

Patient-controlled data

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Quality has become a central focus in health systems, however the notion of quality as what happens within a single care encounter, or in a single setting, fails to reflect the patient's experience of care in today's complex systems. Effective communication between care providers, both within one care setting and between different settings, is a *sine qua non* of quality assurance. However, despite massive investments in information technology, communication breakdowns are common and costly in terms of quality of care.

At the 2017 conference of the McGill University Health Centre's Institute for Strategic Analysis and Innovation (MUHC-ISAI), Laurie Hendren, professor of computer science and breast cancer patient, presented the experiences of communication breakdown that encouraged her current work, with her colleagues Tarek Hijal and John Kildea, to develop a patient-centric solution to the challenge of assuring effective health data management.

I wear 2 hats: the first is as an active breast cancer patient and patient advocate, the second is as a professor of computer science. I have been working to bring my experience and expertise in that field to the communication and information problems I see in healthcare organizations and treatment networks.

Figure 1 represents my treatment network. It covers 36 square kilometres in Montreal, includes 4 hospitals, 5 public clinics (some that simply serve to send patients on to yet other places) and 5 private clinics. In looking for information on how to interact with this type of health bureaucracy while seriously ill, I found on breastcancer.org a statement that one of the most important things to do is to personally keep a copy of your whole medical history and all your documents. I didn't actually understand at the time why people felt it was so vital to keep a copy of everything, however that has since become much clearer.

CURRENT STATUS OF DATA STORAGE AND SHARING

Most of my patient data is stored in paper files, spread across all locations in my healthcare network. As a computer scientist encountering the health system, I was amazed at the number of places where people were still writing on pieces of paper, then putting those into a folder where no one else looks at them. The second place where patient data resides is within hospitals or, more rarely, clinic computers. Each of the hospitals where I receive treatment have firewalls that

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protect the data within and prevent it from being accessed from the outside. Even within each hospital, there are many different databases that are also strongly siloed, complicating interdepartmental communication. The third place where patient data is stored in Québec is the Dossier Santé Québec, and the fourth (which may be less obvious) is in the systems used to collect data in clinical trials.

The principle means of sharing this data remains the fax machine. To my surprise, some information is also still shared by mail. Between databases, information is shared with great difficulty; some lines of communication exist, but even then, many healthcare workers do not access this information, usually because they lack the tools and/or knowledge to do so.

HAZARDS WITH THE CURRENT SITUATION

In what follows, I will provide an account of my own personal experience with current practices of information sharing around the health system. While we can hope it's not representative, and in no way takes away from the skill and good will of the professionals involved in my care, it is useful in identifying potential risks. It has also, as will be discussed a little later, prompted me to work at developing solutions.

WHAT CAN GO WRONG?

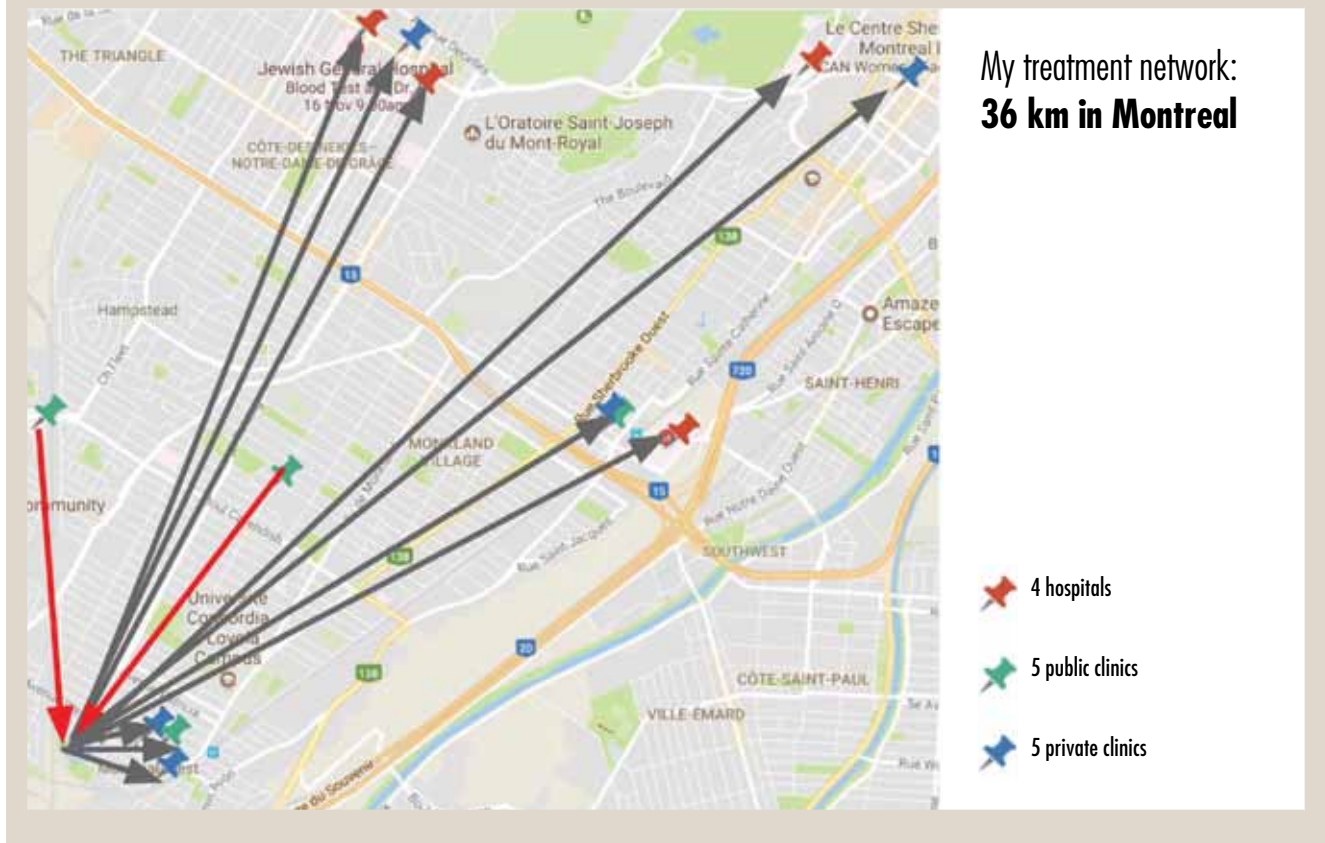
Delayed referrals

My GP looked at my ultrasound report and told me it looked bad and I needed to see the surgeon. The GP's secretary faxed the information and told me the surgeon would call me within 1 or 2 weeks.

I saw the fax sent out from the GP's office. Then I waited and waited, and eventually after 4 weeks, I called, then went in person to the surgeon's office, where they asked me for my referral papers. The fax had never reached its destination.

Luckily, I had listened to the advice from breastcancer.org and had insisted at my GP's office that they give me a personal copy of everything they were faxing. They did, despite insisting that giving me copies was totally unnecessary. As a result, at the surgeon's office I was able to say:

FIGURE 1. Author's personal healthcare network (a.k.a. my cancer schlep)



“Never mind the lost fax, you can copy the personal copy I brought with me, but I definitely want that back, thanks.” That resolved the issue, but only because I’d been able to prepare for that eventuality, which is not something many patients will insist upon. Needless to say, treatment initiation was delayed as a result of that communication failure.

Missing test results

I started into 6 rounds of AC (doxorubicin and cyclophosphamide) chemotherapy (which is really awful) and, because I’ll have to have chemotherapy effectively the rest of my life, they wanted to put in an implantable port. I was meant to receive my first round of chemotherapy, then have blood tests at equal intervals and, if all went well, have the port-a-cath inserted before the second round. By the second blood test, I wasn’t doing very well, and a CLSC (ambulatory clinic) nurse was sent to my home to take my blood, after which a car came by to pick up the blood and take it to the lab. It turns out the lab didn’t have a fax number for my oncologist and sent the results by mail. They never arrived. The result was that I had a port inserted despite suffering from grade 3 neutropenia. Safe care depends on having the right information available when making clinical decisions.

When I later inquired about the missing blood test, the CLSC nurse called the lab and found the originals were there, but they had no way of sending them to me. Thankfully,

the nurse was accompanied by a student nurse who said she would take a picture of the results with her phone and send them to me, which meant I was able to take those results to my next oncology appointment.

My care plan involved 3 cycles of chemotherapy, then a CT (computerized tomography) scan, and depending on the response, another 3 cycles of chemo, and another CT scan. In Montreal, CT scans are booked at whichever hospital in a group has the first available opening. The first CT scan was done at one location within the network; it showed the chemo was working quite well, and thus I continued into the next 3 cycles, after which a second CT scan was done. However, the second CT was done at a different hospital, and the radiologist did not compare against the most recent CT (from the other hospital), but rather an old CT from before chemo (from his hospital). When I saw my oncologist to discuss the effect of the last 3 cycles of chemo, my oncologist was impressed with how well those last 3 cycles worked. However, I had looked at the second CT report, and knew that the progress he was looking at was impossible. No one would have noticed this if I hadn’t noticed that the radiologist was comparing against the wrong CT, and I only noticed it because I made sure to keep a copy of all my records.

In each of these instances, breakdowns in data-sharing led to safety issues that could have had quite serious consequences. The problem with missing data is that no one realized it was

missing, and there was no one to make them aware they were missing information... except me, as the patient, and then only because I had taken great pains to obtain my own copy of the records.

PATIENT-HELD DATA

The advice I received from other patients and patient groups to obtain and keep a copy of all my information was, it turns out, well-founded. My experience as a patient and computer scientist raised 2 important questions: How will you get the information? And where will you store it?

At present, when you want to obtain your data, you can ask for a copy when you go to an appointment or test, but in all likelihood the answer will be no. I found that the best strategy is to say you need a copy for some other medical person. This may not work all the time, but often does. If direct requests fail, you can go home and fill in an access-to-information form, and you may then, weeks later, receive the information requested.

In terms of storing my own data, at first I used a big box. But a better solution is to use infrastructure, and my own personal solution was the Cloud. I now have a Google Doc of all the important information on my phone, and a Dropbox folder I can share with the clinical trials coordinator. This use of the Cloud for data storage makes it possible to think of apps to help organize, understand and share information, just as we do for sensitive non-health data.

What I've learned as a patient is that the common element in my health network is me. I'm the centre. Further, the logical common key is my phone. From my phone, I should be able to securely access my data from my healthcare providers, just like I can securely access my banking data from several different banks. When I receive care at home, the nurse has no information technology, but I still have my phone: that's the infrastructure. As the centre of my healthcare network, I should hold the key to my data.

A MOBILE APP FOR PATIENT-CONTROLLED DATA

I co-lead the Opal Health Informatics Group (HIG) alongside radiation oncologist Tarek Hijal and medical physicist John Kildea at McGill University, supported by the work of a great number of students and our core of professional programmers. Over the last 3 years, we've been working on a patient-centric mobile app called Opal (Oncology Portal and Application) that enables patients to store, organize and share their personal health data. We've surveyed patients and found that a vast majority want access to their information.

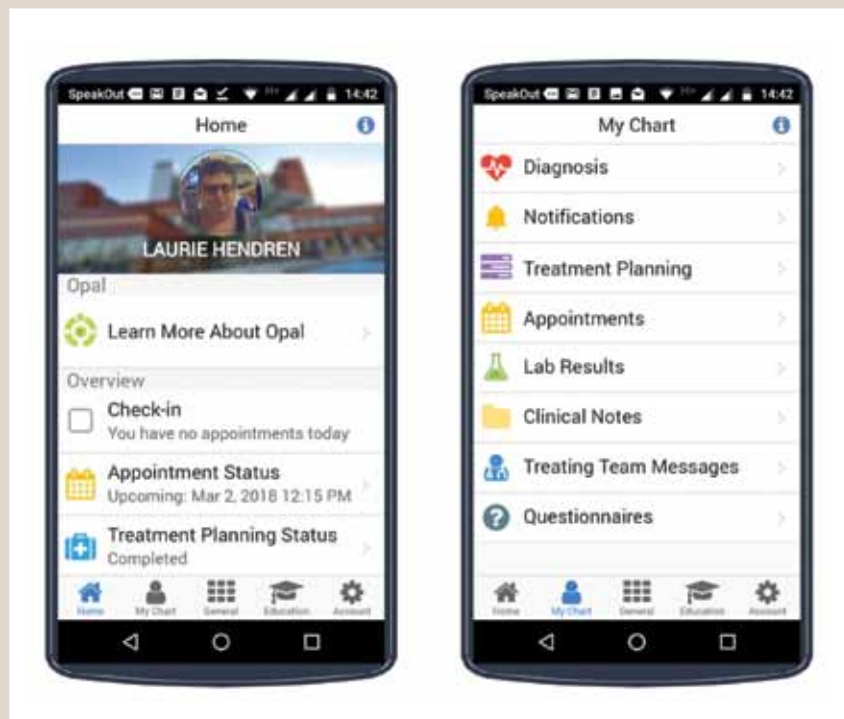
Figure 2 shows Opal's "Home" page, from which a patient can access different modules, including the "My Chart" page that holds personal information automatically taken from the various hospital and clinics, such as lab test results and clinical notes from consultations. This data can then be explored and transferred by the patient to people who need it. For data coming from behind hospital firewalls, the app

uses double encryption and sends data through the Cloud in a way that ensures the app is never directly accessing the hospital database, but the data remains secure.

A core concept in Opal is that a patient's information should be automatically extracted from the hospital databases, and should be personalized to the patient.

Figure 3 shows 2 examples of personalized data provided by Opal. On the left are my lab results for white blood cells (WBC), and you can clearly see where chemotherapy started, in the 4th quarter of 2016. Also, you can see near the bottom of the screen that there is a tab the patient can use to access information about the WBC test. This illustrates our general concept of educating patients as they browse through the app. The right-side of Figure 3 shows my recent and upcoming appointments. The green dots correspond to recently completed palliative radiotherapy to my femur. Upcoming appointments are shown in red, and it was very satisfying to see the red dots turns

FIGURE 2. The Opal "Home" and "My Chart" pages



into green dots after each day, as I finished another radiotherapy treatment.

Through Opal, patients receive personalized information, both through receiving their own clinical documents, as shown on the left of **Figure 4**, but also through patient education material, as shown on the right of **Figure 4**. Educational information is automatically personalized to the patient. Breast cancer patients, like me, get breast cancer information, and they only get it at the right times: prior to treatment, during treatment, and after treatment. Educational material can include videos, virtual booklets or PDFs. A patient may share documents with others, and I recently shared my most recent consultation note and end-of-treatment note with my clinical trial coordinator, who is at a different hospital and did not have access to my documents. This saved her an enormous amount of time, and shows that putting the patient at the centre of their information network helps both patients and medical personnel.

Our Opal HIG group is aiming to pilot the app first within the health centre's radiation oncology department and then extend testing to other Montreal centres. We are also in discussions with the provincial government, with hopes of making the Opal app available to patients throughout Quebec. The project has been presented at conferences, including the recent Canadian Cancer Research Conference in Vancouver, and has won several awards.


There are still a few legal and bureaucratic obstacles to overcome before our ambition becomes reality, but the technology is ready! Most important, however, is the need to change the way we think, as patients and providers, and recognize that it is important for patients to have their own information, and to put them at the centre of their own information health network. 

FIGURE 3. Patient blood test results and appointment calendar

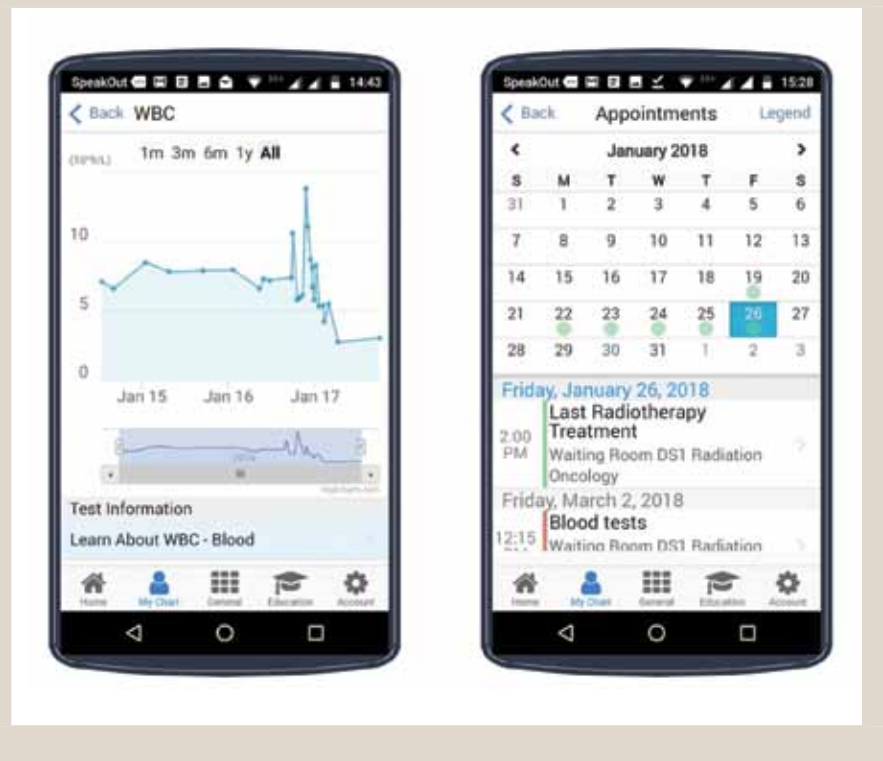
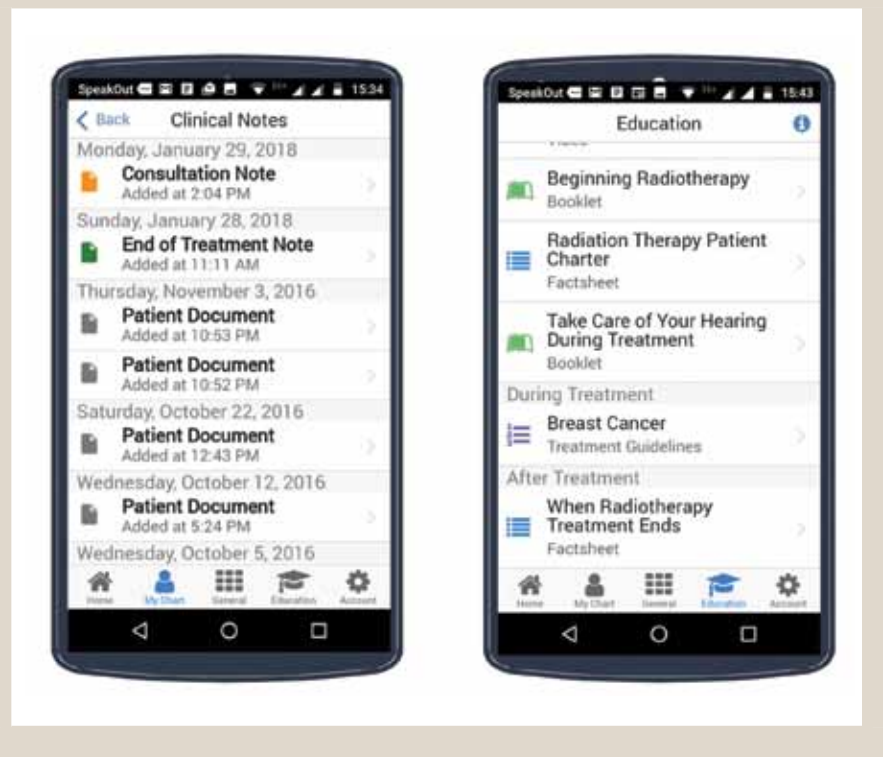


FIGURE 4. Patient documents and personalized educational information



For more information: opalmedapps.com