

Patient Destiny

Patient Empowerment



- By Invitation Only -

One Patient, One Record Workshop “My Blood Work: I Want It”

A Half-Day Workshop to further promote Patient eHealth
September 29, 2009

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On April 21, 2009, Patient Destiny held a symposium which brought together patients and healthcare personnel to support the patient empowerment movement. This symposium, entitled, “One Patient, One Record”, was intended to debate the merits of patients getting access to their own personal health information as a first step on the path to full empowerment. This achievement would also result in the need to re-engineer both healthcare delivery and the nature of information sharing and decision making in patient care.

The outcome of the symposium was outlined in a final report describing this “day of action”, Patient Destiny white paper, April 21, 2009. In essence, there was overwhelming support for patients to obtain electronic access to their own health information through an electronic health record or EHR – this view was shared by patients and healthcare personnel alike. Further, it was noted that there are organizations today that do, in fact, provide some patients access to some or all of their health record. In the majority, however, most patients do **not** have such access and as a consequence, patients must visit face-to-face with a health provider in order to obtain results from tests or updates to their overall health status.

In an attempt to keep the empowerment movement going, and in order to level the playing field, Patient Destiny’s objective is for all patients in the province of Ontario to be able to electronically access a full and comprehensive health record – i.e., have access to “One Record” that would contain all of their health information.

The Realities of Today

Unfortunately, achieving “One Record” is not straightforward. Due to the fragmentation of health delivery services throughout Ontario, data on patients are captured and reside in many disparate databases. This then requires the integration of a multitude of computer systems and software in order to create “One Record” in the first place, and then to make patient access feasible. In addition, there needs to be an understanding of the hurdles and of the benefits directly related to providing such access.

Bearing the vast requirements in mind, we have decided we will concentrate on promoting access to just one component of the health record – blood work results – for Patient Destiny’s second event.

Why Blood Work?

It became apparent in discussions during the first symposium in April that patients with a wide variety of illnesses and conditions uniformly require one diagnostic test – and that is blood work. Although individual diseases require the investigation of different indicators in the blood panel, there is a well-recognized need for blood work to be done as a first step in patient diagnostics and subsequently in monitoring patient health status on an ongoing basis.

Secondly, all blood work results in the province of Ontario are already stored in electronic databases – in hospitals, doctors’ offices and clinics, and in the medical laboratories themselves. The existence of these databases makes the integration of blood work results and remote access immediately feasible.

However, there are still many issues to sort out before achieving this first step. For example, we must resolve:

1. When should the patient be able to access blood work results?
(immediately or only after the doctor’s review?)
2. What kind of support information must be made available?
3. What portal will patients use to access comprehensive provincial blood work?
4. Who will pay for the cost of access to blood work results?
5. What resources will be in place for the patient should they need assistance in accessing and understanding their blood work results?

To reiterate, in order to move ahead successfully, these listed access issues will need to be resolved.

It should be emphasized that selecting only a portion of the Record at the outset is by design. It is believed that granting patients access on a wide scale to all elements of a health Record could create a large negative experience. To mitigate such an occurrence, it is suggested that support documentation be coupled with health information before granting patient access. Limiting to only one healthcare component such as blood work where results are standardized will permit a more manageable scope of our overall strategy to be tested and provide a narrower framework to analyze the above issues and concerns.

**Outline of Day Two – One Patient, One Record Workshop: “My Blood Work: I Want It”
September 29, 2009**

Our goal is to confirm and gain consensus that accessing blood work electronically **MUST** be our next step. On this day, we will bring informed opinion – from patients and healthcare personnel to investigate and make recommendations (maximum of 20-25 people).

Ultimately, we believe in developing an electronic health record for all Ontarians that can be accessed by the continuum of healthcare providers as well as the patients themselves which will then lead to improved health outcomes. Patient Destiny is recommending that the first step in this process is for patients to gain electronic access to their blood work.

We are organizing a half-day workshop to discuss and consult with invited representation from the following groups:

1. Patients
2. Physicians
3. Nurses and other providers
4. Canada Health Infoway
5. LHINs or Local Health Integration Networks
6. Senior hospital administration
7. Ministry of Health and Long-Term Care
8. Technology sector
9. eHealth personnel throughout healthcare
10. Academic/research personnel.

Proposed Agenda

The format will be one roundtable discussion where everyone will contribute to the discussion. To lead discussions, we will hear from three key speakers:

1. A leader in eHealth with a vision for the future.
2. An experienced physician that has used eHealth tools to engage and treat patients.
3. An informed and incented patient who can articulate expected benefits from access to blood work results.

Proposed Discussion Questions

- How is blood work captured today?
- How is blood work shared today with the patient?
- How blood work is managed and where is it stored?
- Where is the best place to integrate all of the blood work results?
- What search mechanism needs to be used to access blood work?
- How can blood work information be displayed?
- By accessing blood work, what measures do we need to show improvement in patient healthcare?
 - Usage
 - Outcomes
 - Satisfaction.