

Patient Destiny

Patient Empowerment



One Patient, One Record

Report on One-Day Symposium to Promote eHealth

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April 21, 2009 in Toronto

Executive Summary

Patient Destiny's first "day of action" was the **One Patient, One Record** symposium held April 2009 in Toronto, Ontario. This one-day event offered a dialogue opportunity between two distinct stakeholders—healthcare personnel and patients. This "By Invitation Only" 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. In this report, we include the day's agenda (Table 1) and the rationale for this first day of action to promote eHealth, present voting results and summarize participants' comments (through both a theme analysis and actual written quotes). We conclude this report with an outline for Next Steps.

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Where We Are

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 illness 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.

Limited Success to date

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
- 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!**

The Patient-Physician Paradigm

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 his/her 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 3C's). This group is very knowledgeable about their condition(s) and extremely motivated to become fully empowered, both individually and collectively!

What We Did

On April 21, 2009, Patient Destiny held its inaugural symposium to advance patient eHealth. This one-day event brought together the two distinct stakeholder groups—patients and healthcare personnel—to consult and collaborate and to move a step forward in the long journey toward patient empowerment and patients accessing their own health information.

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.

Moreover, this symposium introduced an "adopt-a-patient" program whereby the registration fee was paid entirely by healthcare personnel. In essence, each healthcare personnel paid an amount that would cover the cost of two people—his/her self and one patient. As a result, the patient fee was subsidized to support and promote attendance.

Purpose

The symposium's objective was to begin the dialogue between patients and representatives of the healthcare system to arrive at **One Patient, One Record**. Ultimately, we believe in developing an electronic health record or EHR 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.

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 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.

What Participants Told Us

Results of Discussions

As can be seen from the voting results in Table 2, there is an overwhelming desire to allow patients (and their own care team) 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.

In Favour

Each stakeholder group had their own particular issues that were consistently raised. For example, for "Patients voting in favour of patient accessible electronic health records", they expressed two concerns repeatedly:

- a) Patients believe their own health information is their data and, as such, they should have unfettered access
- b) The patients do NOT want to be left alone—they will need support to understand the content and information.

Specific quotes describing these issues included:

"Although access should/is allowed this can be enhanced with paired and necessary education."

Patient 1

"But only if the EHR data is also available to all providers and providers are no longer compelled to repeat testing." *Patient 2*

For Healthcare Personnel voting in favour of patient accessible electronic health records, there was repeated concern on:

- a) The need to have any and all accessible data in a format and language patients can understand
- b) A definite need for “provider-patient” partnerships
- c) The need for providers to be made aware of the fact that patients will now have uncontrolled access to their own health information; this would presumably change the content of what is currently written in files.

Specific quotes describing these issues include:

“BUT [it is] important to know what information, just facts, results? Partnership needed, otherwise danger of ‘offloading’ more information, facts, etc. on patients without context.” *Healthcare Personnel 1*

“Those producing the patient information must be made aware that it will be available.” *Healthcare Personnel 2*

“A result should be accompanied by context/ education that makes sense of the result and perhaps, offers a next step.” *Healthcare Personnel 3*

“Key to patients being informed, educated and responsible for their own wellness!!” *Healthcare Personnel 4*

“Allowing control is consistent with empowering the patient. Providers must be protected, though, if unshared information jeopardizes a care decision.” *Healthcare Personnel 5*

“Keeping in mind that ‘access’ refers to ‘read only’ access. Patients should not control ‘write’ access.” *Healthcare Personnel 6*

“Patient is more incented than physician to improve their health and quality of life. Having access to info and being committed/involved could help to improve results but there are many other factors that can help more.” *Healthcare Personnel 7*

“Smart systems will help with reminders... but so will smart patients. And the patient health system should monitor as well.” *Healthcare Personnel 8*

Against

Even though the results were mainly in favour of patients accessing their own electronic health records, this was NOT unanimous. As such, the two stakeholder groups expressed their concerns.

For Patients voting NOT in favour of patient accessible electronic health records, the main issues are:

- a) Patients are overwhelmed and worried they will be left alone (with their data in hand) outside the system
- b) Patients are concerned about jeopardizing the relationship with providers by questioning their knowledge (inferred from asking to look into their file on their own).

Specific quotes describing these issues include:

“My concern is wondering if my doctor will actually bother to see the result if he knows I’ve seen it without him.” *Patient 3*

“There [must be] a system in place that advises treating physicians that info has been withheld.” *Patient 4*

“Surveillance? A really bad idea. Public health considerations—infectious diseases can put others at risk.” *Patient 5*

“There should be a way for patients to provide different levels of access.” *Patient 6*

Finally, for Healthcare Personnel voting NOT in favour of patient accessible electronic health records, the primary barriers are:

- a) Patients must be able to see the physician soon after access to results for context, thus eliminating the need to have their own access on their own terms
- b) What is more urgently required is a fundamental shift in care delivery and how we manage and measure these healthcare services.

Specific quotes describing these issues include:

“It takes more than the patient, providers need to be on-line/connected.” *Healthcare Personnel 9*

“Until this is better understood there are too many risks to the care providers.” *Healthcare Personnel 10*

“Could be time consuming and counterproductive if patient has to “approve” collaboration between providers/specialists.” *Healthcare Personnel 11*

“It is essential that the results be put in context and that the patient be able to see the physician soon after access to results.” *Healthcare Personnel 12*

Where We’re Going: Next Steps

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 creation of this report 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 “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, the next steps which follow directly from this **One Patient, One Record** symposium can be summarized as:

- 1) Repeat this “symposium process” in regions and cities across Ontario, Canada and globally.
- 2) Host a half-day session on Tuesday, September 29, 2009 in Toronto to solidify themes and set out an Action Plan for long-term Next Steps.

3) Drill down to one of the themes identified during that session in September and host a day in November 2009 with invited participants—half patients and half healthcare personnel—to work out the details of Information Content and Decision Support.

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 two comments submitted by healthcare personnel representatives:

“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.”

On pages 8–13 we provide information gathered from the day, beginning with the symposium agenda (Table 1). As the agenda shows, we were joined by national and international eHealth experts offering detail of their activity to promote patient empowerment. Facilitators led the discussion of the five questions. In addition, a comprehensive listing of the voting results (Table 2), along with a representative compendium of themes and comments (Tables 3 and 4) are provided for review. The themes and quotes contained within this Report provide only a sample of these findings.

Table 1: Agenda—One Patient, One Record

7:30 am – 8:30 am	Coffee and light breakfast / Registration
8:30 am – 9:00 am	Welcome – Kevin J. Leonard “The Patient Perspective” Department of Health Policy, Management and Evaluation (HPME), Faculty of Medicine, University of Toronto
9:00 am – 9:30 am	Keynote – David Wiljer “The Creation of InfoWell” Princess Margaret Hospital, University Health Network
9:30 am – 10:00 am	Break and discussion of first two questions
10:00 am – 10:30 am	Marianna Epstein “Patient Gateway: A Tethered Personal Health Record” Partners HealthCare, Boston
10:30 am – 11:00 am	Daniel Z. Sands “Illness in the Age of “e”: A Case Study in Participatory Medicine” Cisco Systems, Beth Israel Deaconess Medical Center, and Harvard Medical School
11:00 am – 11:30 am	George Tolomiczenko “The Role of Disease Associations in Promoting One Patient, One Record” Crohn’s and Colitis Foundation of Canada
11:30 am – 12:00 pm	Ken Anderson “Privacy + Patients = A Healthy Prescription!” Office of the Information and Privacy Commissioner of Ontario
12:00 pm – 12:45 pm	Lunch break and discussion of next two questions
12:45 pm – 1:15 pm	Jonathan Tritter “The UK Experience – Involving Patients” NHS Centre for Involvement and University of Warwick
1:15 pm – 1:45 pm	Doug Gosling “Empowering Patients”
1:45 pm – 2:00 pm	Break and discussion of last question
2:00 pm – 2:30 pm	Alexander (Sandy) G. Logan, Joseph A. Cafazzo “Remote Patient Monitoring: Empowering Patient Self-Care and Chronic Disease Management” Centre for Global eHealth Innovation, University Health Network
2:30 pm – 3:00 pm	Vaughan Glover “The Leadership Challenges of Evolving to a People- Centred Health System” Canadian Association for People-Centred Health
3:00 pm – 3:30 pm	Dianne W. Carmichael “Achieving Optimal Patient Outcomes through Better Information and Access to Expertise—Is there a Silver Bullet?” Best Doctors Canada
3:30 pm – 4:00 pm	Final discussion – reporting on votes and action plan

Table 2: Voting Results from Prepared Questions (reported by Patients and Healthcare Personnel) Note: Undecided “votes” are NOT included in the counts below

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

	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”)?

	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?

	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?

	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?

	Yes	No
PATIENTS	19 (65.5%)	10 (34.5%)
HEALTHCARE PERSONNEL	34 (81.0%)	8 (19.0%)

Table 3: Summary of Themes from Stakeholder Group Voting (reported by Patients and Healthcare Personnel) Note: Comments from undecided “votes” ARE included in Themes below

1. Patients voting in favour of patient accessible electronic health records

- Patients believe their own health information is their data and, as such, they should have unfettered access
- Please do not leave the patient alone—they will need support to understand the content and information.

2. Patients voting NOT in favour of patient accessible electronic health records

- Patients are overwhelmed and worried they will be left alone (with their data in hand) outside the system
- Patients are concerned about jeopardizing the relationship with providers by questioning their knowledge (inferred from asking to look into their file on their own).

3. Healthcare Personnel voting in favour of patient accessible electronic health records

- Healthcare personnel emphasized the need to have any and all accessible data in a format and language that patients can understand
- There is a definite need for “provider-patient” partnerships
- The providers must be made aware of the fact that patients will now have uncontrolled access to their own health information; this would presumably change the content of what is currently “written in files”.

4. Healthcare Personnel voting NOT in favour of patient accessible electronic health records

- It is essential that the results be put in context and that the patient be able to see the physician soon after access to results—which thereby eliminates the need to have their own access on their own terms
 - What is more urgently required is a fundamental shift in care delivery and how we manage and measure these healthcare services.
-

Table 4: Sample of Written Comments from Stakeholder Groups (reported by Patients and Healthcare Personnel) Note: Specific comments from undecided “votes” ARE included below

1. Patients voting in favour of patient accessible electronic health records

- It's my data, therefore I should have access to it!
- Patients should also have access to health care provider(s) to interpret/counsel on results as needed.
- Health information would benefit from 'diagnostics' and interpretation when practical and appropriate. If my tumour is benign—tell that upfront—I may not even need a follow up.
- Although access should/is allowed this can be enhanced with paired and necessary education.
- Caregivers are an extension of the patient. If permission is granted, it only makes sense.
- Need to shift control to patient to move away from current paternalistic approach.
- Need to share info with other providers, caregivers. Patients may need help with interpretation.
- The patient will be able to provide consistent info to their healthcare provider, not have to recall over and over again their patient history.
- Recognizing that this will take some work/development to get there.
- This access literally saved my life once—I was misdiagnosed with a serious disease which I learned was a false positive through my own investigation.
- Of course. But define “manage”—does this mean they are on their own? Or that they are informed about what to do?
- Patients have the most invested in their care—they need the info and to be aware of the info in order to be responsible for their care and their empowerment to improve.
- For patients who will not access their own health info, at least they have the option. Any set of info can be potentially useful.
- Patient is “Big Brother” who is watching. Patient is most knowledgeable about own history. Patient is most motivated and most interested monitor of accuracy and efficiency.
- Particularly when dealing with multiple doctors in different facilities.
- I have avoided duplication of tests and allergic reactions when I've had access to my own information. Because I was informed and educated.
- But only if the EHR data is also available to all providers and providers are no longer compelled to repeat testing.

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2. Patients voting NOT in favour of patient accessible electronic health records

- More information [does] not directly lead to “better” care.
- [Access is not enough, it] takes informed patients and good quality of data to make any difference.
- There [must be] a system in place that advises treating physicians that info has been withheld.
- Surveillance? A really bad idea. Public health considerations—infectious diseases can put others at risk. But [Patients] should be able to limit access for others (insurers? employers? etc.)
- There should be a way for patients to provide different levels of access.
- My concern is wondering if my doctor will actually bother to see the result if he knows I’ve seen it without him.
- It’s about knowledge and understanding of this information. Shared access is important yet needs all on board.

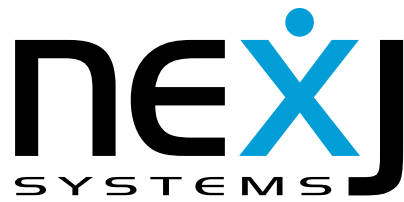
3. Healthcare Personnel voting in favour of patient accessible electronic health records

- If this information is truly theirs then there is only one answer.
- BUT [it is] important to know what information, just facts, results? Partnership needed, otherwise danger of ‘off-loading’ more information, facts, etc., on patients without context.
- In a language they can understand! Also [patients must get access to] a contact on the health team.
- Those producing the patient information must be made aware that it will be available.
- Patients may have to wait for the doc’s interpretation/perspective—and that’s okay.
- A result should be accompanied by context/education that makes sense of the result and perhaps, offers a next step.
- The appropriate processes and supports need to be in place for the patient as well as the doctor.
- Recognizing that some patient and/or health info will require/result in increased engagement with the care team—those implications should be considered.
- With the caveat that ‘unpleasant info’/pathology reports may need further interpretation.
- Partnership is a key assumption between patient/consumer and provider.
- Key to patients being informed, educated and responsible for their own wellness!!
- But there should be a support system in place to respond to the patient/consumer should he/she need it.
- As long as the patient is supported by a care team and that the care team proactively takes steps to see if patients had questions or concerns. Physicians should also make sure that their charting in records is written with the expectation that their patients will be reading the chart.
- If we truly embrace patient empowerment and partnership, why would we not support patients to [also] involve their caregivers?
- [Patient will] need ability to designate which info is shared and which info is not. For example, my chronic disease info would be okay but what if I had an STD or abortion and didn’t want that info shared?

- In the “e-world” [caregivers] should have equal access as the patients, as per the patient’s instructions.
- Let the doctor and the system figure out how to protect themselves from a manipulative patient.
- [Access] for many but not all conditions, e.g., some conditions should override patient’s control.
- If and only if physicians know if something is withheld.
- Allowing control is consistent with empowering the patient. Providers must be protected, though, if unshared information jeopardizes a care decision.
- May be situations that require “break the glass”. Should be able to control what/when/to whom.
- Keeping in mind that ‘access’ refers to ‘read only’ access. Patients should not control ‘write’ access.
- Essential for patient self-management if they know how to use/interpret the test results.
- This value [of accessing health info] is enhanced further by partnership with health provider(s) who may review/chart those results over time.
- Value – reduce anxiety [associated] with lack of control, knowledge. Patient benefit—opportunity to improve knowledge and understanding.
- This is true for some people, though not all patients, but this should not be used to limit their access.
- Patient is more incented than physician to improve their health and quality of life. Having access to info and being committed/involved could help to improve results but there are many other factors that can help more.
- Smart systems will help with reminders... but so will smart patients. And the patient health system should monitor as well.
- Yes, they will be able to help prevent mistakes and support decision making.

4. Healthcare Personnel voting NOT in favour of patient accessible electronic health records

- It takes more than the patient—providers need to be on-line/connected.
- Until this is better understood there are too many risks to the care providers.
- Could be time consuming and counterproductive if patient has to “approve” collaboration between providers/specialists.
- Negotiated—flexibility and the promotion of knowledge, understanding.
- A fundamental shift in care delivery model [is required].
- Very difficult question to answer—caregiver-patient relationship always different.
- It is essential the results be put in context and that the patient be able to see the physician soon after access to results.



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