Many national and international public and private initiatives are forming to collect and share data on a large scale for research and clinical use. Collectively, these efforts may lead to the creation of a medical information commons. Through this project, we aimed to inform policy decisions about effective governance for data sharing, and ensure that the values, rights and interests of individuals whose data may populate the information commons are represented. Specifically we aimed to:
- Identify and analyze existing models for collecting diverse sources of data into a medical information commons to enable large scale research and clinical application
- Evaluate the effectiveness of existing models and develop new approaches to address key policy issues from the perspective of expert stakeholders
- Solicit informed public input on existing models and innovative approaches from individuals whose data may populate a medical information commons.
- Describe incentives to share BRCA variant data and obstacles hindering the sharing of those data, and incorporate BRCA previvors and survivors into the governance and oversight structures for the emergent BRCA data commons.

Over the past four years, we carried out the following:

- A landscape analysis of existing data-sharing efforts
- In-depth interviews with multiple stakeholders from various sectors (e.g., academia, government, and private industry)
- Deliberative sessions with members of the public at three U.S. cities
- In-person meetings with a multidisciplinary external advisory committee

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Where scientists and ethicists look to address and propose solutions to many of the questions that surround medical data sharing
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Publications


Deverka PA, Gilmore D, Richmond J, et al. Hopeful and...


Majumder MA, Zuk PD, McGuire AL. Medical Information Commons.


Presentations


Villanueva AG. The Challenges of Collecting and Sharing Environmental Data in the Current Genomics Era. Poster presented at the: American Society for Bioethics and Humanities Annual Conference; October 2017; Kansas City, MO.

Villanueva AG. Hashtag Who's Missing? Lessons for Participant-Centric and Pediatric Genomic Databases. Presented at the: ELSI Congress; June 2017; Farmington, CT.

McGuire AL. What Does it Mean to Own the Data in a Medical Information Commons? Presented at the: ELSI Congress; June 2017; Farmington, CT.

Villanueva AG. The Data Ecosystem: Current Data-Sharing Policies and Practices. Presented at the: ELSI Congress; June 2017; Farmington, CT.


Majumder MA, Garrison NA, Bonham V, Villanueva AG. Critical Distance in ELSI Genomics Research - More Than Advocacy for the "All-Frills Yuppie Health Care Boutique"? Presented at the: American Society for Bioethics and Humanities Annual Conference; October 2016; Washington, DC.

McGuire AL, Goldstein MM, Rodriguez LL, O'Donnell CJ. Building a Medical Information Commons: Ethical, Policy and Practical Challenges. Presented at the: American Society for Bioethics and Humanities Annual Conference; October 2016; Washington, DC.

McGuire AL. Building the Medical Information Commons: Data Sharing Ethics and Policy. Human Genome Meeting; 2016; Houston, TX.