

## LETTERS

### Challenges presented by a custodian-based medical record access system

In an editorial on electronic health records, published in *CMAJ*,<sup>1</sup> Dr. Nav Persaud raises an interesting argument. In my opinion, antiquated laws that define the powers of custodians of health information to control personal health information is the systemic problem that underlies issues with data interoperability and access to health records in Canada.

Custodians — such as individual practitioners, hospitals and pharmacies — are persons or organizations who possess legal custody or control of personal health information in conjunction with their powers or duties. They make decisions regarding access to records by third parties, including patients. The custodian-based access model made sense in an analog environment with paper records, whereby an entity was needed to store physical records securely and act as the point of access. However, digitized health records are easily copied and disseminated across a variety of platforms. Moreover, much health information is generated outside of patient-provider encounters and, despite technologies like patient portals, remains largely inaccessible to patients.

The current model of data transfer between siloed electronic medical record systems and various other databases places undue administrative burden on the custodian. Custodians are generally given 30 days to respond, but many are inundated with requests from patients, health care institutions, insurance com-

panies and others for information that is increasing in volume daily, making it challenging to meet deadlines. Furthermore, administration costs are not standardized, and can often be prohibitive to patients seeking their information.

Health information custodians serve an important philosophical function in upholding privacy, by protecting patient information from nefarious parties. Yet, this emphasis on privacy substantially hampers patients' access to their records and erodes fundamental rights. The custodian system also creates barriers for health care providers looking to retrieve patient information from other jurisdictions — which Dr. Persaud describes as a lack of portability.

There are 2 possible solutions to these challenges. In a decentralized model, patients can act as their own custodians, accessing their health information in real time and being at liberty to share it with parties of their choosing, such as family and close friends. I do not propose a model in which patients can choose what to share with their doctor, but one that grants similar access to patients and providers so that important diagnostic and therapeutic decisions can still be made. Information security could actually be improved in this model compared with the current variability in technical sophistication of health information custodians.

Alternatively, a model that centralizes the custodian-based system could serve to remedy current issues with information access through a mandate to store all personal health information securely at the provincial or national level, and to be responsible for sharing information with

patients and health care providers. Such a model could foster innovation by — with the express consent of patients — granting access to researchers or companies looking to develop health care technologies (for example, in training artificially intelligent algorithms). Patients could be linked to a unique number identifier that allows information to be transmitted back to the centralized repository and disseminated to the appropriate parties. Although some provincial repositories do currently exist, they generally do not have the authority to allow patients direct access to their health information.

These models present challenges, notably the governance of a central repository or patient custodian-based system, security regarding data transfer, funding and issues related to patient incapacity. However, models should be designed to account for common cases while having dynamic components to accommodate for more unusual circumstances, and not the reverse. Removing the custodian-based access system could mitigate barriers to accessing health information for legitimate parties, improve efficiency and possibly lead to better health outcomes.

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#### Reference

1. Persaud N. A national electronic health record for primary care. *CMAJ* 2019;191:E28-9.

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