

# Patient Destiny

Patient Empowerment



## One Patient, One Record

Report on One-Day Symposium to Promote Patient eHealth

Background

Summary of Speaker Presentations

Five Questions – Roundtable Discussion and Results

Next Steps – Action Plan

April 6, 2010 in Ottawa

This one-day **One Patient, One Record** symposium held April 6, 2010 in Ottawa offered a dialogue opportunity between two distinct stakeholders – patients and healthcare personnel. During the course of the day, the close to 30 attendees heard from five speakers who shared their expertise in the area of patient eHealth and there was a roundtable 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.

### **A. Background – Kevin J. Leonard**

There is an inevitable evolution taking place in healthcare. It's called **Patient Destiny** ([www.patientdestiny.com](http://www.patientdestiny.com)), and it is rooted in the fact that patients are beginning to demand immediate and timely access to their own personal health information. Patients want this access so they can partner effectively with healthcare providers in the management of their health and wellness.

The ultimate goal of Patient Destiny is an informed patient: a person who has all the appropriate information in hand and thereby is able to work within the system to obtain the best healthcare services and outcomes. With a vision of **One Patient, One Record**, Patient Destiny believes in developing an electronic health record (EHR) for all Ontarians that can be accessed by the continuum of healthcare providers as well as by patients themselves which we believe will then lead to improved health outcomes.

Through organized **One Patient, One Record** symposia, Patient Destiny is following an innovative approach by inviting both patients and healthcare personnel to the table to engage in dialogue about how to promote patient eHealth. The results of discussions to date show that both groups strongly support patients being able to access their health information. Efforts are underway to achieve the following objectives:

1. Raise awareness with all stakeholder groups (e.g., patients, caregivers, healthcare personnel) of the importance of accessing health information in managing patient care.
2. Encourage multiple stakeholder engagement in the design and development of pilot patient eHealth projects to respond to the increased awareness and demand for personal health information.
3. Develop key indicators and outcomes to be measured in these pilot projects to determine the value of patient eHealth.

## **B. Summary of Speaker Presentations**

### **1. Kevin J. Leonard: “What is the True Value of One Record?”**

Department of Health Policy, Management and Evaluation (HPME), Faculty of Medicine, University of Toronto, and Founder, Patient Destiny

[k.leonard@utoronto.ca](mailto:k.leonard@utoronto.ca)

**Kevin Leonard** opened the day with a call to recruit new followers in the mission to create **One Patient, One Record** in Ontario. The focus must be on the need to integrate healthcare technology into the system which will enable faster and timely movement of information. As a frequent user of the healthcare system due to his Crohn’s disease, Kevin is an ardent supporter of eHealth as he views this as the only feasible way for patients to be able to access their health information. Currently, access to information in a paper-based health record system is cumbersome, slow and can be costly, as evidenced in Ashley’s story in the symposium’s program.

The power and value of an electronic-based record and information system are described in the symposium program’s case study. Two case scenarios are outlined: a newly-diagnosed Crohn’s patient in today’s system and the same patient in a future system with a Web 2.0 application, termed ‘MyCare’. Continuing with Ashley’s story, we learn how health information currently does not follow the patient as she meets with a number of specialists to diagnose her condition.

Kevin is “One Patient” with “MANY Records”. To treat his Crohn’s disease as well as the side effects that have developed over the years, Kevin has 20 providers who each have their own unique paper file.

Kevin explained that we have a healthcare service delivery “Supply & Demand” problem. Healthcare system’s response to meet increasing demand is to increase supply. Kevin’s approach is to lower demand by empowering patients to access their health information so they can jump sooner on their health status changes (through management of health indicators) and thereby be able to flag something before it requires urgent intervention or hospitalization. Kevin anticipates that this will lead to significant cost savings as expensive treatment options are avoided, wherever possible.

Kevin has coined the term, “Consumers with Chronic Conditions” or “3C’s”. These individuals are the most motivated to stay on top of their care. Kevin pointed to Wagner’s 1998 Chronic Care Model ([www.improvingchroniccare.org](http://www.improvingchroniccare.org)) where one of the key pillars to improved health outcomes is an informed and activated patient. “3C’s” also consume 70-80% of healthcare resources and as a 3C himself, Kevin wants to be able to consume less resources!

In concluding, it was emphasized that patient access to their health information is only half the equation. Providers need access to the same electronic information – patients need to partner with them to achieve optimal health outcomes. As stated above, patient access can only happen through electronic means; therefore, we must achieve interoperability

where health information is captured centrally from disparate electronic sources.

Kevin ended his presentation by stating that he believed that patients will have some form of electronic access to their health information, whether in whole or in part, by July 1, 2013.

## 2. **Keynote – Dr. Daniel Z. Sands: “The Patient and the Physician Face Illness in the e-World”**

Cisco Internet Business Solutions Group, Beth Israel Deaconess Medical Center, and Harvard Medical School, Harvard University  
[dzsands@cisco.com](mailto:dzsands@cisco.com)

**Dr. Danny Sands** began his presentation by describing the “PatientSite” (<http://www.patientsite.org>), a patient website he helped establish in 2000 at Beth Israel Deaconess Medical Center in Boston. There are four major categories on the site including Mail, Services, Education and Records. Functionality includes ability to send secure e-mail messages between patients and providers, complete prescription refills, schedule appointments and view own health records among others. Patients can also store their own personal links, e.g. through Microsoft HealthVault. At this time, provider notes are not included.

Danny then shared the story of treating “e-Patient Dave” or Dave deBronkart. Before an appointment, Dave sends Danny an agenda for their meeting and as his provider, Danny also has an agenda for their encounter. During the appointment, Dave and Danny share the viewing of the computer screen to review health information and results. Dave has been diagnosed with metastatic kidney cancer which was determined after Danny sent Dave for a chest X-ray for right shoulder pain. A mass was found on Dave’s lung and further investigation led to his cancer diagnosis. Danny told Dave to go online to learn more about his illness and through this exercise, Dave learned valuable information about his cancer and approaches to

treatment. Dave credits ACOR (Association of Cancer Online Resources – [www.acor.org](http://www.acor.org)) as a key resource in his wellbeing.

As a physician, Danny stated that his interaction time with a patient is very small in comparison to the rest of the patient’s time in their life where they need to manage their care.

Danny’s main message is one of a shifting paradigm from Information Asymmetry with the physician as oracle to Information Symmetry with physician as partner. It is impossible for a physician to know everything as medical knowledge is doubling. The nature of the relationship is changing from paternalism to participation and we are moving from patient-physician to consumer-provider.

According to the late Tom Ferguson (Consumer Health Informatics, Healthcare Forum Journal, 1995), there is a shift from “Industrial Age Medicine” to “Information Age Healthcare” where the former is focused on primary, secondary and tertiary healthcare and self-care is off the map to a recognition of the value of patients, families and support networks in the provision of care with professionals as partners, facilitators and authorities. (View Tom Ferguson’s slides on e-Patient Dave’s website,

[http://patientdave.blogspot.com/2008\\_07\\_01\\_archive.html](http://patientdave.blogspot.com/2008_07_01_archive.html).)

Danny shared research results that show that 85% of adults go online to look for healthcare information and this number is rising. More adults go online than see a physician and about half are acting on the information ([www.pewinternet.org](http://www.pewinternet.org)).

The Society of Participatory Medicine ([www.participatorymedicine.org](http://www.participatorymedicine.org)) is a movement of networked patients and providers who are working to change the culture to one that embraces and recognizes patients as full partners in the management of their healthcare.

Danny concluded that doctors need to get patients involved and patients need to become active participants – become e-patients! Both groups need to embrace Information Symmetry. Connected technology empowers patients, providers and healthcare organizations. More study is needed; Danny encouraged submissions to the *Journal of Participatory Medicine*.

### **Discussion:**

There are three options when releasing medical test results:

- Release as soon as available for all to see.
- Delay for a fixed or variable timeframe.
- Wait until physician has reviewed result and then gives approval to release.

Danny believes that test results should be made available to patients and providers as soon as

they are available – ‘it is my body’. Patients have the option to connect with a physician at the same time. A patient expressed concern that he has his condition 24/7 and the healthcare system has supports in place from Monday to Friday, 9:00 to 5:00. Once access to health information is 24/7, the patient recommends that there needs to be discussion and consideration on how to extend provider access. It was noted that going online is the patient’s choice.

Adding eHealth to an already-full medical school curriculum would be difficult but Danny said that practicing physicians need to lead by example.

A participant mentioned that a recent Canadian Learning Council study has shown that 60% of Canadian adults do not have basic literacy skills and that Kevin and e-Patient Dave are sophisticated patients and not the norm. Danny replied that Dave demonstrates what can be and that everyone can reach out and teach adults in the office. Start discussions early by asking questions such as ‘do you use the internet?; do you use it for health information? This process of investigation will reveal the level of interests people have toward trying online communication.

The participant continued by stating that he often does not have a family doctor to send his specialist’s notes and by default, the patient needs to become the ‘quarterback’. Kevin said that patients that are motivated and engaged need to take the leadership in promoting patient eHealth and empowering patients to be an effective partner in managing their healthcare. Kevin described one family physician whose diabetic patients all agreed to a handheld device to help with self-monitoring,

much to her surprise. Referring to that example, Danny said that this shows that there is a greater awareness of eHealth and others are seeing the value. There is movement towards late early adopters.

Another participant suggested that we need to get on with the process of providing patient

### 3. Dr. Vaughan Glover: “The Leadership Challenges of Evolving to a People-Centred Health System”

Canadian Association for People-Centred Health  
[vglover@capch.ca](mailto:vglover@capch.ca)

**Dr. Vaughan Glover**, dentist and CEO of the Canadian Association for People-Centred Health (CAPCH – [www.capch.ca](http://www.capch.ca)), began by stating that we need to give power to the patients, to move from a model of ‘fixing’ to a model of ‘helping’ where we consider the whole human being, and enable them to be all that they are capable of being.

According to Vaughan, a paradigm shift for the millennium is required – “I’m the centre of my healthcare system” and we need leadership to help us evolve to a people-centred health system. To achieve this goal, we need to transition from our current health system focused on preventable and treatable illness to a system that supports the health of the people, where health is a personally defined balance of mental, physical, spiritual and emotional well being. System principles include personal responsibility, autonomy, informed health management, and partnerships.

The people-centred working model places an informed person at the centre surrounded concentrically by a coach, support groups, and management and legislation. With respect to

access. Consumers are already moving in the direction of wanting electronic information access. As an example, seniors show the largest rise in users who are managing their finances on the internet. Individuals need to accept the risk of transformation in healthcare.

health records, the vision would be for patients to be able to download information for their use – physicians and other providers would have their own records.

The time is now to move from theory to action and CAPCH is undertaking several initiatives to support the vision of **One Patient, One Record** including:

- CAPCH Academic Research Collaborative – including representation from the following groups: Academic, Provider, Political, Patient, Technology, Industry, Education
- North York Research and Innovation Centre
- Jane Finch diabetes remote monitoring project
- Healthy Community Project focused on wellbeing of students in Colleges across Ontario.

Vaughan concluded that we need to unite around a vision and Canada has the opportunity to be a world leader.

#### 4. Khaled El Emam: “What Does the Canadian Public Think About the Privacy of Their Health Information?”

Faculty of Medicine and School of Information Technology and Engineering, University of Ottawa, and Canada Research Chair in Electronic Health Information

[kelemam@uottawa.ca](mailto:kelemam@uottawa.ca)

**Khaled El Emam** began his presentation by stating that he is providing a descriptive summary of results based on public opinion surveys that show consistency in findings, thereby providing confidence in the results. Data breaches are loss of medical information by custodians, providers and health insurers.

Over a 3-year period from January 2007 to December 2009, Khaled reported that there have been 174 breaches and 9,000,000 records were involved in these breaches. While the number of breaches is small, the individual record impact is large. For more detail about the data, Khaled referred the group to the website, [www.ehealthinformation.ca](http://www.ehealthinformation.ca).

There is always significant media hype around breaches which then affects public trust. Media make it sound like these events happen all the time but they are extremely rare.

In a 2007 public survey done on privacy, it was revealed 39% believe that health information is safe and secure. In a 2009 survey, 56% were very concerned about the privacy of their information. In perhaps the most significant

finding, it was determined that when the patient has concerns about privacy, 11-13% of them subsequently change their behaviour in response (such as asking physicians not to include certain information in their patient record).

Individuals have trust in medical institutions holding their health information. This trust is hard to gain but easy to lose when there are concerns about privacy. In turn, trust is hard to gain back.

Patients feel in control when they can access their own records, and as such 84% state that they are less concerned about their privacy. Other control dimensions include correcting records, masking or hiding sensitive information, being notified of breaches and knowing when information is shared. Collection activity must explain purpose and there is a greater concern about sharing sensitive information, e.g. presence of STDs. As well, control is strengthened when patients know of the breach safeguards in place as well as evidence of strong technological safeguards.

## 5. Dr. Jay G. Mercer: “Meeting Patients Online to Actively Manage Chronic Illness”

Central Ottawa Family Health Organization, Department of Family Medicine, University of Ottawa, Canadian Medical Association, and MD Physician Services Inc.

[jay.mercer@cma.ca](mailto:jay.mercer@cma.ca)

Using one of the first patient portals in Canada, **Dr. Jay Mercer** has concluded the following:

- 1) Primary Conclusions:
  - i) Most patients are already online.
  - ii) Most patients make good use of their online activity.
- 2) Secondary Conclusions:
  - i) Older patients are biggest users.
  - ii) Acceptable use needs training – it is not appropriate to send an e-mail stating “I have a chest pain, what do I do?”
  - iii) Collects data in a structured manner.

Jay shared some statistics about the current state of use of Practice Solutions – mydoctor.ca Health Portal:

- Number of data points – 135,117
- Number of patients in the portal – 2,252
- Number of physicians actively using the portal – 138.

The portal collects patient health information such as blood pressure and pulse rate captured outside the office which can then be reviewed and discussed at the next appointment. Jay showed snapshots of the portal – blood pressure and pulse rate were graphed demonstrating trends.

Secure e-mail is available and Jay receives on average about two e-mails per week. When Jay

is away and one of his patients logs on, they will see a message that Dr. X is taking over for Jay.

Once armed with his clinical information accessed through the portal, Jay described how one of his patients developed his own measures of tracking “Mercer Interventions” through graphs and percentages to trend the impact of treatment. Patient reports success and continues to do well.

Jay described the pain tracker, a new portal application that will measure the progression of pain over time, an important advancement.

There are companies working on online systems for health monitoring including Biosign Technologies ([www.biosign.com](http://www.biosign.com)) which has a wrist monitoring device attached to a computer to measure and capture vitals. Another similar wrist device can also measure blood glucose levels and pricking of the skin is not required.

Jay concluded by stating that providers need to be open to the free flow of information.

### **Discussion:**

When asked how to broaden the application of use of mydoctor.ca portal by more physicians, Jay had several recommendations. Attract other physicians by mentoring its use at the grassroots level. Attitudes need to be adjusted in teaching centres. Payment model for physicians needs to be expanded or adjusted – Jay is paid through the capitation method but in

the fee-for-service model, there is currently no billing code yet for online activity.

Twenty percent (20%) of Jay's patients are using the portal. When a patient appears an appropriate candidate for the portal, Jay prescribes access just like he does other treatment interventions. In the current version of the portal, patients generate data points and they are providing information to the doctor. The next software version will have the capability for providers to push data to patients.

Physicians and patients see the same screen and they can have online interactions. Both Jay and Danny mentioned that the value and significance of websites like [www.patientslikeme.com](http://www.patientslikeme.com) cannot be underestimated.

Jay suggested that the physician approach to work needs a paradigm shift from diagnosing, treating and billing to collecting, processing and disseminating.

### **C. Five Questions – Roundtable Discussion**

The five questions and voting results of **One Patient, One Record** Ottawa symposium participants are listed in Table 1. The voting numbers build on the tallies of a previous symposium. Ottawa attendee questionnaire comments are found in Table 2 and responses are separated by patients and healthcare personnel. Finally, Table 3 includes a summary of stakeholder themes from multiple **One Patient, One Record** symposia.

Overwhelmingly, attendees at the Ottawa symposium agreed with earlier findings that patients and their caregivers should have access they can control to the patients' health information. Further, with this access, managing patient care is enhanced and patient safety is improved.

Along with the casting of votes and adding comments, there was a rich roundtable discussion of the five questions throughout the course of the day. The following is a summary of the general discussion.

While there was agreement for access, our current healthcare system does not enable timely, feasible and reasonable access to healthcare information. Access needs to be 'enshrined' as a right in the healthcare industry. Allowing unfettered access should be the goal and if we keep up with the caveats, patients will never get access. Kevin remarked that healthcare seems to be constantly striving for perfection in the system; we need to give healthcare a break. ATMs today do not look the same as when they were first introduced in the early 1990s.

One participant remarked that this discussion of access to health information reminded him of the brokerage industry where it was once believed that consumers needed a broker to complete their trades which is no longer the case.

Another attendee turned the questions around and stated that the action should be the patient allowing the provider access to their health record. In Queensland, Australia, patient fills out a paper record which is basis for the EMR,

Patient's Healthcare Record. Patient knows and understands what is in their record. Here, there seems to be a disconnect between the system and patients.

There are now consumer repositories of health information (such as Microsoft HealthVault) where patients can download their information from different sources for ready access. The provider also needs access to patient's information to make informed clinical decisions and where necessary, authenticate data elements.

With the private sector already involved in consumer health platforms, can we not leverage their expertise in helping to figure out what patients want – e.g. putting a picture together of how lab results would look?

Health information is generated in a number of places and it is more a question on how to provide value when accessing information. Participant suggested tapping patients in the community to help provide input and direction.

The information is the patient's to share with their circle of care, and it is their decision to make.

Canada Health Infoway has done surveys and found that consumers value EHRs for life or death issues and many still view the electronic task as digitizing paper records.

It was suggested that being able to access health information is analogous to Smart Meters in homes where consumers have instant access to electricity usage and they can react and adjust behaviour immediately to affect electricity usage. Timely access to health indicators could help with personal motivation to make required lifestyle changes. We need measures to help affect change in behaviour.

It is critical to innovate on how to give knowledge to people. One hospital has a team of developers working on iPhone applications for use by physicians at the bedside. Healthcare is about ten years behind in IT development and there might now be an opportunity to catch up and potentially, leapfrog ahead.

#### **D. Next Steps – Action Plan**

1. Reach out to University and College communities to develop educational initiatives for patients, caregivers and the public focused on patient empowerment enabled through eHealth.
2. Promote development of a new healthcare position or stakeholder group – health coaches or concierges who can assist with healthcare system navigation.
3. Partner with other initiatives such as the Canadian Patient Summit and the Patients' Association of Canada.
4. Work with Canada Health Infoway re a large national campaign supporting the rollout of EHRs.
5. Work on patient eHealth projects within local and regional centres (i.e., LHINs) – vast majority of care happens locally (estimated at over 95%).
6. Work with physicians and other providers to spread the value of shared decision making between patient and provider to optimize patient health outcomes.
7. Explore consumer-based opportunities with the private sector.

## Table 1

### Voting Results from Prepared Five Questions

#### UPDATE

- Twenty questionnaires were received: 8 from **patients** and 12 from **healthcare personnel**.
- The voting numbers below build on the tallies of a previous **One Patient, One Record** symposium.
- All the **patients** at the Ottawa symposium voted **Yes** to the five questions below.
- The majority of **healthcare personnel** voted **Yes** to the questions; there was one vote of **No** cast in Questions 2 and 3, and two **No** votes in Question 5.
- **In conclusion, the attendees at the Ottawa symposium agreed with earlier findings that patients and their caregivers should have access they can control to the patients' health information. With this access, managing patient care is enhanced and patient safety is improved.**

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

	YES	NO
<b>PATIENTS</b>	39 (84.8%)	7 (15.2%)
<b>HEALTHCARE PERSONNEL</b>	68 (95.8%)	3 (4.2%)

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
<b>PATIENTS</b>	45 (91.8%)	4 (8.2%)
<b>HEALTHCARE PERSONNEL</b>	63 (95.5%)	3 (4.5%)

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?

	<b>YES</b>	<b>NO</b>
<b>PATIENTS</b>	38 (79.2%)	10 (20.8%)
<b>HEALTHCARE PERSONNEL</b>	59 (93.7%)	4 (6.3%)

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?

	<b>YES</b>	<b>NO</b>
<b>PATIENTS</b>	46 (97.9%)	1 (2.1%)
<b>HEALTHCARE PERSONNEL</b>	64 (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?

	<b>YES</b>	<b>NO</b>
<b>PATIENTS</b>	27 (73.0%)	10 (27.0%)
<b>HEALTHCARE PERSONNEL</b>	42 (80.8%)	10 (19.2%)

## Table 2

### Written Questionnaire Comments from 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?

##### PATIENTS:

- The key is having access but it is their choice whether to view it or not.
- We need to build a competent and accessible support network so that we have 24/7 access to data/results and we have 24/7 access to resources to help understand or to deal with the ramifications of the results; authoritative info/net sites and/or access to a practitioner over the phone.
- Yes, the information is the property of the patient. There are more cases of information than just doctors – alternative providers, e.g. physio, chiropractic, massage therapy.
- Take ownership and responsibility. The simple answer is yes.
- Stop the “caveats” discussion. Yes – full stop!
- By the word information, I understand the routine “information” as opposed to measurement data which needs expert’s interpretation which is given to patients rather in a setting like physician’s office. Access – YES.

##### HEALTHCARE PERSONNEL:

- They already can!
- Patients have the right! Clearly it is the patient’s information / “enabling” this is another issue.
- I completely agrees with the CF patient – we have to be prepared to provide support for the patient to interpret the test result (and provide other supports should they be required).
- This is a fundamental patient right!
  - There should be an implementation process and follow the “do no harm” principle.
  - Routine, yes; but Dr. gets the pathology and share with someone on hand.
- Requires varied supports – MD, allied health, online, etc.
  - Requires culture change on part of practitioners – right to access PHI (*personal health information*) still challenged by most. Access on own is very important & distinctive from access in principle.
- Ownership of a patient’s information has to be embraced by the patient.
- However, I would think some test results should be embargoed to allow for a physician to interpret or provide perspective.
- Yes – provide the data – results of hemoglobin – this is a done deal.
  - How do we get the data into information and hardware and get it out there?

**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”)?**

**PATIENTS:**

- As a patient, I should be able to designate my care team and what type of information they can have access to.
- You can’t enter into a cooperative consumer-provider relationship unless both sides have full access.
- Important to have approval as there is an age of consent.

**HEALTHCARE PERSONNEL:**

- That’s part of their ‘CARE’.
- Requires robust functionality for consent change over time.
- Patients and providers need to partner and use the same information.
- I suppose it will depend on how you define ‘support network’, and how wide that is, but with consent it would be accountable.
- No, based on wording! “Same access”. Assuming patient granted access it needs to be access required to deal with current situation.
  - Objection is not to appropriate sharing info – objection is to “same access”.

**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?**

**PATIENTS:**

- There are some who may have access whom I would not want to share my info with and who do not need access to certain segments, i.e. a woman’s dentist does not need to know that she had an abortion 20 years earlier.
- Access meaning only READ access. Privacy leakage from owner – to X – to Y – to Z needs to be controlled access. Access to read YES but without passing on access.
- Yes, as owner of EHR – and whatever providers – e.g. homeopaths, chiropractor, eye doctor, dentist, etc.
- Patients and/or those who advocate for them; simply yes, i.e., when police subpoena whole chart indiscriminately – and they only need a portion.

## HEALTHCARE PERSONNEL:

- They already ultimately can control to some extent now.
- Yes BUT. Assumed appropriate access for the purpose of care; define “others”.
- Yes. Providers require own records on which to base care.
  - Are benefits to patients. To withhold and many risks to forcing access to all.
  - Need 2 kinds of records – for provider, for patient and info may flow.
- Patients need to own access to their record while ensuring integrity as providers use it for decisions in care.
- Control should reside with the patient, however physicians cannot be held accountable for information they do not have access to (and therefore have no knowledge of it).
  - Requires “break the glass” provision.
- It depends if it is to be used by HC providers. If so, only with appropriate authentication, non-repudiation, time stamps and integrity controls.
  - Also physician must know what data is withheld.
- No. Access yes – health care is free. How can healthcare providers take care of a patient if the information is withheld?
  - I agree, not all segments of healthcare professionals need access to everything.

#### **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?**

## PATIENTS:

- It is someone’s job right now to manage my results and information. Conversely, it is my life. Due to the greater stakes, I am likely to be able to add value.
- People are more likely to change behaviour when they see their data, e.g. weight, blood pressure, etc. and even lab results, etc.
- In reference to Peds – the caregiver – 6<sup>th</sup> sense – I feel there will be a period of “I told you so”: where the values will substantiate their “gut feeling”.
- Critical.

## HEALTHCARE PERSONNEL:

- If they participate in its creation.
- Yes, ownership – manage = motivation.
- Needs to be supported by decision support tools, e.g. trending/reference ranges, connecting the patient and the data.
  - Needs to be of value for the patients.

- Value to more than patients. When patients have access to consult notes, the quality of the notes increases (if providers know!). This improves the quality of care provided and received.
  - The information needs to be meaningful to the patients.
  - Yes BUT it is an interesting question – for people who can interpret this info good/great; for those who cannot interpret we have to provide them with assistance.
    - We all need to have a protocol for delivery of very bad news!
    - Good point – should patient and provider co-create their EHR/portal?
    - Question – improve health outcomes / lower cost
    - Agreed difficult to manage if you don't measure!
  - They could provide it to a wide range of providers than simply their GP (e.g. those outside the traditional circle of care).
  - Assume that access to more info results in behaviour change. Behaviour change requires attitude change and supports. If this exists already (e.g. already have engaged patients), will get early adopters of a system.
- 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?**

#### **PATIENTS:**

- The Rx system only captures prescription drugs. Many patients who supplement their care through naturopathic medicine, which is not captured by their doctor's or pharmacist's system. If I felt I had ownership of my records, I would ensure its accuracy (again, as long as I could control access). Increased accuracy should help improve safety.
- Can only improve patient safety with respect to drug mixing prevention. Can only improve safety.
- Absolutely – with good info with it.
- In most cases.
- Assuming: the knowledge gained by this access can be used well – by patients on their own? or through some support systems.

#### **HEALTHCARE PERSONNEL:**

- Informed patients have to have a positive effect!!
  - Interpret the question as – “I could say to a specialist I had a CT scan 2 months ago – can we use this first?”
  - Note: I like the take your hat off! And wear only the hat of a patient – because you are or have been a patient!! Think like that – not a vendor; not investor, not privacy.
- People will become more aware of cause and effect of behaviour, compliance and lifestyle choices.

- Access to you own health information will improve patient safety – nobody is more interested than the patient or has a more invested interest than the patient.
  - Drug profiles – we have those now.
  - Quick access.
- Patient’s role is making sure that the record is as complete as they are aware.
  - Complete my profile: these will contribute to patient safety, but currently data is not available for providers.
  - Avoidance of duplicate tests: Patients will tell doctors that they have had these tests; unless (1) providers see all test results and (2) patients see all test results, we will not get resolution of duplicated tests done.
  - Poor hospital outcomes: Requires communication and collaboration pre-, peri- and post-hospital stay.
- If physician-to-physician exchange of test results is not possible, this would allow patients to facilitate this; # of duplicate tests, ADES, etc. would definitely improve.
- No. Some outcomes will improve – but true risk management triggers can occur within EMRs for care providers before signs and symptoms occur.
  - Effects on safety only if patients putting in data (e.g. pain scores after discharge).
- I am not sure asking for opinions on this question are useful. We need actual data to test these hypotheses.

## Table 3

### Summary of Themes from Stakeholder Group Voting from Multiple One Patient, One Record Symposia

#### 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.
- Patients do not want to be left alone – they 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 (perhaps 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).

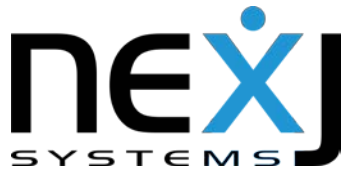
#### 3. *Healthcare Personnel voting in favour of patient accessible electronic health records*

- 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; changing relationships should be reflected in a new reimbursement structure for physicians.

#### 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.

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