Data Protection and Artificial Intelligence in Health: Risks and Regulatory Frameworks (Canada)

Artificial Intelligence and Health: Dialoges and Convergences in Brazil-France-Canada Regulation

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Dr Teresa Scassa

Canada Research Chair in Information Law and Policy

University of Ottawa

Demand for health data for research

Quality data for health research is in high demand

Health system data is closely governed (for privacy and research ethics considerations) leading to complaints and concerns over the ability of researchers to access the data they need in a timely fashion

AI is driving up the volume of data needed for research; it is also changing the types of data that may be used

Stress points and challenges: Health data and federalism

- Canada is a federal state and the delivery of health care falls within provincial jurisdiction
  - Each province has its own health care system
  - Provincial data protection/privacy laws govern personal health information (PHI) that is collected and used within the system
  - Provincial public sector data protection laws also govern the collection by each provincial government of health administrative data
  - Private sector data protection laws govern the collection and use of personal health information in the private sector

Cross-jurisdictional health data challenges within this system

- Each province has its own health data system with the result that there may be data interoperability issues across provinces
- Each province has its own rules that govern the collection, use and sharing of personal health information (PHI)
- The need to comply with the requirements of health privacy laws in each provincial jurisdiction makes it challenging and time consuming to conduct multi-jurisdictional health research

Stress points and challenges: What laws apply to health data privacy

- Although most provinces have health data privacy laws, these laws focus on health care custodians in the formal health care system
  - They may also draw upon professional legal and ethical obligations
- Private sector companies that collect, use, and disclose health-related data do so under private sector data protection laws, which tend to be more fluid and flexible
- These laws may also be very different in the countries where the company that provides the technology or service is based, leading to issues with compliance and enforcement

Stress points and challenges: anonymization and the privatization of public and health sector data

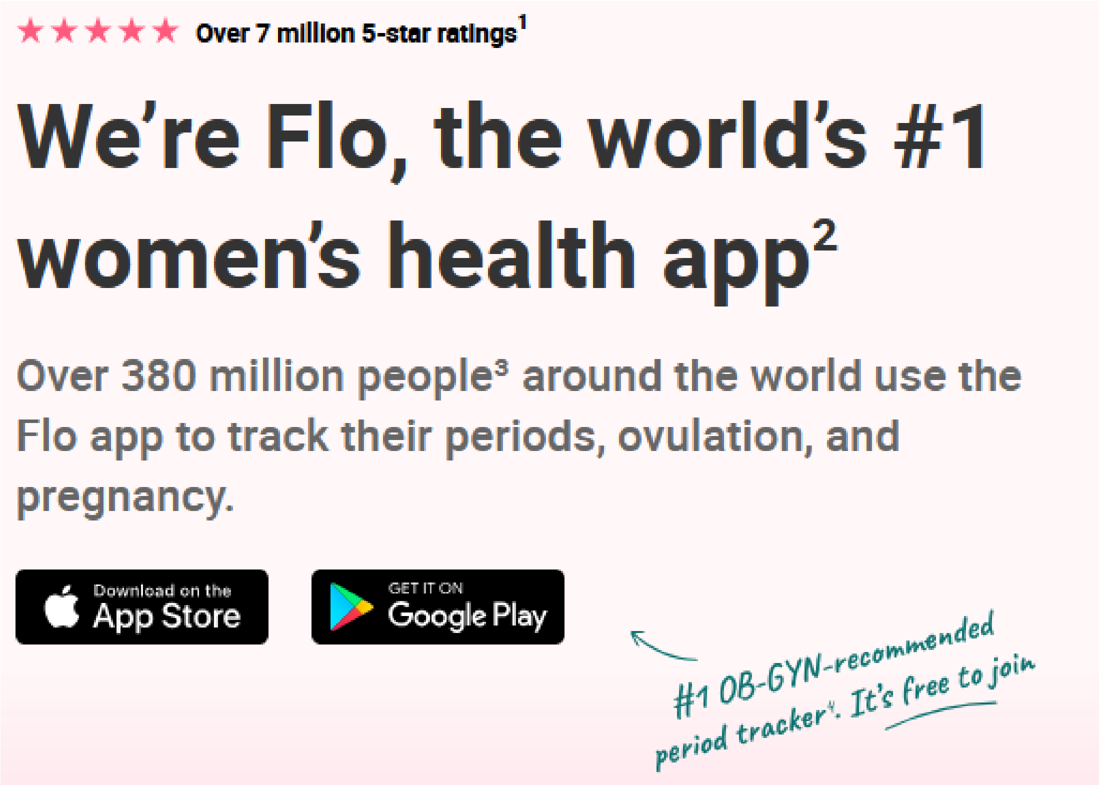
- PHI laws (and other data protection laws) distinguish between personal information and anonymized data; with anonymized data falling <u>outside the scope of the legislation</u>
    - Actors within the health care system increasingly anonymize PHI, and may then sell it or use it for research purposes (e.g., anonymization by Electronic Health Record service providers; “anonymization” of AI medical scribe data for use in training AI scribes)
- This can raise “social licence” issues and can create reidentification risks

Penalties for reidentification

- In Ontario, PHIPA has been amended to include new administrative monetary penalties that can be imposed on organizations to encourage compliance with the legislation, or to prevent anyone from deriving direct or indirect economic benefit from a breach of the legislation
- It is also an offence under PHIPA to wilfully use or attempt to use deidentified information to identify a person (alone or in combination with other information)

Stress points and challenges: The changing nature of health data

- Large volumes of health-related data is now collected about people’s bodies and their functions by private sector companies through devices or apps (and not by health care custodians)
- In some cases, these apps enable the sharing of the data with health care practitioners, blending private sector data with health data
- Where sharing features are enabled, data may also be shared by the user with family members, friends, researchers – and with the whole world if they choose



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What constitutes health data is changing

Using Social Media in Health Care Research Should Proceed With Caution. Comment on "The Use of Social Media for Health Research Purposes: Scoping Review"

Abdias Girardi[1], Nikhi Paul Singh[1,✉,#], Carter Joseph Boyd[2]

Mining Social Media Data for Biomedical Signals and Health-Related Behavior

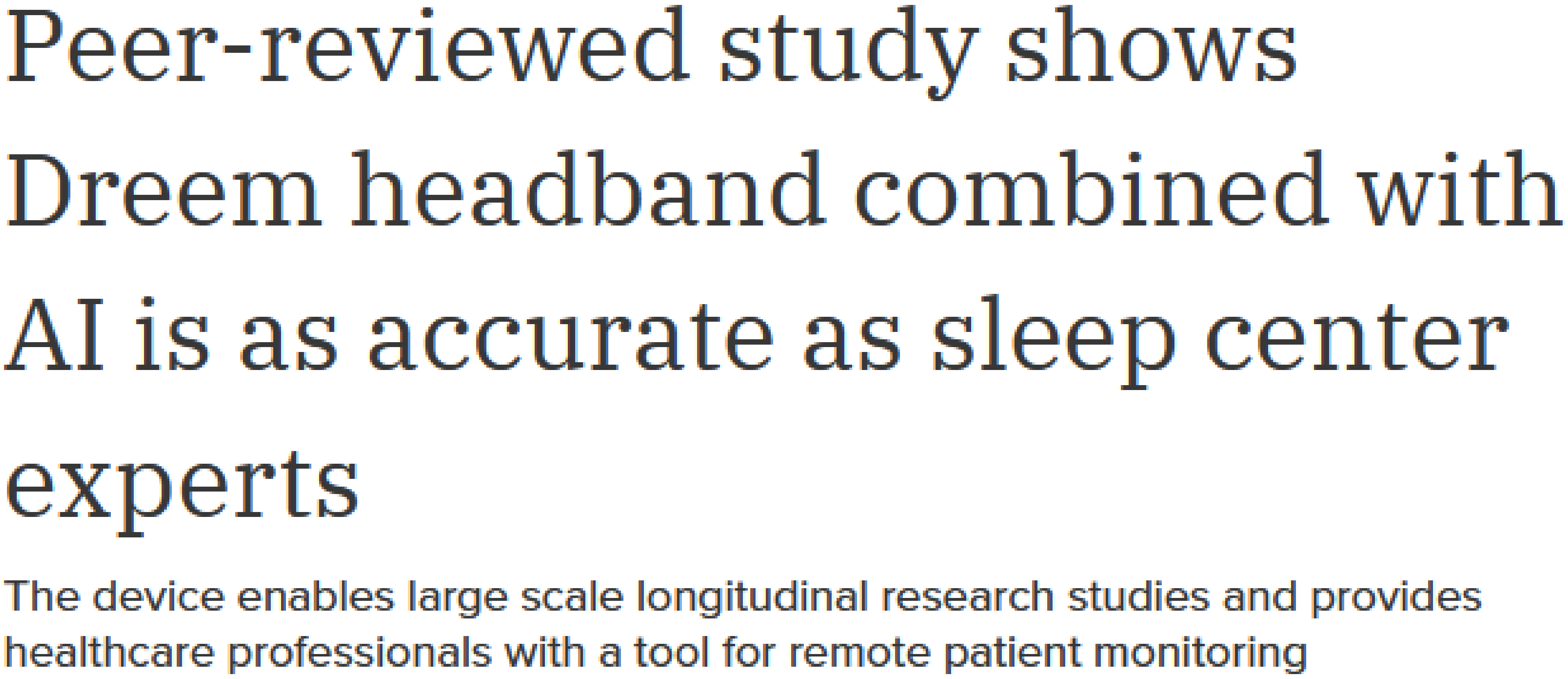
Rion Brattig Correia[1,2,3], Ian B. Wood[2], Johan Bollen[2], and Luis M. Rocha[1,2]

- Data not directly related to health and obtained from non-health specific sources *<u>such as social media</u>* are being used in health-related research

What volume and variety of data is collected

- Many health tracking apps collect **large volumes of data**, multiple types of data (e.g., heart rate, sleep patterns, diet, exercise, etc.), and do so **almost continuously**
- This can create important privacy risks
- It also raises questions about who has access to this data and under what conditions
- This data collection also has significant research potential, particularly in combination with AI tools

Where health data is collected and how this is changing



Peer-reviewed study shows Dreem headband combined with AI is as accurate as sleep center experts

The device enables large scale longitudinal research studies and provides healthcare professionals with a tool for remote patient monitoring

Stress points and challenges: New privacy risks and exposure

- Privately collected health data may be used in ways not anticipated by app or social media users
  - 23andMe data breach and bankruptcy
  - Concerns that period tracking app data could be subpoenaed by investigators if abortion is criminalized in the US
  - Health device data could be sought by insurance companies or by employers

Stress points and challenges: Governance

- How do you ensure that personal health information is as secure in private sector hands as it is in the health sector?
- How do you ensure that research carried out using non-traditional health data sources is ethical, appropriate, robust, and reliable?
- How do you ensure that individuals are not compelled to share personal health information collected through apps and wearables for purposes that are not necessarily in their interest?
  - Consider the Genetic Non-Discrimination Act

Technology outpacing health privacy legislation

- Health data from non-traditional sources will fuel health sector research and innovation outside of frameworks designed to protect privacy and provide ethical oversight
- The research might involve not only sensitive personal data, but the use of AI technologies which raise their own governance challenges
- The research might not be governed by the same ethical principles or approaches put in place by research ethics boards
- It might also not be carried out with domestic public benefit in mind

Stress points and challenges: greater individual control over personal health data

- Technology is increasingly available to give patients greater access to and control over the sharing of their PHI
- This can support more seamless health care
- It may support (or undermine) the willingness of individuals to contribute to health research (or access to patient data for health research)

Summary

- Health data legislation in Canada has the goal of:
  - Protecting the privacy of personal health information that is shared within the health care system
  - Facilitating the privacy protective use of health data in medical research

- In our current context, this framework is under stress:
  - Poor harmonization between provinces makes interprovincial and national data sharing challenging
  - Anonymization and private sector actors in the health system are changing how data is accessed for research
  - Data used for health research and AI innovation is increasing collected outside the health care context
  - Technologies for better health information access for patients may change how data is accessed for research purposes

Thank you!

Teresa Scassa

tscassa@uottawa.ca

uOttawa

CIHR IRSC
Canadian Institutes of Health Research
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AI + Society Initiative