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Effective Healthcare Reform Must Include a Patient Perspective

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Abstract
Patient Destiny's first "day of action" was the One Patient, One Record symposium held April 2009 in Toronto, Ontario, Canada. The one-day event offered a dialogue opportunity between two distinct stakeholders – healthcare personnel and patients. This symposium brought together key healthcare decision makers and service delivery personnel in direct communication with highly motivated and informed patients. There were more than 100 participants in attendance including close to 50 patients and patient representatives, along with invited healthcare personnel.
During the day, there were 10 presentations from global leaders focused on the area of electronic health records (EHRs) and the dynamic and innovative role that patients can play in a revolutionized healthcare delivery system. In addition, there was open discussion on five previously prepared questions. These discussions each concluded with a vote (in favour or against) of the question and allowed for detailed comments to be submitted. Herein, we include the rationale for this first day of action to promote eHealth and present voting results summarizing the participants' varying perspectives.

Keywords: eHealth; Health Informatics; Patient eHealth; Patient Empowerment

1 Introduction

In today's healthcare system, the objective, put quite simply, is to treat the patient. One can argue that it is much more complicated than just "treating patients" – it's about many complex factors including illness care, wellness strategies, population and public health initiatives, and varying degrees of trauma management. While this detail is accurate, from a very broad perspective, health system operations are "all about the patient" – if there was no disease or trauma, there would be no need for a healthcare system.

Yet, even though the patient group is the fundamental foundation of the healthcare system, patients have seldom been seen as anything more than the "end product" or "result". To illustrate, patients are not typically involved in: 1) setting healthcare policy; 2) conducting and disseminating research; 3) coordinating patient networks; 4) providing or managing individual care; and 5) evaluating the performance and outcomes of varied healthcare delivery plans.

The trends in the healthcare field pertaining to information technology (IT) development have focused around supporting the traditional decision makers. These are typically providers, administrators and researchers. There has been an unprecedented amount of effort and funding invested in healthcare over the last decade in an attempt to advance this field of eHealth by supporting these traditional healthcare delivery methods. To date, this investment has not focused on the consumer or patient information needs.

The literature is rife with evidence of how poorly the healthcare field has been at overall eHealth development. This is due to many reasons; a short non-exhaustive list includes:

- Inability to identify the benefits from eHealth adoption
- Inability to measure the benefits
- Inability to adequately finance the IT initiatives

- Poor communication between system developers and health providers around identifying needs and functionality
- Inability to effectively define the requirements for successful implementation
- Inability to fully engage clinicians in the design, development and implemntation
- Underestimating the training and support that are required
- Automating inefficient systems without re-engineering processes.

Regardless of the specific reasons relating to particular installations, few would argue with the statement that "many questions remain". While we have implemented many systems, the expected efficiency and effectiveness gains that were projected have not been realized. Further, doing more of the same will not add any incremental benefits to health delivery systems globally. *A new approach is needed!*

2 Methods

The key to the success of our movement, Patient Destiny, is that patients and doctors want the same outcome – overall health and well-being for the patient. This means that initiatives to allow patients access to their own information MUST help achieve both the patient's and the doctor's objectives. There is no such thing as effective priority access to information for the patient if the physician cannot get access to it as well, because the patient must still then USE the information in some way. After the patient has spent time with their own information and shared it among a team of caregivers, they must still interact with the healthcare system. Treatment must still be executed, diagnostics still determined and post-treatment follow-up must be completed and measured. Therefore, the end of the game is NOT patients accessing information, but rather an informed patient, with all the appropriate information in hand, being empowered and working within the system to obtain the best healthcare services and possible outcomes.

Research to date has identified a very specific patient group eager to challenge the status quo. We refer to these patients as **Consumers with Chronic Conditions** (or the **3Cs**) (Leonard et al, 2008). Preliminary research indicates that this group of patients is knowledgeable about their condition(s) and is motivated to become more empowered, both individually and collectively!

On April 21, 2009, Patient Destiny held its inaugural symposium to advance patient eHealth. There were more than 100 participants in attendance including close to 50 patients and patient representatives, along with invited healthcare personnel. Patients were recruited in several ways: contacted through disease associations and foundations, cross-patient representatives and communications to the public at large through health providers. The healthcare personnel group was comprised of providers, administrators, researchers, academics, vendors and funding organizations.

3 Results

The symposium's objective was to begin the dialogue between patients and representatives of the healthcare system to arrive at One Patient, One Record. Discussions were targeted at creating a firm deliverable: an action plan to move the Province of Ontario forward regarding patients accessing health information or, if you will, to provide a framework for "ePatients". Innovative research that focuses on putting information in the hands of the consumer in healthcare (i.e. the patient) is now attempting to achieve two major objectives:

1. Bring the healthcare system in line with many other industries by incorporating consumer inputs; and
2. Improve the adoption of information technology, and thereby increase eHealth benefits, by combining the efforts of two groups – the current active stakeholder decision makers (i.e. healthcare personnel) with the patient group.

The symposium was set up with assigned tables comprising both healthcare personnel and patients. At different points during the day, there was discussion on five previously prepared questions. After each question had been discussed, each participant was required to vote via a confidential ballot and the votes were tabulated and reported back at the end of day. Table 1 below outlines these results.

4 Discussion

As can be seen from the voting results in Table 1, there is an overwhelming desire to allow patients (and their own care team – from questions one and two) to have access to their own health information, in electronic form, which currently resides in databases resident in health provider organizations. This perspective is shared by both patients and healthcare personnel.

1. Should patients be able to access their own health information without having to wait for their doctors' approval and consent?

Group	Yes	No
Patients	**31 (81.6%)**	**7 (18.4%)**
Healthcare Personnel	**56 (94.9%)**	**3 (5.1%)**

2. Should caregivers or the patient's support network have the same access to the patient's health information as the patient does (assuming permission granted by the patient or through "power of attorney")?

Group	Yes	No
Patients	**37 (90.2%)**	**4 (9.8%)**
Healthcare Personnel	**52 (96.3%)**	**2 (3.7%)**

3. Should patients be able to control access to their own EHR to allow others access to certain segments of their EHR or to all of their record?

Group	Yes	No
Patients	**30 (75%)**	**10 (25%)**
Healthcare Personnel	**48 (94.1%)**	**3 (5.9%)**

4. Is there value in patients accessing their own health information (such as lab results/consult notes/radiology images) to enhance their ability to manage their own healthcare?

Group	Yes	No
Patients	**38 (97.4%)**	**1 (2.6%)**
Healthcare Personnel	**52 (100%)**	**0 (0.0%)**

5. Will patient access to their EHR data/information improve patient safety outcomes ... i.e. avoid duplicated tests, cross-effects of drug mixing, poor hospital outcomes?

Group	Yes	No
Patients	**19 (65.5%)**	**10 (34.5%)**
Healthcare Personnel	**34 (81.0%)**	**8 (19.0%)**

Table 1: Voting Results from Prepared Questions Reported by Patients and Healthcare Personnel. Note: Undecided "votes" are NOT included in the counts above.

It became evident throughout the course of our symposium that there was a lot of excitement and interest in pursuing this initiative. While there are many patient support initiatives, very few involve patients across a number of health conditions and illness issues. Consequently, it is our belief that Patient Destiny can play a significant role in eHealth adoption throughout the Province of Ontario in the short and medium terms.

The second step, therefore, is the publication of findings and the need to promote more events of this type. The more we repeat this exercise, the more likely it is that we will uncover new and innovative approaches to involving patients and promoting "patient eHealth applications".

Further, we believe there is a need to represent the collective patient voice and to do so effectively we will need to engage smaller groups of patients in order to identify very specific opportunities and gaps in healthcare system delivery today. It is anticipated that future meetings will cover less breadth and more depth to particular topics.

As a result, our immediate "next step" is to follow directly from this One Patient, One Record symposium and repeat this "symposium process" in regions and cities across Ontario, Canada and globally.

5 Conclusion

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.

We close this report by providing a comment submitted by a healthcare personnel representative: *"Overall, I think access [to the patient's own health information] will play a constructive role rather than improve outcomes outright. Either way, an empowered patient is a powerful partner in the healthcare team."*

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Conflict of Interest

None to report.

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