



News Release

Balancing privacy with access to health and health-related data can be achieved, finds Expert Panel

Ottawa (March 31st, 2015) — Today, the Council of Canadian Academies released its newest Expert Panel report. ***Accessing Health and Health-Related Data in Canada*** examines the challenges of accessing data while ensuring privacy is protected and public trust is maintained. Overall, the Panel determined there is an important opportunity for Canada to move from a culture of caution to a culture of trust.

"This report is particularly timely as we have seen an explosion in the volume and variety of health data that is generated," said Andrew K. Bjerring, Chair of the Expert Panel. "Health data are essential for research aimed at improving health outcomes, managing costs, and accelerating health-care sector innovation. However, accessing data in a timely way must be weighed against respecting privacy and maintaining public trust. Our report considers best practices that meet these twin goals."

The Panel's key findings include:

- *The risk of potential harm resulting from access to data is tangible but low. The Panel concluded there are four types of potential privacy risks: accidental release of data, illicit access (e.g., hacking), inadvertent access, and data re-identification. To date, breaches have been rare and a non-issue for organizations that adhere to good governance.*
- *Evidence shows that timely access to data enables high-quality research that can have far-reaching effects for health care and the overall health of Canadians.*
- *Timely access to data is hindered by variable legal structures and differing interpretations of the terms "identifiable" and "de-identified" across jurisdictions. Instead of rigidly classifying data as either identifiable or non-identifiable, it is useful to view de-identification on a continuum and to adjust access controls accordingly.*
- *A shift is occurring from a "data custodianship" model to a "data stewardship" model. Central to the success of this shift is the adoption of good governance practices.*

The Panel also observed that through timely access to health data researchers will be better positioned to identify opportunities for health-system innovations that can ultimately lead to improved efficiencies, economies, and patient care.

This Expert Panel assessment was requested by the Canadian Institutes of Health Research (CIHR). It will provide numerous stakeholders with practical insights on how to move forward so that health data can be accessed and used for the benefit of health-care and health-system innovation.

For more information or to download a copy of the Panel's report, visit the Council of Canadian Academies' website, www.scienceadvice.ca.

About the Council of Canadian Academies

The Council of Canadian Academies is an independent, not-for-profit organization that began operation in 2005. The Council undertakes independent, authoritative, science-based, expert assessments that inform public policy development in Canada. Assessments are conducted by independent, multidisciplinary panels (groups) of experts from across Canada and abroad. Panel members serve free of charge and many are Fellows of the Council's Member Academies. The Council's vision is to be a trusted voice for science in the public interest. For more information about the Council or its assessments, please visit www.scienceadvice.ca.

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