

Intelligence MEMOS



From: Trevor Jamieson and Ewan Affleck

To: Canadian Healthcare Observers

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Re: **BETTER HEALTH DEPENDS ON BETTER HEALTH DATA**

Canada's governments recently came to broad agreement on renewing federal-provincial health transfers. Ottawa asked the provinces and territories to modernize Canadians' access to their electronic health information with "standardized health data and digital tools." Bilateral negotiation will define the details of these digital aspirations.

Canadians should pay attention: their health depends on it.

Canadian healthcare is not so much a system as a complex network of interdependent agents – governments, publicly funded services, private providers, professional orders and others. Whether you're a nurse, doctor, health researcher, public health practitioner, health administrator or in government, trustworthy information is essential to good decisions. It's also obviously vital to patients.

Though this is the information age, all too often information and how it's stored have been afterthoughts. It is subject to a chaotic mix of technologies – including, infamously, fax machines – policies, governance models and workflows that leave essential information fragmented, sometimes impossible to find and generally hard to use. It's not unusual for doctors or nurses to have to search for patient results — often one by one – across platforms run by different vendors, jurisdictions, sectors and health services and defined by unique rules for how or what information is shared. Often they can't even do basic summaries like graphs, let alone more substantial analysis of patient or population data. Navigating the chaos is time-consuming and error-inducing, contributes to practitioner burnout and, critically, risks patients' health and well-being.

Despite bold predictions and billions invested in digital health technologies, the promised improvements in system function and quality of care have been slow to arrive.

The basic solution is clear: organize information around the patient. Health information's technology, governance, policy and workflow need to be designed to ensure that Canadians' personal health information follows them throughout their lives. This has been achieved in other domains – consider our credit histories and banking information. The challenge is human, not technical, and traces back decades to the health sector's mistaken decision to design health information around individual services. It's as if our credit histories existed only in the files of every financial institution with which we had ever done business, instead of being amalgamated into one file.

People often think that "shared digital architecture" means everyone will have to use the same tool – a single portal, say, for all Canadians. That's not necessary, would be generally unmanageable in any case, greatly restricting both choice and the opportunities for innovation. Instead, Canadians should have the power to aggregate and then share their information with the tools that will help them most, in much the same way as they might download disparate financial transactions and share them with one of many budgeting or planning tools. Agreed-upon rules of engagement are what is required, on which various tools – portals, research registries, apps, or AI-driven large-language models – can be built. It is the lack of a common set of principles around access, consent, security, data-sharing and interoperability that has caused the current fragmentation of Canadians' data – not the absence of a monopoly vendor or of shared digital infrastructure.

This won't change overnight. But the bilateral federal-provincial agreements could move us in the right direction.

First, our governments should adopt the guiding principle that patients' entire records should be available, not just to health providers, but to the patients themselves. Not only is this consistent with Supreme Court decisions and the principles of good ethics, but there is growing evidence it improves participation and trust in the system.

Second, governments should agree that this information be useful and interoperable, meaning that it can be shared securely, with consent, both within the circle of care but also, after appropriate anonymization, with those engaged in health research and study.

Third, governments need to appreciate that in a person-centric system health information has to be portable when citizens cross jurisdictions. Without a harmonized approach across Canada, citizens, clinicians, governments and the Canadian companies that build information technology will continue to face high barriers to innovation and better care.

Our currently fragmented approach to health information prevents healthcare providers and patients alike from seeing the whole person – and that can put lives at risk. Canadians should demand health information tethered to the individual, through time, wherever they live. And the information needs to be useful (i.e., computable and sharable), not simply a chronological ledger on a website. Getting beyond fragmentation to usefulness and portability will require commitment and cooperation from everyone involved. But it's time for Canadians to insist on that; our health depends on it.

Trevor Jamieson is a general internist and the Chief Medical Informatics Officer at Unity Health in Toronto. Dr. Ewan Affleck, a hospitalist, is an expert adviser to the pan-Canadian Health Data Strategy.

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