

Indicators for assessing the interoperability of health data in Canada

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■ Cite as: *CMAJ* 2024 December 9;196:E1389-90. doi: 10.1503/cmaj.241351

See related article at www.cmaj.ca/lookup/doi/10.1503/cmaj.241123.

In Canada, federal, provincial, and territorial governments have embarked on a major effort to improve the interoperability of health data, as indicated by Bill C-72 making data blocking by commercial software vendors a criminal offense,¹ endorsement of the Pan-Canadian Health Data Charter,² and the billions of dollars of federal support (e.g., Canada Health Infoway) and fiscal transfers to the provinces and territories to improve access to and quality of data and health information.³ The interoperability of health data is the ability of patients, their health care providers, and researchers or analysts — subject to stringent confidentiality and security safeguards — to access patient health data. For patients and their carers, this is critical to ensure full communication, where failures can be deadly.⁴ For health services research and health care quality analyses, access to these data is critical for managing Canada's expensive health care sector more efficiently, both to ensure the best interventions are being applied, and to weed out overly costly and useless procedures.

To this end, I propose 3 indicators to gauge whether these objectives of interoperability are being achieved. These indicators of progress are essential for high-quality health care and for holding governments and others (e.g., software vendors, health care organizations) accountable. These indicators do not need to measure every aspect of health data interoperability comprehensively but, considered together, they are designed to assess the most important components. These proposed indicators build on the principles in the Pan-Canadian Health Data Charter to enable rigorous assessment of progress toward interoperability of health data in Canada.²

To start with key definitions, a patient's electronic medical record (EMR) should hold computerized data related to all their health care encounters, including primary care and emergency department visits, hospital admissions, vaccinations, imaging, and drug prescriptions. Each encounter's data may include date, reasons for the encounter, health information collected at the time (e.g., blood pressure, symptoms, health status), what was done, and information about the providers. These data are typically spread across different organizations and databases. For EMRs in Canada to be considered interoperable, authorized users

Key points

- In Canada, patient health data are held by many organizations in different databases that are not currently interoperable.
- Interoperability means that authorized users, including patients, health care providers, and researchers, can access all relevant data across all databases, which is important for high-quality care and assessing health system performance.
- Patient access to their entire electronic medical records, provider access to a patient's entire electronic medical record, and analyst access to data needed for assessment of health care quality are 3 valid, focused, and sentinel indicators of interoperability.

must be able to access all relevant data elements across these different distributed databases.

The health care providers involved in a patient's care — including primary care providers, nurses, specialists, and pharmacists — constitute each patient's circle of care and should be able to access all relevant data, provided the patient has given consent. Further, some people outside a patient's circle of care should be able to access select data elements for analytical purposes. They would be duly authorized based on legislation (e.g., the federal *Statistics Act*, provincial legislation for health quality councils, organizations with specific exceptions in privacy legislation such as the Canadian Institute for Health Information). In some cases, EMR data could be anonymized, but for most sophisticated analyses, the data would have to remain identifiable even if names, addresses, and other personal attributes were removed. Access to an EMR needs to be subject to a prescribed set of role-based permissions. The details of these permissions should be established in legislation or regulation and embedded in the interoperability software (e.g., such that a dentist cannot read a patient's full medical history, a statistician cannot modify anything in an EMR).

Given the absence of existing indicators for health data interoperability, basic principles should guide the development of new indicators. At the conceptual level, one is construct validity,

meaning that each indicator should measure the intended concept well (not perfectly). Another is face validity, meaning that the indicator should be obviously important and make sense to everyone. At the practical level, each indicator should build on a specifically tailored program of data collection (e.g., by Statistics Canada, Canada Health Infoway, the Canadian Institute for Health Information). Specially trained and authorized staff in the organization would log in to the relevant EMRs to determine, in real time, the capacity to access the relevant health data, based on carefully designed samples of patients, providers, and data types.

The first of the 3 proposed indicators is the proportion of a province's or territory's population that can access and read their entire EMR. The extent to which parents should be able to access their children's EMRs is an open question. Given that EMRs contain data from many different health care providers, subindicators for each type of data held by providers or organizations are needed, including primary care, laboratory tests, hospitals, vaccinations, and drug prescriptions (issued and filled). To the extent that a patient's circle of care includes providers in other jurisdictions, these parts of their EMRs should also be accessible.

The second proposed indicator assesses provider access to permitted patient data elements. For instance, using a modest sample of patients in each province or territory, every provider who has been in a patient's circle of care over the previous 5 years could be determined. Subsequently, using a sample of these providers, staff in the testing organization would log in as if they were one of the providers and seek access to several data elements in the other provider's portion of the EMR, subject to relevant role-based permissions. The result would be a percentage of successful accesses to the data elements queried for each of the sampled patients in each jurisdiction. The specific measures for these indicators would be the mean and selected quantiles of the percentage distributions across each jurisdiction's sample of patients.

The patient samples should be stratified at least by age, sex, comorbidities, urban or rural residence, and race or ethnicity. Identifying providers in these patients' circles of care will require a form of snowball sampling. For example, where a primary care provider's portion of the patient's EMR contains a reference to a laboratory test or imaging result, the snowball sampling would have to find links to those providers' own EMRs. Although potentially expensive, this kind of sampling has been standard in the United States Medical Expenditure Panel Survey for decades.⁵

The third proposed indicator focuses on secondary uses of EMR data for statistical, health quality, and research purposes. It requires the ability to access but not modify large samples of EMRs by duly authorized people both within and across jurisdictions in Canada. These read-only EMR data could also be linked to data from population health and other surveys. Patient-level, longitudinally linked health and health care data in EMRs are essential for assessing quality of health care. Many different areas of study would benefit from comprehensive, interoperable EMR access. For this indicator, patients' health status before

and after a procedure needs to be tracked and compared with otherwise similar patients who have not had the procedure.⁶ Cardiac revascularization, joint replacement, and cataract surgery are specific procedures that would likely produce notable findings and could serve as sentinel areas. If interoperability were adequate for analysis of health outcomes from these 3 procedures, it would likely be adequate more generally.

The proposed indicators span critical kinds of interoperability. They are considerably more ambitious than those being developed pursuant to decades of First Ministers' Health Accords.⁷ If Canada can succeed on all of the 3 proposed indicators, the objective of interoperability will have been greatly advanced. Accepting anything less ambitious means that major gaps in interoperability will remain.

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Competing interests: No competing interests were declared.

This article has been peer reviewed.

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