



Center for Medical Ethics and Health Policy

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BASIC

BabySeq

Citizen Science

HGSC

Information Commons

MedSeq

Mendelian Center

Microbiome

MilSeq Project

NGS Policy Analysis

Past Biobanking

Past Clinical Sequencing

Information Commons

Building the Medical Information Commons: Participant Engagement and Policy

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:

—
Past Genome Research

—
PeopleSeq Consortium

—
Returning Research

Results of Pediatric
Genomic Research to
Participants

Sequencing Trade-Offs

—
Sulston Project

—
Texas KidsCanSeq

- 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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Areas of Research

- [Clinical Ethics Research](#)
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Special Issue in the Journal of Law, Medicine & Ethics

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



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Project Personnel

Principal Investigators

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Publications

Publications

Bollinger JM, Sanka A, Dolman L, Liao RG, Cook-Deegan R. BRCA1/2 Variant Data-Sharing Practices. *J Law Med Ethics*. 2019;47(1):88-96. doi:10.1177/1073110519840487

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

Concerned: Public Input on Building a Trustworthy Medical Information Commons. *J Law Med Ethics*. 2019;47(1):70-87. doi:10.1177/1073110519840486

McGuire AL, Roberts J, Aas S, Evans BJ. Who Owns the Data in a Medical Information Commons? *J Law Med Ethics*. 2019;47(1):62-69. doi:10.1177/1073110519840485

Majumder MA, Bollinger JM, Villanueva AG, Deverka PA, Koenig BA. The Role of Participants in a Medical Information Commons. *J Law Med Ethics*. 2019;47(1):51-61. doi:10.1177/1073110519840484

Bollinger JM, Zuk PD, Majumder MA, et al. What is a Medical Information Commons? *J Law Med Ethics*. 2019;47(1):41-50. doi:10.1177/1073110519840483

Villanueva AG, Cook-Deegan R, Robinson JO, McGuire AL, Majumder MA. Genomic Data-Sharing Practices. *J Law Med Ethics*. 2019;47(1):31-40. doi:10.1177/1073110519840482

Villanueva AG, Cook-Deegan R, Koenig BA, et al. Characterizing the Biomedical Data-Sharing Landscape. *J Law Med Ethics*. 2019;47(1):21-30. doi:10.1177/1073110519840481

McGuire AL, Majumder MA, Villanueva AG, et al. Importance of Participant-Centricity and Trust for a Sustainable Medical Information Commons. *J Law Med Ethics*. 2019;47(1):12-20. doi:10.1177/1073110519840480

Cook-Deegan R, Majumder MA, McGuire AL. Introduction: Sharing Data in a Medical Information Commons - Robert Cook-Deegan, Mary A. Majumder, Amy L. McGuire, 2019. *The Journal of Law, Medicine & Ethics*. 2019;47(1):7-11.

Majumder MA, Zuk PD, McGuire AL. Medical Information

Commons. In: Hudson B, Rosenbloom J, Cole D, eds. *Routledge Handbook of the Study of the Commons*. 1st ed. <https://www.routledge.com/Routledge-Handbook-of-the-Study-of-the-Commons-1st-Edition/Hudson-Rosenbloom-Cole/p/book/9781138060906>

Deverka PA, Majumder MA, Villanueva AG, et al. Creating a data resource: what will it take to build a medical information commons? *Genome Med*. 2017;9(1):84. doi:10.1186/s13073-017-0476-3

Majumder MA, Guerrini CJ, Bollinger JM, Cook-Deegan R, McGuire AL. Sharing data under the 21st Century Cures Act. *Genet Med Off J Am Coll Med Genet*. May 2017. doi:10.1038/gim.2017.59

Cook-Deegan R, McGuire AL. Moving beyond Bermuda: sharing data to build a medical information commons. *Genome Res*. 2017;27(6):897-901. doi:10.1101/gr.216911.116

Majumder MA, Cook-Deegan R, McGuire AL. Beyond Our Borders? Public Resistance to Global Genomic Data Sharing. *PLoS Biol*. 2016;14(11):e2000206. doi:10.1371/journal.pbio.2000206

Presentations

Majumder MA. Back to the Future: A Snapshot of Current Genomic Data-Sharing Practices. Presented at the: American Society for Bioethics and Humanities Annual Conference; October 2018; Anaheim, CA.

Majumder MA. What Role for Participants? Views of Expert Stakeholders Influencing Data-Sharing Policies and Practices. Presented at the: American Society for Bioethics and Humanities Annual Conference; October 2017; Kansas

City, MO.

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. Big data sharing in precision medicine. Presented at the: World precision Medicine Congress; May 2017; London, UK.

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.

Villanueva AG, McGuire AL, Majumder MA. Genes and the Environment: Current Data Collection, Sharing and Privacy Protection Practices. Poster presented at the: American Public Health Association's Annual Meeting; November 2016; Denver, CO.

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

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