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A framework to facilitate interprovincial sharing of secondary health data in Canada

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Introduction

The use of administrative health data can generate knowledge to improve the delivery and outcomes of health care. Yet, the sharing and use of secondary health data presents concerns given these data were not collected for health research purposes. The sharing of patient-level health data across Canadian provinces is uncommon.

Objectives and Approach

The Maritime SPOR SUPPORT Unit (a patient-oriented research unit serving the three Canadian Maritime Provinces of New Brunswick, Nova Scotia, and Prince Edward Island) struck a Working Group to develop a conceptual framework for the interprovincial sharing of secondary health data for research purposes. Membership comprised a researcher, two privacy managers/officers, and a manager of research ethics. The framework sought to: (1) facilitate researchers' understanding of the foundational elements (legal/ethical) of interprovincial data sharing for health research; and (2) identify challenges and opportunities for improving sharing of data across the Maritime Provinces to support patient-oriented research.

Results

In all three Maritime provinces, de-identified personal health information may be used for approved health research purposes, with each province having its own data holdings and repositories. Applying the applicable governance principles and regulations (i.e., the ethical governance of research involving human subjects and the legal governance of health information) and drawing on best practices nationally and internationally, a framework was developed to incorporate and address the various aspects of sharing and using health data across provinces for the purposes of health research. The resultant framework discusses when and how the legal and ethical frameworks apply, the de-identification of data, degrees of data sharing, and information governance. It also identifies challenges and opportunities to moving forward with interprovincial data sharing.

Conclusion/Implications

Development of this framework was the first phase of a multiphase approach to move towards improved interprovincial data sharing for patient-oriented research. Cross-provincial sharing and linkage of data can lead to comprehensive, costeffective, and multi-disciplinary research that benefits patients, the health system, and the public at large.



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