



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 providers.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.

References:

- ¹ A caregiver is a person who takes on an unpaid caring role for someone who needs help because of a physical or cognitive condition, an injury, or a chronic life-limiting illness. Definition retrieved from Carers Canada at <http://www.carerscanada.ca/carer-facts/>.
- ² Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbin, K.A. & Straus, S.E. (2011). Personal health records: a scoping review. *Journal of the American Medical Informatics Association*, 18, 515-522.
- ³ Nazi, KM., Turvey, CL., Klein, DM., Hogan, TP. & Woods, SS. (2015). VA OpenNotes: exploring the experiences of early patient adopters with access to clinical notes. *Journal of the American Medical Informatics Association*, 22, 380.
- ⁴ Curtis, J., Cheng, S., Rose, K. & Tsai, O. (2011). Promoting adoption, usability, and research for personal health records in Canada: The MyChart experience. *Healthcare Management Forum*, 24, 149.
- ⁵ *Personal Health Information Protection Act*, 2004. S.O. 2004, c. 3, Schedule A.
- ⁶ Gagnon, M-P., Payne-Gagnon, J., Breton, E., Fortin, J-P., Khoury, L., Dolovich, L., Price, D., Wiljer, D., Bartlett, G. & Archer, N. (2016). Adoption of electronic personal health records in Canada: perceptions of stakeholders. *International Journal of Health Policy Management*, 5(7), 425-433.
- 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>.
- ⁹ Registered Nurses' Association of Ontario (RNAO). (n.d.) *Patient and public engagement*. Retrieved from <http://mao.ca/about/PPE>.
- ¹⁰ RNAO. (2017). *Adopting eHealth solutions: Implementation strategies*. Retrieved from http://mao.ca/sites/mao.ca/files/bpg/Adopting_eHealth_Solutions_WEB_FINAL.pdf.
- ¹¹ Canada Health Infoway. (2016). *Connecting patients for better health: 2016*. Retrieved from <https://www.infoway-inforoute.ca/en/component/docman/3152-connecting-patients-for-better-health-2016/view-document?Itemid=101>.
- 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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- ¹⁷ Kerns, JW., Krist, AH., Longo, DR., Kuzel, AJ. & Woolf, SJ. (2013). How patients want to engage with their personal health record: A qualitative study. *BMJ Open*, 3, e002931.
- ¹⁸ Glauser, W., Petch, J. & Cumpson, D. (2018). Why can't you access your health record online? *Healthy Debate*. Retrieved from <https://healthydebate.ca/2018/07/topic/patient-medical-record-online>.
- ¹⁹ Gagnon, M-P., Payne-Gagnon, J., Breton, E., Fortin, J-P., Khoury, L., Dolovich, L., Price, D., Wiljer, D., Bartlett, G. & Archer, N. (2016). Adoption of electronic personal health records in Canada: perceptions of stakeholders. *International Journal of Health Policy Management*, 5(7), 425-433.
- ²⁰ Jackson, C. & Bradley, R. (2014). A new approach: Patient portals for primary intervention. *University of Ottawa Journal of Medicine*, 4(2), 16-18.
- ²¹ Usher, S., Jayabarathan, A., Russell, M. & Mosher, D. (n.d.). Personal health records in primary care: One province takes steps to make sure they're available. Retrieved from <https://www.healthinnovationforum.org/article/personal-health-records-in-primary-care/>.
- ²² Kerns, JW., Krist, AH., Longo, DR., Kuzel, AJ. & Woolf, SJ. (2013). How patients want to engage with their personal health record: A qualitative study. *BMJ Open*, 3, e002931.
- ²³ Hansen, C., Christensen, KL. & Ertmann, R. (2014). Patients and general practitioners have different approaches to e-mail consultations. *Danish Medical Journal*, 61(6), A4863.
- ²⁴ Davis, S., Roudsari, A. & Courtney, K. (2017). Designing personal health record technology for shared decision making. In F. Lau, J. Bartle-Clar, G. Bliss, E. Borycki, K. Courtney & A. Kuo (Eds.), *Building capacity for health informatics in the future* (pp75-80).
- ²⁵ Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbin, K.A. & Straus, S.E. (2011). Personal health records: a scoping review. *Journal of the American Medical Informatics Association*, 18, 515-522.
- ²⁶ Lester, M., Boateng, S., Studeny, J. & Coustasse, A. (2016). Personal health records: Beneficial or burdensome for patients and healthcare providers? *Perspectives in Health Information Management*, 13(Spring).
- ²⁷ Group Health Centre. (2016). *Connecting patients for better health 2016: 2016 myCARE benefits evaluation and final report*. Retrieved from <https://www.inforoute.ca/en/component/edocman/2954-group-health-centre-s-mycare-benefits-evaluation-plan/view-document?Itemid=0>.
- ²⁸ Vydra, TP., Cuaresma, E., Kretovics, M. & Bose-Brill, S. (2015). Diffusion and use of tethered personal health records in primary care. *Perspectives in Health Information Management*, 12(Spring), 1c.
- ²⁹ Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbin, K.A. & Straus, S.E. (2011). Personal health records: a scoping review. *Journal of the American Medical Informatics Association*, 18, 515-522.
- ³⁰ Sunnybrook Health Sciences Centre. (n.d.). MyChart. Retrieved from <http://sunnybrook.ca/content/?page=mychartlogin-learnmore>.
- ³¹ Sunnybrook Health Sciences Centre. (2016). MyChart PHR Program. Retrieved from <http://imaginationchallenge.ca/wp-content/uploads/2017/02/MyChart.pdf>.
- ³² Sunnybrook Health Sciences Centre. (2016). MyChart PHR Program. Retrieved from <http://imaginationchallenge.ca/wp-content/uploads/2017/02/MyChart.pdf>.
- ³³ The increased mobility of patients and care providers requires that electronic PHRs can be accessed anytime, anywhere – ideally through a web-based application.