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?

Will you support implementing mandatory electronic medical records in all primary care settings?

A key component of person-centred care is to put patients – and, in cases where patients consent, their family and/or caregivers[1] – 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 2017, 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 is pursuing two strategies for electronic record-keeping: the EHR and the EMR. Ontario's EHR system is the provincial electronic health information system developed and 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 also made significant progress in advancing the use of EMR systems. According to OntarioMD,[13] almost 11 million Ontarians (approximately 79 per cent of the population) already have an EMR through one of the 14,000 providers using EMRs in Ontario.[14] While the provincial EHR system has one record for each patient, multiple EMRs may coexist for patients that have seen multiple primary care providers.

There are 17 different OntarioMD-certified EMR systems available. These approved EMR systems interface with 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. The HRM electronically sends hospital and diagnostic imaging reports directly into a patient's chart within the provider's EMR.[15] The OLIS is a system that electronically connects laboratories, hospitals, and providers to facilitate the exchange of lab test

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orders and results.[16] This means that primary care physicians, nurse practitioners, and specialists with access to a certified EMR offering can receive patient data that has been electronically collected outside of their practices.

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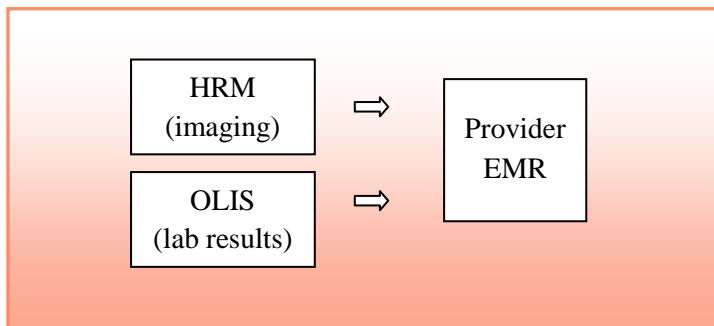
The emergence of EHR and EMR systems are important advances in collating and making information more accessible to providers. However, these were not designed with patients as end users, and are not systems with which patients can interact.

Introducing the personal health record (PHR)
RNAO is calling for eHealth solutions that are specifically tailored to what patients and family caregivers want and need. Specifically, all patients in Ontario should have the option to access an electronic PHR, which will give them more control over their personal health information. They would otherwise only be able to obtain this information through expensive and time-consuming release-of-information processes. This information typically includes all, or a portion of, their primary care provider-maintained EMR. It can also include information from other health-care providers, such as a discharge summary, and the patients themselves.

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

PHRs have many capabilities and benefits, specifically:

- Patients can use their PHR to view information, such as test results, and verify that all information is accurate.

- 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.[18] [19]

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- Patients can share PHRs with any provider involved in their care. In this way, PHRs can create a more efficient and safe system by enhancing the flow of information and care co-ordination among different health-care providers.[20] 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 repeat their health history at every point of contact. As a result, providers can focus on delivering care, instead of retrieving information.

- PHRs can also facilitate communication between patient and health-care providers.[21] 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.[22] 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).

- 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.

Province-wide use of PHRs will enhance the patient experience for Ontarians by making our system more patient-centered. PHRs support patient decision-making by facilitating access to patients' own health information.[23] When patients are empowered in this way, they can take greater control of their own health.[24] Patients, families and caregivers can have more informed discussions with their doctors,[25][26] and enhance their confidence in managing their health.

Tethered personal health records model
The design of the PHR system is important. PHRs take one of two forms. Standalone PHRs require patients to fill in and maintain information themselves, usually through an Internet-based service. Standalone PHRs are useful to store, organize and share health information with providers. The drawback of the standalone PHR model is that patients must manually enter all of the 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.[27][28]
The most appropriate and feasible PHR system is one that is tethered to providers' EMR systems, which RNAO prefers to standalone PHRs that require patients to manually enter data. OntarioMD-certified EMRs are an enabling structure as they interface with HRM and OLIS data repositories to provide a comprehensive set of health information.

Examples of promising practices

In Ontario, adoption of PHRs is being driven at the institutional and organizational levels. One of the most successful examples of an electronic PHR system in Ontario is MyChart, an initiative of Sunnybrook Health Sciences Centre. It was designed specifically for patient use and allows patients to 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).[29] Launched in 2006 as one of Canada's first PHR solutions, MyChart has 152,000 users with approximately 45,000 system logins every month.[30] 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).[31]

Nova Scotia introduced a two-year, province-wide PHR pilot project in 2012 whereby a web-based PHR system was selected for use across the province that would interface with whichever pre-approved EMR system participating primary care providers had chosen. Patients involved in the pilot could view information in their PHR, like test results and specialist reports, and also log their own information for their provider to see.[32] More than 30 primary care providers and over 6,000 patients were involved in the pilot project. Reviews were very positive, with 99 per cent of patients saying they wanted to continue to receive their results online, and 100 per cent of doctors saying that sharing test results online was valuable or extremely valuable to patients. The majority of 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).[33]

Principles for personal health records systems

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

- Patient-controlled – the PHR is viewable and editable by patients, and 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
    - Real-time updates
    - Available at all times, from any location[34]
    - No out-of-pocket expenses
    - Tutorials provided to make PHR easy to use for all who choose to

- Publicly-funded and administered

- Rigorously evaluated, with results transparently shared

RNAO's PERSONAL HEALTH RECORDS ASKS

- Mandate that PHRs be made available to patients, and families or caregivers when appropriate, to provide increased access to medical care information and encourage their participation in health-care decision-making. Patients, families, caregivers, RNs, NPs, and other health-care providers must be consulted in the development of a provincial PHR plan so that it reflects what patients need and want

- Mandate the use of EMR systems in all primary care settings in Ontario, as a complementary and enabling step to the development of a provincial PHR system

NOTES FOR RNAO LEADERS

They say, we say

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 patients notice an error in their records, they can flag this for their provider, who can then make corrections.

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.[35] For instance, PHRs could provide terminology and decision support in the form of online dictionaries or info buttons to explain difficult concepts.

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.[36] 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 majority of patient respondents (81 per cent) in the evaluation of the Nova Scotia pilot project disagreed or strongly disagreed with the statement, "I find online test results confusing and difficult to understand."[37]

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.[38]

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How do we keep health information 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 family member or caregiver – whether they will use a 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.[39]

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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