

Patient Destiny

Patient Empowerment



One Patient, One Record

Report on Patient eHealth Workshop My Blood Work: I Want It

Opening Remarks

Keynote Address

Roundtable Discussion

Case Study

Next Steps

September 29, 2009 in Toronto

Opening Remarks

Kevin Leonard

As a Crohn's disease patient for the past 40 years, Kevin Leonard has had significant experience navigating the healthcare system. This navigation is often difficult and patients are required to do it when they are at their most vulnerable. Kevin is a strong advocate of the patient (and the patient team) being able to access the patient's health information.

Building on the discussions from the inaugural **One Patient, One Record** symposium held April 21, 2009, **Patient Destiny** seeks to move ahead in building a better healthcare system for patients with the help and input of patients. Patients are both payors and users of the system and experience has shown there is more successful uptake of electronic systems when users are actively involved in their development. This successful scenario has been observed and measured in the deployment of physician electronic medical records or EMRs.

To improve today's current healthcare system, building the ability to integrate information is the 'home run' and is wanted by providers and patients alike. Consumers with chronic conditions (or 3C's) are often called upon to provide and repeat clinical information as they interact with multiple providers. Enabling the seamless electronic sharing of clinical status will help improve their health outcomes. With the ability to access their own indicators electronically, patients can alert providers and take action sooner which, in turn, can avoid worsening of their condition and occurrence of major complications that might lead to hospitalization.

Technology is not the only hurdle. Considering the economic supply and demand theory, healthcare's approach to dealing with more demand is to increase supply which includes, for example, adding hospital beds, increasing number of doctors/providers among others. The proposition is that patients are capable of alleviating some of the 'volume delivery stress' on the system by helping to manage their care. As one example, demand for face-to-face interactions can be lowered by communicating electronically.

The high cost of caring for the chronically ill is undisputed and efforts to alleviate these costs through eHealth are critical. This view that eHealth is a necessary ingredient for effective healthcare reform was shared by both patient and healthcare personnel attendees at the April 21st symposium.

Ultimately, Patient Destiny believes 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.

Blood work is recommended as all patients uniformly require one diagnostic test—and that is blood work. As well, a vast majority of blood work results are already captured electronically in the Ontario Laboratories Information System (OLIS), meaning that the technology infrastructure is already in place.

Keynote Address

Dr. Daniel Sands

A long-time proponent of physicians having ready access to patient information at the point of care, Dr. Daniel Sands also trained in medical informatics and clinical computing during a fellowship at Beth Israel Deaconess Medical Center in Boston. A mentor was Dr. Warner Slack, a man ahead of his time in looking at the use of computers in healthcare in the 1960s. He developed interviewing models where the patient interacted with a program to determine a diagnosis. Slack stressed that patients were both under-utilized and under-appreciated in providing information. Their interface with the healthcare system is all too brief: there's a whole life to draw from outside the system.

An advocate of physician/patient e-mail exchange, Danny co-authored a 1998 paper published in JAMIA (Journal of the American Medical Informatics Association) on guidelines for the use of e-mail in clinical care. He has spent a lot of time explaining to other physicians how effective electronic communication with patients can be. He said there is concern among physicians that too much communication is a bad thing.

After originally forming the e-Patient Scholars Working Group, Danny now co-chairs the Society for

Participatory Medicine, www.participatorymedicine.org. This is not strictly a medical group, but rather a group of like-minded individuals who believe in and share the concept of active healthcare involvement by all parties (patients, caregivers, health professionals, etc.). The inclusive Society shares stories, hosts a blog, and a journal is in the planning stages.

In addition, Danny described an electronic "PatientSite" developed at Beth Israel in 2000 as a platform for secure e-mail patient/provider interaction and resources. Patients can view their health records online and can carry out specific transactions, such as accessing prescription renewals. Patients have a fundamental right to see their information. They shouldn't have to always be required to visit their physician's office to find out what's going on.

Danny noted that, traditionally, physicians have held all the power and the result has been informational asymmetry. Giving patients the tools for empowerment—the tools to access their own information—results in a shared model of care. And this gives physicians more time to spend with the patients in their office. Engaging patients through e-mail or blog discussions definitely advances participatory medicine.

To quote Sir Francis Bacon: *Knowledge is Power.*

Roundtable Discussion

The key question that launched the roundtable discussion for the 21 participants was **“How can we move forward to access blood work results?”**

Defining the context for examining ideas and suggestions, participants noted that we presently work within a fee-for-service model of healthcare. Increased patient/physician communication could present billing challenges—how to bill for time spent on e-mailing? However, it’s not all a question of payment. There’s also a culture working against the patient/physician partnership dynamic, a culture of fear among physicians: fear of being overwhelmed by e-mails; fear of patients not being able to either understand or handle their medical information, and the possible liability issues that might ensue.

For the patient, having access to their own health records provides the comfort of having some control. One of the attendees reported that during an interview with a cancer patient, the patient explained that cancer patients value information and know it empowers them. She said when she feels anxious, looking at her test results can often make her feel better.

Physician concerns about being overwhelmed by the volume of patient e-mails are not borne out by the experience of those who use it. Patients don’t bombard their doctors with an overload of internet information they want explained. However, there is concern that patients may need a physician present to interpret their results and allay their concerns. Danny mentioned that at Beth Israel Deaconess Medical Center, only patients who see physicians there can access their health record. It was noted that firm ‘rules of engagement’ are needed for

patients accessing their records through a secure, but common, portal.

In the response to the question of how they currently access their blood work results, one patient said one of her physicians will e-mail results, while others require an office appointment. Another patient, being treated for cancer, has access through the patient portal *InfoWell* at Princess Margaret Hospital. She noted there is a lot of useful information provided and since she has learned the complex terms she is able to read her own blood scans. While her family physician is very helpful, her oncologist is not forthcoming in terms of sharing information and won’t allow the patient to see her own chart.

A third patient sees his family physician for blood work results. He has found Sunnybrook Health Sciences Centre’s *MyChart* ‘hit and miss’ because sometimes test results are posted and other times are not. He cautioned about the need for patients to have information put in the proper context to ensure they can handle it.

One participant noted that, especially during flu season, it would be preferable to access blood work electronically or over the phone as opposed to sitting in the physician’s waiting room with a bunch of sick people.

Building on what we have

One proposal to move forward is to select one hospital and enable patients and physicians access to health records. It could start with a specific disease group, or a certain group of physicians. Next Systems has offered to set up the architecture and enable integration of data in a unified viewer. By integrating engines, data could be consumed and routed through a portal to pull hospital and clinical information together.

It was noted there are a number of competing e-health priorities resulting in budget challenges. A blood work initiative may seem like an 'add-on' rather than a priority. One suggestion was to dedicate 1% of the health budget to give patients what they want: namely, access to their own health information. It may be a matter of reframing requests for funds with the emphasis on patient empowerment. A set of standards could be developed to contextualize information for patients and define how lab results could be shared.

In response to the questions: "what should the patient see?" "should the information be the same for patient and physician?", participants agreed that the level of knowledge will grow naturally, as has happened with other areas where the public engages in electronic interactions.

The patients most wanting access to their information are those with chronic conditions who already have a lot of experience with the healthcare system. These individuals will be the early adopters. This is the group that should be served and this is where the most valuable feedback will come from. The cycle of innovation and improvement will evolve quickly.

There is much happening on the patient portal front right now with a variety of projects in place, trials underway and new developments under consideration. One example is the e-prescribing project operating in the two communities of Georgian Bay and Sault Ste. Marie. Physicians in the area are already 'tech-savvy' and use electronic health records, community pharmacies are participating, and the professional colleges are supporting the venture. Everyone wanted to be involved and there is the opportunity to gain valuable lessons. It was pointed out that research publications focused on the implementation of this

project and detailing 'best practices' will be coming out in the near future.

Privacy/security/confidentiality concerns were raised and the need for appropriate data-sharing agreements was expressed. It was also noted that privacy concerns have stood in the way of many initiatives, preventing them from moving forward. One participant noted that his hospital resolved privacy issues for patient involvement with *MyChart* through the consent process. It was suggested that consent to share information could be built right into the portal.

Patients attending the workshop questioned whether privacy is really such a huge concern among patients. While fear may be an issue there is a need to build the architecture capable of serving all involved. Many of the issues that arise may be solved on a pilot-limited basis. An example is the effective pilot study that now informs a large diabetes registry in the province.

Inter-institution sharing agreements would have to be developed so data, i.e., lab results through OLIS, could be available among different jurisdictions. It was pointed out that OLIS has a consent directory to track and audit information, and limit dissemination where necessary. Consumer strategy is part of the development of this provincial initiative to provide consistent and accurate information through a designated portal.

All participants agreed on the need to leverage what the province is already building. The following Case Study distributed for the workshop was cited as an illustration of the need for getting health records into patients' hands: it shows how more timely information could head off complications that, in turn, lead to greater demand on healthcare resources.

Case Study

The first section is a diary of a patient with a chronic condition interacting and **managing his healthcare in today's system** and the second section is a diary of the **same patient managing his healthcare after the implementation of an invented and innovative Web 2.0 application, termed 'MyCare'.**

Introduction

There has been much written over the last 24 months or so pertaining to the new and improved World Wide Web—also known as Web 2.0. While this has progressed to more than just a discussion topic in many industries, “Web 2.0-type” applications have not developed as rapidly in healthcare. Part of the reasons for this slow development in healthcare is that the Value Proposition surrounding eHealth Investment for patients is not straight-forward thereby questioning whether the information infrastructure development is cost-effective or not. Many in healthcare believe that this delay in

investment is due to the fact that the parties (i.e., single-payor system such as Ministry of Health and Long-Term Care) “picking up the tab” are not the same parties that will “reap the rewards” pertaining to the benefits after implementation. In other words, the system is required to invest in eHealth, however only the patients benefit from such investment. The foundation of **Patient Destiny** is that these eHealth investments will provide benefits for all stakeholders—including patients and the healthcare system delivery as a whole.

In order to aid this debate, and ultimately the design and development of said infrastructure, the following is a diary of a newly-diagnosed patient in a world both before and after the adoption of Web 2.0 functionality in healthcare. It is hoped that this unique perspective and portrayal will help many of the other health stakeholders understand the benefits to the patient and ultimately, to the system itself.

This case study is entirely fictitious and is meant to portray the situations in the two environments and does not reflect any one individual's sole experience.

Patient Diary 1 One year in the life of a patient with Crohn's disease at the time of his diagnosis through his ongoing management within the current healthcare informatics infrastructure.

1) Experience symptoms

I have been experiencing cramping on a more regular basis. For some reason, it seems to follow eating by about an hour or two. Sometimes the pain is so bad that I have to stop what I am doing to hold my stomach to ease the pain. I have very few other symptoms.

2) Search for information

It's been two weeks now of pain every day ... and it does not seem to be getting better. On a couple of occasions I have felt very nauseous. I cannot avoid it any longer—it is now time to look into this more. I went to a couple of Internet search engine sites specializing in health—looked up the symptoms but really could not narrow it down to anything I could follow up on. I finally phoned my GP and got an appointment for a week from Friday.

3) Disease diagnosed

My GP did a full physical and found little evidence of symptoms to follow up on. When he measured my weight, I was shocked to find that I had lost 15 pounds since my last appointment two months ago. I was sent for a full GI series tests. My doctor's office phoned a week later with my results and told me that I have Crohn's disease (he wanted me to come in for an appointment but I forced him to tell me over the phone). He did not have much to provide except that there is no known cause or cure but that people can lead healthy normal lives once the disease is managed effectively and in remission. I asked for next steps and I was told his secretary would phone with a referral to a specialist... a gastro something!

4) Disease learning

I went back to the Internet to search for information on Crohn's disease. I found a number of sites that explain it in varying details. I even found the Canadian association for Crohn's, but didn't really find what I wanted. This may sound odd, but I am not really sure what it is I wanted to find out, but I just know that I didn't find it—I was left wanting. Unfortunately, I had to go to my son's hockey game and did not want to disappoint him by not attending... again—so I could only search for so long. I have an appointment with my new doctor in one month.

5) Health provider search

I met with my new gastroenterologist today and honestly, I have more questions now than before I went to see her. I went to her clinic and waited for two hours before I could see her for about 20 minutes. She reviewed all my test results and confirmed my GP's diagnosis of Crohn's disease. I tried to get out a lot of questions but I felt rushed and didn't even get to ask the first question on my mind—what should I be eating? She put me on a new drug and scheduled an appointment for three months from now. I am still suffering from cramps and am not sure that these pills alone will help my pain—or continuing loss of weight.

6) Educating friends/family

It has been four weeks since my gastroenterologist's appointment and all I can think about is my newly-diagnosed illness. I cannot find out too much from websites other than that most patients experience a lot of pain and cramping with significant weight loss when the disease is flared up. Much of the research literature that I found discussed treatment options but none of them discuss the drug that I am taking. Also, I don't know how to get the flare-up to subside or alleviate the symptoms. A friend of my sister says that her cousin has had Crohn's disease for about ten years and would be happy to talk to me. This

sounds like a good idea but I don't think I will call because I just don't feel comfortable talking about cramping and diarrhea with a woman I don't even know.

My family has been very supportive and my job has understood that my absences over the last couple of months are due to being sick and/or going to doctor's appointments. However, I still feel there is so much I do not know in comparison to what I do—and I don't know where to turn.

7) Finding support groups

I found through the Canadian association for Crohn's disease that there would be a group information meeting; this meeting took place last night. It was very useful and I connected with a number of people—I was surprised how much we all share the same symptoms. I also received some great advice that I did not get from my doctor! I guess, in fairness, these little tidbits were more patient-related on how to personally manage the disease.

8) Self discovery and reliance

It has been three months since my diagnosis and I just had my second appointment with my gastroenterologist. Some of my symptoms improved over this time, probably due to the drug that I was put on but also due to several lifestyle changes that I made with respect to my eating habits and diet that I learned from some of my "new friends". Although I know that I have much to learn, I have become much more accustomed to my indicators of my health. I have been sent for another series of tests and will have to re-schedule another appointment to get my results. Honestly, since I am feeling better, I am a little reluctant to have these barium tests as they seem to upset me almost as much as my Crohn's.

9) Managing information

Now that I have become more fluent with my healthy status and the indicators that evaluate same, there appears to be lots of numbers and data—yes, even information!—for me to "keep handy". I try to help my gastro in every way possible. During our appointments, she often cannot find information in the paper file when she is looking for it. She likes to say "how come you can't find anything when you are looking for it?" Recently, I have been able to help her by having some of the history of my indicators with me. I usually take notes when I meet with her and I write down my "scores". This approach does not help with regard to my most recent results causing me to suggest at my last appointment, to moving all of her files over to a computer system. Her answer was "computers!?"

10) Managing expectations

It has been one year and I have grown to accept my chronic condition. I realize that I will have to take charge of my health management. In the last two months, I experienced three bouts of bleeding and the first time I saw blood in the toilet bowl, I just freaked out—I thought I was going to bleed to death right there. My wife drove me to the Emergency Department and I was admitted almost immediately. As it turns out this is very common in Crohn's disease but no one told me this "could even" happen, let alone that it is likely to occur over the course of my illness. Having repeated this scenario on two more occasions, I am desperate to learn more so that I can do anything to avoid these highly "panicked trips" to the Emerge. Whether I like it or not, I need to be more involved; I guess I have come a long way from the time where I put off the first trip to my GP because I didn't want to know or confirm that anything was wrong!

11) Ongoing management

Having now experienced my illness and symptoms, I am becoming much more knowledgeable about my overall health and well-being. I know that there are certain foods that I eat that make my condition better or worse. However, when I combine these foods with different exercise regimens and drug therapies, it is hard to know overall what the effect of any single one of them is.

I am very happy to be more involved in the ongoing management of my healthcare but I don't seem to be able to get the information I need and want. My gastro is very helpful and lets me have copies of anything that I want in my chart, but really this is a rather fruitless exercise. I now have the same amount of paper at home as she does at her office, but I cannot seem to find anything either. I want to be able to track my indicators and see how I am adjusting to the treatment over time.

For example, given the infrequent bleeding, some of which can be so minimal that it goes undetected in a bowel movement, there are frequent swings in my blood results and overall health status. For instance, a steady loss of blood can lead to a low hemoglobin and iron counts. This can result in me feeling tired or even short of breath, depending on the severity. Often I will go on for weeks with deteriorating health until my next gastro's appointment. When I finally do see her, I am sent for blood work. I then have to wait until my next appointment to find out what the counts are and what treatment I may need. This can take weeks at a time and my health continues to slip. Once I do see my gastro again, we often modify my medications; sometimes it requires a trip to the Medical Day Unit at my hospital where I can get an infusion of saline or even iron. In some severe cases, I have required a blood transfusion because my red blood cell count had become so low!

In order to shorten the typical timeframe of three months from "first symptoms to getting treatment" which can entail multiple doctor visits, trips to the Emerge and even admission to the hospital for a couple of days of IV nourishment, I have worked out a great arrangement with my doctor's assistant. When I am feeling poorly, I ask her assistant, Mary, to enter a diagnostic test or two into the hospital's electronic ordering system. I am not sure how "legit" this is, but it is my only way to circumvent the waiting! Recently, Mary was able to request a chest X-ray and blood work for me right while I was on the phone with her. Within a day, I went to the hospital and underwent the requisite tests.

With the tests completed, I phoned Mary the next day and she informed me that the chest X-ray showed that I had signs of pneumonia which meant that my immunosuppressive drugs may be too high. Also, the blood work showed all normal levels except for two. One was my creatinine which was too high and my iron which was low. She would ask my gastro to interpret the results and get back to me. At my gastro's recommendation, I went to the Medical Day Unit (where I can get treatment as an out-patient) the following day for an infusion of iron and two liters of saline—to help with hydration and lower my creatinine. My gastro also ordered a consult with a respirologist to check my lung function and perhaps prescribe some inhalers.

In the meantime, my gastro immediately lowered the dose of my Crohn's medications and will redo the chest X-ray in two weeks. All of this took place without requiring a scheduled appointment and within 24 hours of developing symptoms that I could recognize. This saved me, and my gastro (and all of the others within the system), weeks of waiting, hours of time waiting in the clinic, and the amount of the work required to get me better after my health would have deteriorated over a delayed time interval.

Patient Diary 2 A Crohn's disease patient with support of a Web 2.0 application focusing on Chronic Disease Management—referred to in the diary below simply as 'MyCare.'

1) Experience symptoms

I have been experiencing cramping on a more regular basis with the pain being so severe that I have to stop whatever I am doing. I saw a story in the paper about a new patient website that supports patient learning, empowerment and talks about how to navigate the healthcare system. I decided to see what it had to offer. I "Google-ed" patient empowerment and was led to MyCare. The site contained much information that I printed out. I will look at this in more detail over the next few days.

2) Search for information

It's been three days of increasing pain every day... and it does not seem to be getting better. I decided to sit down and review the information that I printed out from MyCare. One neat option the site provides is a connection to people who have like symptoms. I have never seen anything like this—where all you need to do is describe your own experience. I found three people and sent them e-mail. I was also able to submit a question to "ask an expert" and could describe in detail my symptoms... and I did not feel embarrassed at all! It was so easy—they even have a pull-down window for varying degrees of diarrhea—with a full description—can you believe that!? I never thought you could describe diarrhea in so many ways! I can't wait to see what response I get back!

3) Disease diagnosed

I just went back onto MyCare and had two responses this morning—one from Ask an Expert and one from a patient in Delaware. Both oddly enough needed more information and asked me

directed questions. The patient from Delaware gave me some good advice about diet and roughage—especially when cramping is bad. I will go grocery shopping today.

I logged on again later and the Expert, given more follow-up information, recommended that I contact my GP as soon as I can in order to get a full GI series work-up?! He stated that there was no way to be sure what I have or the seriousness without first doing a formal set of exams. One thing for sure is that he felt this is serious and severe cramping to the degree that I am having should not be dismissed—it is probably a sign of something more significant than just a stomach virus, for example. I phoned my GP and with a little persuasion I was able to schedule an appointment this week—I told them that a doctor "friend" said it was urgent.

My GP did a full physical and when he measured my weight, I was shocked to find that I have lost seven pounds in the last three weeks! I was sent for a full GI series tests. I phoned my doctor's office a couple of days later and he told me that I have Crohn's disease (he wanted me to come in for an appointment but I forced him to tell me over the phone). He did not have much to provide except that there is no known cause or cure but that people can lead healthy normal lives once the disease is managed effectively and in remission. I asked for next steps and I was told his secretary would phone with a referral to a specialist... a gastro something!

4) Disease learning

I went back to MyCare immediately after I got home and searched for information on Crohn's disease. I was able to drill down and find all sorts of facts. First, I found statistics on life expectancy and the impact that an inflammatory bowel disease can have—I must tell you that this little fact was just so reassuring. Second, I found a list of all gastroenterologists in my city near where I live, and

which ones are taking new patients. I was able to link to their sites right from MyCare and found out more about them and their education materials. Third, I could order a second opinion on my test results—I think this is a great feature that I will use down the road. Most importantly, I was able to join a chat room and my new contact from Delaware was there to help me get over the intros. I must say that there is something to that old saying “misery truly does love company”!

This may sound odd, but when I started out I really was not sure what it was that I wanted to find out or even what I was looking for, but somehow MyCare worked—must be because there are so many patients like me!

5) Health provider search

I met with my new gastroenterologist today and honestly, I really like her a lot. She was not in a rush, like my GP always seems to be and seemed to be very empathetic about my situation. She reviewed all my test results and confirmed my GP’s diagnosis of Crohn’s disease. I printed out my questions beforehand (with the help of MyCare’s neat decision tool “help me ask”) and this allowed me to feel very prepared and not panicked as we went through the questions and answers. In the past, I usually became sidetracked with my doctors and never seemed to get to the most important question—until I was back in my car and on the way home! After discussing many treatment options with a full consideration of potential side effects, we decided together to put me on a new drug. At my insisting, we scheduled an appointment for four weeks time, which is the minimum amount of time it should take to see some results. I want to stay on top of this! I told her that I had received a possible diet that I could follow—and she encouraged me to try different foods to see what I tolerate and what I

do not as everybody and every bowel are different. I feel very happy in just discussing it and getting her feedback!

6) Educating friends/family

I decided to take my family on a tour of MyCare—my wife stated that she found out the secret to my newfound intelligence! Seriously, MyCare has truly been extremely helpful in dealing with the whole newly-diagnosed process. As a patient, you have many more questions than answers and MyCare has been there to help me not only with the answers, but to help frame the questions. This way I have confidence in my opinion before I go to see my gastro—as a result, I am not afraid to tell her what I think and what I want. Further, MyCare has helped me describe my symptoms to my wife and my kids—something that I was hiding from them all because I thought it was my fault—something I did wrong to get this. The reassurance provided by MyCare means improved confidence and better decision making. As my new doctor said, it’s about making me well—and not just about treating symptoms! Finally, I was able to provide my employer with much information about my illness so that they could appreciate what I was going through.

Another great option is that MyCare helps translate into lay terms much of the research literature that previously I found very complicated as it uses language that I just do not understand. I am even going to the linked research sites now to learn more about recent developments in Crohn’s disease.

7) Finding support groups

MyCare led me directly to the Crohn’s and Colitis Foundation of Canada where I learned of a group information meeting; this meeting took place last night. It was very useful and I connected with a

number of people—I was surprised how much we all share the same symptoms. Given my MyCare experience, I was able to offer plenty of insight and a different perspective. In the end, the doctor leading the discussion was so impressed that he put the web-page address on the white board because so many people wanted to know more!

8) Self discovery and reliance

It has been two months since my diagnosis and I have learned a great deal about managing my condition. Although I have not found the cure, I am much more comfortable in “my own skin”. I know when I am feeling well and when I begin to feel poorly. I then know to contact my gastro sooner rather than wait for the symptoms to get worse—one thing I have learned is that very few things get better on their own! Further, I know when to jump in and help my gastro by giving her up-to-date and honest feedback about my current well-being. This openness and trust are the main reasons I think why I am feeling better.

9) Managing information

With all of this newfound information, I started wondering about where I could store my health-related data. It is not the same as financial data, but I feel it must be secured somewhere and my identity kept anonymous. It turns out that MyCare also has a “my record” section where you can store all of the information. The neat thing is now my gastro has been leaving me journal papers about recent findings and research on new Crohn’s disease drugs. MyCare provides a “fine-print” blurb about security, which I really don’t understand, however, they say they use the same technology as my bank—so that’s okay with me. I figure this is a very small risk to pay for such an improvement; for the first time in my life I feel that I am now in charge of my health information... and on the way to empowerment!

10) Managing expectations

It has been three months and I have grown to accept my chronic condition. I realize that I will have to take charge and be involved in every area of my health management. Ever since my first experience with the MyCare site, I have become virtually addicted to it—I think I am on it two or three times every day. Mostly, I am constantly in touch with a circle of about four patients with Crohn’s or colitis. One of us is really going through a bad time now and is facing her fourth surgery this year. I think we have been very supportive as she works through all of the issues. Her biggest one is her job—it wasn’t easy after the last surgery to go back to work and get her job back... and then within two weeks, she started missing work again. Her husband left a couple of years ago and she is alone to cope with her illness and her kids—not to mention all of the financial worries. But I think we are helping her—one member of our group knows a company in her area and they are trying to set up an interview for her where she can do some part-time work from home— isn’t that great! We are all coaching her on how to answer her interview questions!

11) Ongoing management

In the end, I feel that I have learned so much about my illness and the role that I must play in its management. To this end, my gastro and I exchange communication through MyCare where she posts my most recent test results. The MyCare “get your results” section has software that makes it real easy for my gastro to upload blood work results or diagnostic notes from my most recent CT scans or other diagnostic tests. This has allowed me to even “trend” my results to see if things are getting better or worse. And I can save the results to show my wife later and not have to recalculate everything. Perhaps the best thing about MyCare is that all of my health information gets integrated into one place—

regardless of the source. Sometimes I need to have blood work done but I am nowhere near my doctor's office due to my work. I can go to any lab in the city and the results get forwarded to MyCare—which is great because I can get a true overall consistent picture of my health!

Recently, I have been experiencing some fatigue, shortness of breath, and a general overall lack of energy. I e-mailed my doctor through MyCare and she sent me for blood work and a chest X-ray. I went the next day and logged into MyCare later that same day to check my results. There are a lot of results there that can be very confusing, but MyCare has a special "patient's column" that identifies when the results are normal or not. When I first started using MyCare, my gastro reviewed the ranges of various indicators with me and even modified some of the "normal intervals" so that they are specially tailored for me. So when I check my results on MyCare, they are reported based on my specific intervals in order to provide a personally-tailored health picture. Today, when I checked my blood work, I had two "abnormal results"; when I clicked on them a window popped up with a good explanation of the readings and the possible ramifications. MyCare also allows me to send my gastro a note just in case she had not yet seen the results and to append any special questions that I might have. I also checked the radiologist's notes about the chest X-ray which had similar supporting documentation.

Within a couple of hours, my doctor's assistant, Mary, called and said that she had scheduled me to go to the Medical Day Unit the next day for some infusions. I also received an e-mail from my gastro answering my concerns and modifying my drug doses just a little bit. She is sending me to redo these tests in two weeks. She encouraged me to ask any other questions—but I really feel that she is on top of "my care". It sounds strange, but even though I see my gastro less because of MyCare, I feel so much more connected to the health system and more in charge of my own healthcare!

Ultimately, my involvement and management of my care through MyCare is truly the only way to effectively maximize my health outcomes and live my life to its fullest! In short, I am not sure where I would be without it....

Conclusion

It is anticipated that patient empowerment will lead to earlier recognition of problems and more timely diagnoses resulting in faster and more effective treatment—and thereby better overall health outcomes. In addition, it is hoped that this case illustration will provide a forum for discussion on the many other, less tangible benefits from eHealth and Electronic Health Records.

Next Steps

The need for patients to have access to their own health information is a message that must be promoted and publicized loud and clear at every possible level. Suggestions to get the message out include:

- develop a business case focused on the patient level and underscore the return on investment
- strongly engage at the LHIN (Local Health Integration Network) level and exert pressure where possible
- key people need to speak out as often as possible—to the media, to healthcare forums, to the public, etc.
- the ‘converted’ need to push in their own jobs, even to the point of earmarking a portion of budget to patient needs for access to information

Public education needs to involve citizens taking a ‘Storm the Bastille’ approach! We have to recapture momentum and encourage patients to get involved en masse. All agreed a highly effective way to get

the message out would involve direct patient stories of their experiences with the healthcare system.

In fact, stories could be gathered from around the world using open source networks such as *Twitter*. These stories could demonstrate what it means to a patient to get their blood work results electronically.

In order to build on what is already going on there is a need to develop a repository of projects currently underway or under consideration. Since the Ministry of Health and Long-Term Care chooses where to put resources, it would seem counterproductive to come up with something new, rather than linking up with what is there. Too many strategies are being built in silos. Pilot projects, such as that involving Type 2 diabetes strategy, can inform broader strategies.

It was noted that there must be one focus for unifying the patient voice.

Patient Destiny: One Patient, One Record has become this voice!

