



Patient-centred health records

Do you agree that Ontarians should have ownership and control of their own personal health records and that this information should be electronic and portable between health-care settings?

A key component of person-centred care is to put patients – and, in cases where patients consent, their designated family and/or caregivers¹ – in control of their own health records. This will allow them to make informed decisions and manage their health care.² The evidence shows that patients are more satisfied, more informed, and more engaged in their care if they have access to their health information.^{3 4}

Current state of health records

Currently, technologies and some Ontario laws support patients being able to view their own health information. The *Personal Health Information Protection Act*,⁵ passed in 2004, gives patients the right to see their own health information. However, this is an onerous and potentially expensive process.⁶ The records provided to patients are typically photocopies of patient charts. This format can be confusing for a non-medical professional to understand. If patients wish to access their imaging results, they often need to request and pay for CDs, which can be inconvenient and costly. It is unacceptable that, in 2019, Ontario relies on antiquated methods to share information with patients.

Some patients desire and require access to their health records for continuity of care. Ontario legislation only requires that patient records be kept for 10 years (and in the case of children, 10 years after they turn 18).⁷ This is a significant issue for people with chronic conditions who need access to their full medical history – not just the past 10 years.⁸

In most cases, patients' health records belong to their health-care provider and patients cannot make notes in their charts. Patients and the public, including members of RNAO's Public and Patient Engagement Advisory Council (PPE Council),⁹ want access to their own health information. They want to be able to exchange information, including viewing and monitoring their medical records and adding their comments in their own personal health records. For instance, a patient who routinely self-monitors some aspect of their health, such as blood glucose levels, may wish to store their day-to-day results electronically so that they are easily accessible at future health appointments. With the emergence of electronic health and medical records, this is now possible to implement.

RNAO's best practice guidelines provide evidence that eHealth solutions can advance health-care delivery.¹⁰ Canadians recognize the importance of eHealth as well: 96 per cent of Canadians

believe it is important for health records to be kept electronically so that they can be easily transferred within the system.¹¹

Types of electronic health records

The **electronic health record (EHR)** is a longitudinal, systematic record of clinically relevant information, created from information drawn from multiple data sources. It is capable of being shared across different health-care settings.

The **electronic medical record (EMR)** is a digital version of a paper chart that contains a patient's medical and clinical data gathered from one provider organization (e.g., physician's office, family health team). It is not easily shared with providers outside of that organization.

The electronic **personal health record (PHR)** is controlled by patients. It can integrate information from a variety of sources (e.g., medical records from multiple health-care providers and patients), and helps patients securely store and monitor their own health information. A PHR will include all or some information from an electronic medical record or electronic health record, but it is separate from, and not a replacement of, the records of any health-care provider.

Ontario's provincial EHR system was developed and is maintained by eHealth Ontario to enable health organizations to collect, use, and disclose personal health information for the purpose of providing or assisting in the provision of health care. It is not currently accessible by patients.¹²

Ontario has made significant progress in advancing the use of EMR systems. Millions of Ontarians already have an EMR through one of the 16,000 providers¹³ that use EMRs in Ontario.^{14 15} While the provincial EHR system has one record for each patient, each provider creates an EMR for each patient, so patients treated by multiple providers will have multiple EMRs. Twelve different EMR systems certified by OntarioMD are also kept in two important health data repositories – the Health Report Manager (HRM) and the Ontario Laboratories Information System (OLIS) – to create a comprehensive record of health information.¹⁶ Primary care providers and specialists with access to a certified EMR offering can therefore receive patient data that has been electronically collected outside of their practices, like diagnostic imaging and lab reports.

The emergence of EHR and EMR systems are important advances in collating and making information more accessible to providers. However, these were not designed with patients as end users, and are not systems with which patients can interact.

Introducing the personal health record (PHR)

RNAO is calling for eHealth solutions that are specifically tailored to what patients and designated family caregivers want and need. All patients in Ontario should have the option to access an electronic PHR, which will give them more control over their personal health information.

Patients are the custodians of their PHR and exert control over it, for instance by deciding with whom to share its information. Research shows that patients rate "access to their personal health information" as the most important feature of a PHR.¹⁷ The information contained in a PHR

typically includes all, or a portion of, their primary care provider-maintained EMR. The PHR can also include information from other health-care providers, such as a discharge summary, and notes from the patients themselves.

PHRs have many capabilities and benefits, specifically:

- Improve patient safety by enabling patients and designated family or caregivers to view test results and verify accuracy.¹⁸
- Support patients to better manage their own care. Most PHRs have advanced capabilities through which patients can manage and participate in their own health care, such as entering and tracking blood pressure readings or requesting routine prescription refills.¹⁹
²⁰ Much of what patients do for their health happens outside clinical settings. The tracking functions of PHRs support self-management of health, and this information can easily be shared with relevant providers.
- Create a more efficient and safe system by enhancing the flow of information and care co-ordination among different health-care provide.²¹ When providers can see all of a patient's health information, they are less likely to duplicate tests or make medication errors. Patients will not have to restate their health history at every point of contact. As a result, providers can focus on delivering care, instead of retrieving information.
- Facilitate communication between patient and health-care providers.²² Many PHRs have capabilities for direct, secure communication between patients and providers to communicate test results, or ask quick questions to clarify a treatment plan.²³ This opens lines of communication and can improve the patient-provider relationship. RNAO's PPE Council members emphasized the importance of, and their preference for, electronic communication with providers and health-care organizations (e.g., appointment reminders).

Province-wide use of PHRs will enhance the patient experience for Ontarians by making our system more person-centered. PHRs support patient decision-making by providing them access to their own health information.²⁴ When patients are empowered in this way, they can take greater control of their own health.²⁵ Patients, families and caregivers can have more informed discussions with their doctors,^{26 27} and enhance their confidence in managing their health.

PHRs take one of two forms. Standalone PHRs require patients to fill in and maintain information themselves, usually through an Internet-based service. While standalone PHRs are useful to store, organize, and share health information with providers, the drawback of the standalone model is that patients must manually enter all data. Reliability is dependent on patient memory and scope of knowledge. It is also not a complete record of all relevant health information.

Integrated, 'tethered' PHRs are linked to a specific provider's EMR system. The majority of information in the tethered PHR is automatically drawn directly from the primary care provider's pre-existing EMR. Patients can access and add to their records through a patient-facing, Internet-

based portal.^{28 29} In the view of RNAO, the most effective PHR system is one that is tethered to providers' EMR systems. Such a system may be enabled by OntarioMD-certified EMRs that already interface with HRM and OLIS data repositories to provide a comprehensive set of health information.

A made-in-Ontario example of promising practice

One of the most successful examples of an electronic PHR system in Ontario is MyChart, an initiative of Sunnybrook Health Sciences Centre and now used in hospitals across Canada. It was designed so patients can view their test results, clinical reports, and discharge reports, as well as request and schedule appointments, submit consultation assessment forms, and see pertinent medical information like allergies and conditions. MyChart also includes a section where patients can enter their own information – they can record symptoms or keep track of other factors that could have an effect on their health or course of treatment. Patients can share their health records with anyone they choose (i.e., family caregivers, other health-care providers).³⁰ Launched in 2006 as one of Canada's first PHR solutions, MyChart has over 150,000 users.³¹ Patient survey results indicate almost all patients agree that access to their health information via MyChart has improved their patient experience (91 per cent of respondents), and that MyChart helps them self-manage their own or a family member's health (94 per cent).³²

Principles for personal health records systems

RNAO recommends the following principles to guide the development of a PHR system for Ontario:

- Patient-controlled – the PHR is viewable and editable by patients, and designated families or caregivers when appropriate
- Trustworthy – personal health information is accurate, up-to-date, secure, and private
- Comprehensive – integrates information from patients, EMRs, and clinical reports from all health sectors (including hospitals, community, diagnostic imaging, labs, and pharmacy)
- Accessible – available at all times, from any location,³³ with real time updates. Tutorials provided to make PHR easy to use for all who choose to
- Publicly-funded and administered – no out-of-pocket expenses
- Rigorously evaluated, with results transparently shared

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- In consultation with patients, families, caregivers, RNs, NPs, and other health-care providers, develop and maintain a province-wide strategy to make PHRs available to all patients.

NOTES FOR RNAO LEADERS

They say, we say

This section is for RNAO leaders only. It provides additional information and suggested responses for statements we may receive about this issue.

A personal health record is not a good idea. Patients might delete or alter notes made by health providers. Patients might become anxious or confused if they have access to their charts and health information.

One of the capabilities of PHRs is that patients can record their own health information. This is done in a separate section of the PHR. Patients would not have editing access to make changes to provider records. If a patient notices an error in their records, they can flag this for their provider, who can then make the appropriate corrections.

Research shows that patients who have access to EHRs find them beneficial, not anxiety-provoking or incomprehensible. In a study by Canada Health Infoway, 76 per cent of patients who received test results online were confident that they understood the results.³⁴ This study also shows that patients who viewed their results online were no more anxious than those who received their test results in person.

The results of a province-wide PHR pilot project in Nova Scotia involving 30 primary care providers and over 6,000 patients were positive.^{35 36} Virtually all patients (99 per cent) wanted to continue to receive their results online, and 100 per cent of doctors reported that sharing test results online was valuable or extremely valuable to patients. The majority of patient respondents said they felt more involved in their care (77 per cent) and that the project had made a positive difference to them in managing their health (85 per cent).³⁷ The majority of patient respondents disagreed or strongly disagreed with the statement, "I find online test results confusing and difficult to understand" (81 per cent).³⁸

RNAO believes that for PHRs to be useful, the information they contain must be easily understood by lay readers. Potential comprehension barriers such as unfamiliar medical terminology and abbreviations or difficult concepts can be effectively addressed in carefully designed PHRs.³⁹ For instance, PHRs could provide terminology and decision support in the form of online dictionaries or info buttons to explain difficult concepts. To develop patient-friendly and easily accessible PHRs, we recommend that the government consult with patients, families, and caregivers about their information and comprehension needs related to PHRs.

We also recommend that patients receive education about what information will appear in the PHR, so that patients can proactively determine which data points to review. For instance, an individual may choose to review blood work but may avoid reading MRI results until after meeting with their primary care provider. There could also be safeguards built into the PHR system, for instance to delay highly sensitive or life-changing test results being loaded into the PHR until these results are reviewed at an in-person visit.⁴⁰

How is health information kept secure in PHRs?

Privacy and protection of patient health information cannot be compromised. Any province-wide PHR strategy would need to ensure that information is exchanged electronically in a manner that respects the sensitivity of patient health information. Ontario has existing security legislation and standards that set out the requirements for the provincial EHR system, and every approved EMR system, that can be used to develop equivalent regulations for PHR systems.

Will patients be forced to use PHRs?

RNAO is advocating that every individual in Ontario have a PHR available to him or her. It is then the patient's choice – or, when appropriate, the choice of a designated family member or caregiver – whether they will use their personal health record.

While all efforts should be made to promote participation in the provincially held EHR and organizationally held EMR, since they will improve care and strengthen data quality, some individuals may prefer not to have their personal health information stored in this format. RNAO believes that the option should be available for individuals to opt out entirely of the provincial EHR and organization EMRs.⁴¹

Some health-care organizations in Ontario already offer PHRs to their patients. Why should the ministry do anything?

RNAO believes that the government should take a systematic, co-ordinated approach to implementing PHRs so that they are accessible to all Ontarians, not just those who are patients at health-care organizations that have provided access to a PHR system.

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- ⁷ O. Reg. 114/94, s. 19.
- ⁸ Recent media has highlighted the challenges this poses for children with chronic conditions, such as congenital heart disease. Their medical records as they age can become incomplete, missing vital information about childhood surgeries and their earliest conditions, all of which is essential for their continued care. Source: Rushowy, K. (2017, July 28). Medical record of sick kids should be kept for life, group urges. *Toronto Star*. Retrieved from <https://www.thestar.com/news/queenspark/2017/07/28/medical-records-of-sick-kids-should-be-kept-for-life-group-urges.html>.
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- ¹² eHealth Ontario. (n.d.). Accessing your EHR. Retrieved from <http://www.ehealthontario.on.ca/en/ehr/accessing-your-ehr>.
- ¹³ Providers refers to both nurse practitioners and physicians.
- ¹⁴ OntarioMD. (2018). *Annual report 2017 – 2018*. Retrieved from https://www.ontariomd.ca/documents/annual_report_2018.pdf.
- ¹⁵ This uptake is not surprising, given that investments in e-health in Ontario have focused on core infrastructure projects (e.g., the provincial EHR system) and the adoption of EMRs.
- ¹⁶ The HRM electronically sends hospital and diagnostic imaging reports directly into a patient's chart within the provider's EMR. The OLIS is a system that electronically connects laboratories, hospitals, and providers to facilitate the exchange of lab test orders and results.

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- ³² Sunnybrook Health Sciences Centre. (2016). MyChart PHR Program. Retrieved from <http://imaginationchallenge.ca/wp-content/uploads/2017/02/MyChart.pdf>.
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