



Patient Destiny

“Patients as partners in their healthcare”

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Report of Conference and Workshop, November 2 and 3, 2011

The Faculty Club, University of Toronto

The overriding objective of the “Patients as Partners in their Healthcare” Conference and Workshop was to bring more patients into the decision-making process surrounding their own individual care. The focus was on the role patients play in their own healthcare management and how this active involvement can affect their personal health outcomes. We strongly believe patient participation will lead to quicker implementation of care action items, an enrichment of the care process and, ultimately, better health outcomes for all patients.

Close to 100 interested and involved individuals registered for the two-day event, providing an opportunity for a broad range of healthcare personnel to interact productively with patients and caregivers. Each participant received a comprehensive Workbook containing all relevant meeting materials, including guiding questions for roundtable and large group discussions, as well as reference articles focusing on patient-centred care.

Nationally and internationally-renowned speakers led the discussions, sharing their knowledge and expertise. We acknowledge and thank Ted Ball (Quantum Transformation Technologies), Dr. Danny Sands (Cisco Healthcare Business Transformation and Harvard Medical School, Boston), Dr. Warren Winkelman (Consultant), and Dr. Ed Brown (Ontario Telemedicine Network) for their contributions.

Panelists – representing both patients and providers – offered firsthand experience and facilitated discussions in four Workshops (Engaged Patient, Enabled Patient, Equipped Patient, and Empowered Patient) scheduled over the two days. Highlights of Workshop discussions are included below.

Speakers from Patient Destiny’s October 2011 eHealth Speaker Series were also featured on the agenda as they summarized their presentations for event participants. Thank you to Judy Burns and Melissa Kaan (Cancer Care Ontario), Mary Lou Ackerman (Saint Elizabeth Health Care), Femida Gwadry-Sridhar (Lawson Health Research Institute, London ON) and Dr. Wendy Graham (Mihealth Global Systems Inc.).

To view Conference and Workshop presentations on the Patient Destiny website, click [here](#).

Below is an overview of the dialogue and exchange of ideas that took place over the two days. We worked to emphasize the opportunities presented to the “4 e” patient (engaged, enabled, equipped, empowered): to explore what “patients as partners in their healthcare” means, where we are, where we want to go, and what we need to do to get there.

1. Engaged Patient Workshop

As lead-in speaker to the Engaged Patient Workshop, Susan Anderson described Alberta's Personal Health Portal (<https://myhealth.alberta.ca>) which currently offers access to comprehensive general health information. Work is well underway to add functionality to the portal that will allow all Albertans to access their own personal health information.

The public is engaged and is now being asked how the healthcare system can help patients manage their care. Being able to access their health information is viewed as an important first step in this engagement. Dr. Danny Sands noted that information is key to patient engagement and levels the playing field. However, there is still reticence on the part of physicians to allow patient access to their own health information. Patient Destiny suggests that physicians are wary of "opening the pipe" because once opened, there is a fear that their loss of total control of healthcare information sharing may result in worse care for the patient. How do we really know that patient access to their own health information improves health outcomes? Pivotal to addressing physicians' concerns and showing health improvement is measurement.

2. Enabled Patient Workshop

Sarina Cheng presented a demonstration of Sunnybrook Health Sciences Centre's MyChart™, Sunnybrook's personal electronic health record (EHR) where patient and family can access the patient's personal health information. Nancy Dudgeon, a patient user, described her personal experiences with MyChart™.

Roundtable discussion groups were tasked with thinking about indicators that would measure the benefits of patient enablement. In other words, once a patient is able to access their own health information, as patients can through MyChart™, how do we measure whether or not health outcomes improve?

Once enabled, patients need to work with the system to understand health data and how to make it meaningful. Over time, conversations between patient and provider are expected to become more productive and offer better decision support to care decisions. For example: Did I get enough information to make an informed decision? Where applicable, were multiple options offered to me? Was there an opportunity to feed back my experience to the system?

We learned from Nancy Dudgeon how once she shifted from immediate and timely access to blood test results through MyChart™ to a 14-day delay (resulting from a change in registration to another Sunnybrook service), it negatively impacted on her ability to access the necessary care to immediately deal with the care concern at hand.

3. Equipped Patient Workshop

The three panelists, Dr. Wendy Graham (Mihealth Global Systems), Sue Kelly (We Care Health Services) and Laurie Poole (Ontario Telemedicine Network) each described methods they use to equip patients. Patients are provided with immediate and timely access to their healthcare information and clinical

indicators; in consultation and collaboration with their healthcare providers, they learn how to better manage their healthcare. The emphasis is on patient self-management and decision-making through health provider coaching.

There was consensus following a large group discussion that technology was necessary, but not in itself sufficient. Technology offers the vehicle to share health data that traditionally has not been shared before with patients. Now that health information is being shared and there is a method for access, healthcare providers need to stop and “train the patient”, i.e., bring the patient up to speed on what their clinical indicators mean and how they relate to patient health outcomes. As an example, the patient has an iron count of 137 today which is simply data: but this data can become meaningful information when the patient is able to compare this number to previous iron blood counts and symptoms experienced at various points in time.

4. Empowered Patient Workshop

Nancy Lefebre summarized the findings of an October 2011 Saint Elizabeth Health Care study funded by Health Canada seeking to define “client-centred care”. It was determined that there is a shift to empowering patients to be active participants in their care which can be gained through technology. Patients’ Association of Canada’s Sholom Glouberman explained that the healthcare system needs to shift from managing acute care to managing complex care and that a patient-centred system offers easier access to the system and increases the patient’s capacity to self-assess and self-manage through mutual support.

The question raised in a large group discussion was: “How do we know we have a patient-centred system?” One suggestion was to start at the individual patient level by asking them what they want and what they need, and developing metrics across a number of interactions to feed back into the system. Patient Destiny suggests that we would have a “patient-centred system” when patients are able to access their health information and drive their care, and their input is valued, resulting in shared decision-making. With this explanation in mind, Patient Destiny sees the progress of activity to arrive at a fully empowered patient must include the steps of engaged, enabled and equipped. Patients are engaged as they seek to access their own information which has been enabled by the provider and in consultation and collaboration with their provider they are equipped to understand their own health indicators and, as a result, achieve self-management of their care.

Concluding Remarks

The journey towards a patient-centred system is a long one and can be hijacked at many points. We must stay the course and find creative ways to keep patients involved and to continue being innovative in terms of measuring our progress toward this ultimate goal. Patients are now being asked, for the first time, if they would like to be on this journey with the healthcare system; a patient-centred system is one where patients are not just along for the ride, but do much of the decision-making and monitoring through measurement!