Opening Access to Patient Data – Finding a Balance

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Privacy and Patient Data

A fundamental expectation

Harms are possible if privacy is not protected

Has tended to be a predominant consideration
Supports innovation, data are the ‘new oil’ for a learning health system

Social and economic implications are large

Has tended to be a secondary consideration
Ontario’s Health Ministry mulls sharing health data with researchers, certain third parties as part of privacy update

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PUBLISHED NOVEMBER 13, 2019
UPDATED NOVEMBER 14, 2019
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23 COMMENTS
Increasing Demands for Access

- Big data are needed for precision medicine
- AI requires big computing next to data
- Biased or missing data skews analyses and reinforces inequalities
Two Strategies for Opening Access and Protecting Privacy

- Anonymization
- Access control
Anonymization

- Removes personally identifiable information (e.g., names, dates, locations, unique variables)
- Trades off information loss against risk of re-identification
- There are limits in theory and practice
... we find that 99.98% of Americans would be correctly re-identified in any dataset using 15 demographic attributes.
Access Control

- Requires researchers to access data in secure location
- Data cannot be removed, only approved results
- Limits linkage, sophisticated analysis
Example of MUHC Data Warehouse

- Requests for access directed by default towards anonymized data
- Encrypted data made available in secure cloud environment
- Investigators sign data use agreement and additional approvals for external collaborations
Closing Reflections

Placing more weight on anonymization reinforces focus on certain types of data and health contexts.

Value of data for health system improvement is blurring the line between research and business of healthcare.
Google Is Slurping Up Health Data—and It Looks Totally Legal

Tech giants can access all of your personal medical details under existing health privacy laws. The question is how else that data might get used.

Last week, when Google gobbled up Fitbit in a $2.1 billion acquisition, the details were months away from the company would do with all that.