/1073110519840479)

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