

Revolutionizing patient control of health information

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In traditional health care interactions, clinicians are the holders of patients' medical information. In recent years, this information has become increasingly likely to be in a structured electronic health record (EHR), the control of which lies with the physician. The general argument for EHRs is that they can improve quality of patient care by better coordination of information—indeed the province of Ontario is investing enormous resources to “provide a single, harmonized and coherent ehealth strategy for Ontario that supports the government's health agenda” by 2015.¹ The United States has a more aggressive plan to ensure wide implementation of EHRs by 2014 as part of the economic stimulus plan.²

In addition to better information coordination by clinicians, EHRs make it possible for patients to have access to their own health information. There are many reasons why providing patients with their health information and tools to manage their health might be beneficial. The role of the clinician as the “protector” of patients' health information is being questioned,^{3,4} as an increasing number of patients are taking advantage of online personal health records (PHRs) or patient-controlled health records (PCHRs) to collect, manage, and control their own health information.

A Web-based PCHR

A PCHR is different from a PHR in that it is designed with user input to give a patient a lifelong, standard-based EHR (ie, EHR-related features that are based on industry standards) that is under his or her control. It can gather information from other EHR sources, as well as contain information generated by the patient and by health applications that the patient chooses to participate in. Important applications include secure messaging, online booking, disease-specific self-management applications, and other applications that are designed to promote health and wellness. Patients obtain copies of their records either by requesting them from their health providers or by “subscribing” to EHR sources that provide this service.

In 2002, the Department of Family Medicine at McMaster University in Hamilton, Ont, began developing a Web-based PCHR called My Open Source Clinical Application Resource (MyOSCAR), which launched in 2007. (Visit www.MyOSCAR.org for more information.) Patients with MyOSCAR accounts can choose their own data-sharing policies or use the default data-sharing

policies that are available (eg, parents or a power of attorney may read and manage the entire record; a public health nurse may read and write only to the immunization folder; a friend may only read and write to the secure messages). A patient can decide which specific health care professionals can read certain areas of his or her record, such as the drug allergy list, medication list, and problem list, if the patient's doctor is 1 of the 1500 physicians (covering about 2.5 million patients) across Canada currently using the EHR Open Source Clinical Application Resource system. Patients can also choose to enable the “glass-breaking” option, which gives other health care professionals access to those same lists in case of emergencies. Every time the patient record is accessed, the activity is tracked and recorded in the audit trail. Patients can choose to be notified when their records have been accessed. The ability to receive information or documents from the EHR would require confirmation of the patient's identity (known as *authentication*) and signing of consent forms for appropriate use.

Because MyOSCAR is a free and open-source software (FOSS) product, the software source code is available for peer review and customization. The possibilities of FOSS have been shown to foster community support and involvement.⁵ A FOSS product allows for development and contributions from users internationally, and it can be freely distributed.

The implementation of evidence-based, high-quality care depends on successful interaction with patients and access to appropriate information on patients' disease status. It has been proposed that PCHRs might provide more and better health information for clinical decision making; improve efficiency; increase patients' involvement in their own care and hence their health outcomes; and enhance patient-clinician interactions and relationships.⁶ Currently, MyOSCAR supports the collection of information such as patient-reported symptoms, which can be anything from headaches to pain. These symptoms can be reviewed by either a physician or a pharmacist for a variety of reasons including monitoring of drug safety and effectiveness.

Patients can have test results from their family practices accessible at appointments with other specialists. They can also track their blood pressure (BP) measurements that were taken at pharmacies, as well as have a list of all their medications, including

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over-the-counter drugs, thus giving their treating health care providers a dynamic, longitudinal view of their health care status.

Increased interest


There is tremendous interest by many researchers (as well as funding agencies) who are undertaking projects to evaluate different potential uses of MyOSCAR. A growing network of researchers from across Canada and elsewhere is emerging as a large collaborative. At McMaster University's Department of Family Medicine, approximately 300 people have participated in several small pilot tests; examples include using MyOSCAR for pregnancy care, hypertension management, and medication management. The pregnancy randomized trial gave the intervention group of women specific information from their health records that related to their evidence-based personal pregnancy care needs at appropriate times. The MyBP study was a randomized controlled trial investigating MyOSCAR for patient self-management of hypertension. Patients entered BP readings, shared these results with health professionals at their convenience, and received recommendations on management, in addition to education on lifestyle and risk factors. The MyOSCAR system produced graphs of BP readings, indicating whether readings were in the controlled range. The MyMEDs study examined the feasibility of MyOSCAR to capture information on drug safety and effectiveness by capturing symptom information before and after receiving a new medication. Feedback across the pilot studies indicated that patients believed there were benefits to using the PCHR to record and monitor their health status over time, appreciated the opportunity to communicate with clinics via secure messaging, and liked being able to receive health record documents from the clinics. Nevertheless, patients had varying levels of comfort with using the software and at times found it difficult to navigate the software; as such, a better support system would likely improve future larger scale implementation.⁷⁻¹⁰ Other research studies, funded by the Canadian Institutes of Health Research, include the Electronic Asthma Action Plan System, Empowering Patients: Making the Personal Health Record Accessible and Relevant for Primary Care, and an in-depth exploration of users' perceptions of various features.

Scope for growth

Since late 2011, the family medicine population of 3 large teaching practices in Hamilton and Kingston, Ont, has been examining the implementation issues of MyOSCAR. The practices of 10 physicians are participating in the pilot. Approximately 10 000 patients received an invitation letter to open a MyOSCAR account.

The uptake of PCHRs has been slow in Canada and elsewhere. There are concerns by health care providers

about increased workload, liability of electronic communications, accuracy of patient-entered information, and patient privacy.¹¹ Patient-controlled health records with EHRs have the potential to contribute to higher-quality care and improved efficiencies, which are desperately needed in order to sustain health care systems, through better coordination of clinical information, improved patient-provider relationships, and the ability for some patient groups to have more control over their health. No studies to date have rigorously demonstrated the benefits of the PHR on quality of care and patient outcomes.¹² Therefore, much more research is needed on how to overcome the logistic challenges of design, implementation, and sustainability; the effect on clinical practice processes and patient behaviour; and, of course, the effects on health outcomes and cost-effectiveness.

For more information on MyOSCAR, contact Dr David Chan (dchan@mcmaster.ca). For more information on MyOSCAR research, contact Dr Lisa Dolovich (ldolovic@mcmaster.ca). 

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Competing interests

Dr Chan is one of the developers of My Open Source Clinical Application Resource (MyOSCAR). Drs Dolovich, Bartlett, and Howard have provided strategic input into the development of MyOSCAR. Dr Price is responsible for overseeing the administrative development of the Open Source Clinical Application Resource system and MyOSCAR.

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