

## Barriers to accessing data are bad medicine

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The lack of access to data makes it challenging to do interprovincial research, though Australia and New Zealand have both worked out the issues.

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Canada needs to “get its act together” so researchers can benefit from the nation-wide investment in electronic health records, says researcher Dr. Robyn Tamblyn of McGill University in Montréal. “Each province has population-wide information on hospitalizations, long-term care, physician visits, lab results and diagnostic imaging, and some information on drugs dispensed. Only a couple of countries in the world have this. We could benefit from the richness of all of this,” to shed light on clinical care and health services, says Tamblyn, who works in McGill’s Department of Epidemiology, Biostatistics and Occupational Health.

Tamblyn is one of many researchers in Canada frustrated by overwhelming barriers to using health care data in research. Researchers point to disconnected databases and concerns about privacy of personal health information as the main reasons data on everything from diagnoses

to prescriptions remain locked down. They say other countries have figured out ways to use the data in research, but Canada lags.

There are some exceptions. Earlier this year, Tamblyn published a study showing that more than 30% of prescriptions given to primary care patients in Quebec were not filled. The findings came from a Quebec project that integrates data from provincial health insurance and drug insurance databases into one electronic health record. Without these data, she would have been unable to conduct the study, Tamblyn says.

Ontario is likewise “lucky” to have access to databases from the Institute for Clinical Evaluative Sciences, says Tara Gomes, the principal investigator at The Ontario Drug Policy Research Network. “It is more difficult in other jurisdictions.”

ICES researchers can follow a patient’s path through the health care system by using the patient’s health insurance number, thanks to legislation that allows ICES and other organizations to use health data for analysis. This couldn’t happen in many provinces, where health care numbers and other personal information are restricted under privacy laws.

Provincial laws differ and are interpreted differently, Tamblyn says. In some provinces, managers evaluate researchers’ requests for information. “It’s easier to say no than it is to say yes” in these situations.

Even in provinces with organizations like ICES, it may not be possible to share data across provincial borders. This hit home recently when Gomes wanted to run analyses outside of Ontario. Linking drug information to diagnosis information was impossible because of privacy concerns.

“It introduces challenges to doing interprovincial research,” she says. “Colleagues in Australia and New Zealand can compare drug data across the country fairly consistently, but in British Columbia and Ontario we may not be able to compare our results.”

“There are many reasons to bring data together from multiple sources,” adds Dany Doiron, research coordinator with Maelstrom Research, located at the Research Institute of the McGill University Health Centre in Montréal. “You can do comparative research among jurisdictions, or build up sample sizes — with larger statistical power you are better able to detect effects.” But there are dams to pooling data, such as the lack of provincial resources to accommodate researchers’ requests for data. In addition, data from different jurisdictions may come in different formats. Doiron’s group develops software to “harmonize” these data, but without it, analyzing the data may not be possible.

There are initiatives underway to solve some of these problems. To protect confidential health data, the Ontario Information and Privacy Commissioner’s office advocates an approach called “privacy by design,” in which privacy protection is built into the way data are collected, stored and used.

One of the main methods for protecting privacy is “deidentification” of data. For example, names and addresses can be removed, and a health card number can be encrypted before matching information in databases. Ontario’s *Personal Health Information Protection Act*, introduced in 2004, allows “use and disclosure of personal information for secondary uses, including research,” says Debra Grant, director of health policy at the Office of the Information and Privacy Commissioner. The law explicitly exempts deidentified health care data from protection, and allows

organizations such as ICES to get data from health care providers, then deidentify and analyze it.

Manitoba and British Columbia have had organizations similar to ICES for many years, and several recent initiatives are also using health care data for research, including a health analytics network in Alberta, a population health data organization in Nova Scotia and specialized databases on neurology and maternal and infant health in Ontario.

Two of the largest national cohort studies in Canadian history — the Canadian Longitudinal Study on Aging and the Canadian Partnership for Tomorrow Project — are solving the privacy problem by asking participants for broad advance consent to use and link their data. They plan to collect large amounts of data for 20 to 25 years and link the data to provincial health databases on hospitalizations, physician billing and prescription drugs. “One of the objectives of the projects is to make the data available to a large number of investigators across the country for a number of different research questions” not yet imagined, says Doiron.

Gomes adds that she hopes the infrastructure available in Ontario to help researchers will be adopted across Canada “to allow people to... answer important health research questions.”

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