Overcoming culture of caution key to achieving greater health data sharing in Canada: Expert Panel report

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The barriers to greater health data sharing in Canada are fundamentally social and political, and a new CCA expert panel report details how overcoming this culture of caution could yield significant benefits for patients, researchers, and healthcare providers. Connecting the Dots shows how it’s possible to protect the privacy of patients while achieving robust data sharing systems and that a continued absence of improved health data sharing could deepen existing negative impacts.

“Health systems are approaching crisis levels with respect to accessibility, quality, and equity,” said Chaim Bell, M.D., Chair of the Expert Panel. “Health data and their exchange present an opportunity to improve patient outcomes, population health, and health workforce sustainability by enabling a health system that continually improves and generates new knowledge.”

Health data sharing has been shown to reduce unnecessary testing, time spent re-entering information, and preventable hospital admissions. With health systems across Canada facing severe capacity problems, these efficiencies could improve patient care, enhance the cost-effectiveness of care delivery, expand health research capabilities, and encourage productivity and innovation.

Canada excels at health data sharing for research purposes and has the opportunity—with broad coordination—to build on the experience of existing, smaller scale domestic health data sharing networks and learn from data-sharing initiatives abroad. Other opportunities to coordinate data sharing across sectors are explored in the report.

Enhanced sharing is not without risks, including the potential for breaches of privacy, stigmatization and bias, a widening of the digital divide, and additional burdens for health professionals. However, failure to improve health data sharing could exacerbate existing health inequalities, hinder public health monitoring and interventions, and limit opportunities for new research and innovation. Mitigating risk is possible through thoughtful implementation that builds trust and prioritizes transparency.

"Canada is well-positioned to evolve its current approach to health data sharing while continuing to safeguard patient's personal health information," said Eric M. Meslin, PhD, FRSC, FCAHS, ICD.D., President and CEO of the CCA. "This report details the various opportunities that could advance health data sharing in Canada and help to inform a collective effort to connect the dots for the health and well-being of people in Canada."
Connecting the Dots examines the opportunities for maximizing health data sharing in Canada. It focuses on the benefits and risks associated with increasing that exchange, the legal and regulatory considerations related to health data governance, and the opportunities to implement solutions that facilitate health data sharing among organizations and federal, provincial and territorial health authorities, while protecting patient privacy.

Visit www.cca-reports.ca to download the report.

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