BIG THOUGHTS ABOUT BIG DATA

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Building a better EMR

Chris Simpson

The framework developed by the AMA and an external advisory panel of practising physicians, health information technology experts and others is intended to leverage the potential of electronic records to enhance patient care, improve productivity and reduce administrative costs.

"Physician experiences ... demonstrate that most electronic health record systems fail to support efficient and effective clinical work," said AMA President-elect Steven J. Stack. "This has resulted in physicians feeling increasingly demoralized by technology that interferes with their ability to provide first-rate medical care to their patients."

For Canadian physicians who are unhappy with their own experiences with EMRs, the list developed by the AMA will surely prompt some nods of recognition.

Here are the AMA's eight challenges and potential solutions:

1. **Design EMRs to enable physician–patient engagement.** The AMA points out that electronic health record (EHR) design gets in the way of face-to-face interaction with patients because physicians are forced to spend more time documenting required information of questionable value. "Features such as pop-up reminders, cumbersome menus and poor user interfaces can make EHRs far more time-consuming than paper charts," the AMA says.

2. **Support team-based care.** "Current technology often requires physicians to enter data or perform tasks that other team members should be empowered to complete."

3. **Promote care coordination.** "EHR systems need to automatically track referrals, consultations, orders and labs so physicians can easily follow the patient’s progression throughout their care."

4. **Offer EMRs that accommodate physicians’ practice patterns and workflows.**

5. **Support medical decision-making with concise, context-sensitive, real-time data.** "Many physicians," the AMA notes, "say that the quality of the clinical narrative in paper charts is more succinct and reflective of the pertinent clinical information. A lack of context and overly structured data capture requirements, meanwhile, can make interpretation difficult."

6. **Promote interoperability and data exchange.**

7. **Facilitate digital patient engagement.** "Most EHR systems are not designed to support digital patient engagement," says the AMA.

8. ** Expedite user input into product design and post-implementation feedback.** "EHR systems should give users an automated option to provide context-sensitive feedback that is used to improve system performance and safety."

In a rebuttal, Dr. Andy Spooner, chief medical information officer at the Cincinnati Children’s Hospital Medical Center, noted that while the type of customization sought by the AMA is good it does not make a product simpler. He urges the AMA to get to know EMR companies and align its statements with what these companies are doing, as many are trying to address the very issues the association raises.

Spooner also wrote: "(O)rganized medicine could really help things along by setting professional standards, promoting advancement of knowledge and, most importantly, by lobbying for regulations that reduce complexity of the practice of medicine."

Many of the issues raised resonate here in Canada and some, such as the need to promote interoperability and data exchange, have been CMA priorities for some time.

However, perhaps more important than the content of the document is the fact that the AMA has shown itself willing to stand up and speak out on behalf of its members. The digitalization of medical records will inevitably impact all practising physicians, so the AMA is right to advocate for EMRs that help physicians provide good care and ensure patient safety.

At the national level, the CMA has long advocated — and will continue to advocate — for having physicians at the table when policies and procedures governing EMRs are developed and implemented.

And while we’re at it, the CMA is not averse — in the words of Spooner — to "help(ing) things along" by working to set professional standards and promote the advancement of knowledge.

Dr. Chris Simpson is the president of the Canadian Medical Association.
Pat Rich

HEALTH INFORMATION TECHNOLOGY (IT) MAY HAVE BEEN A MINOR theme at the annual General Council meeting of the Canadian Medical Association held in Ottawa in August, but the topics addressed were very broad.

As in the past several years, GC delegates approved resolutions on a wide spectrum of health IT issues — from big data to the perennial challenge of ensuring physicians are involved in discussions concerning electronic medical records (EMRs) and other health IT issues.

Concerns about the electronic exchange of patient information, while not directly focusing on technology, were also the subject of several delegates’ resolutions.

One resolution that was adopted endorsed the CMA’s longstanding approach to physician engagement on health IT, encouraging Canada Health Infoway to consult with physicians. The resolution can be seen as an adjunct to the association’s call in its pre-budget submission for the 2015 budget for the federal government to continue funding Infoway.

Moved by Dr. Allan Garbutt, then-president of the Alberta Medical Association, the resolution came from recognition that funding of EMRs by the United States government under the HITECH Act is intended to link clinical practice to quality outcomes and accountability.

“As a result,” Garbutt notes, “Canada Health Infoway may be required to study, recommend and strategically invest in the development and implementation of enhanced EMR use linked to various quality improvement initiatives (and) evidence shows that quality improvement initiatives are more effective if physicians are proactively engaged in their design and implementation.”

While acknowledging that Infoway does have a physician reference group and other physician advisors, Garbutt noted the organization could do more to draw on the expertise of all CMA members.

“Because of its experience in continuing education and professional development, the CMA encourages Canada Health Infoway to engage in consultation with physicians.

The CMA supports the creation and use of secure modes of electronic communication between patients and health care providers.

The CMA will propose guidelines to ensure optimal use of big data while limiting its negative impact on professionalism and the confidentiality of medical data.
CMA is well positioned to partner in the roll-out of an enhanced use agenda,” he stated.

A resolution brought forward by Dr. Bill Cavers, president of Doctors of BC, endorsed broader use of email and other electronic forms of communication between patients and physicians.

“The use of email and video conferencing by physicians can reduce non-essential office visits and save patient travel time (particularly for those living in remote and rural communities),” Cavers noted in his rationale. “Furthermore, secure email communication and store-and-forward telehealth allows patients and providers to communicate at times convenient for their schedules.”

While acknowledging that privacy and security considerations must be addressed, delegates supported having the CMA endorse the creation and use of secure modes of electronic communication between patients and providers.

Privacy was also central to a resolution brought forward by Quebec delegates stating the CMA will propose guidelines to ensure optimal use of big data while limiting its negative impact on professionalism and the confidentiality of medical data.

In bringing the resolution to General Council, Dr. Ruth Vander Stelt raised concerns about who owns and has access to patient data once it has left a doctor’s office, especially in electronic format. She referenced physician prescribing data as an example of information that should be subject to guidelines on appropriate use.

Concern about the sharing of patient information between the US and Canada was the subject of two resolutions. One noted that the indiscriminate sharing of mental health information between the two countries threatens the principle of non-discriminatory border crossing; the other stated the CMA will work with appropriate stakeholders to establish guidelines for the sharing of mental health information between the US and Canada.
Looking at e-health through a telecom lens

Conrad Amenta

TEN YEARS ON AND MORE THAN two billion dollars in, Canada’s e-health landscape is starting to take shape.

Adoption of electronic medical records (EMRs) among physicians has increased dramatically over the past decade, and policymakers are starting to transition from an adoption agenda to an enhanced or ‘meaningful use’ agenda. Mobile health, consumer-facing health solutions and big data analytics have the potential to be game-changers. But progress has not been timely, or cheap.

In a recent article, Tom Daniels of the University of British Columbia and University of Birmingham, UK, argues that the creation of Canada Health Infoway was a less-than-perfect but reasonable approach to governing the rollout of EMRs, given constitutional constraints on the federal government in a provincial jurisdiction like health care.

Those constraints are certainly real because beyond funding the federal government has few levers with which it can influence the health care agenda. Daniels’ article assumes that a top-down approach to building a pan-Canadian, interoperable network was the only option available.

But if the vision for e-health in this country is of an interoperable communications network established in light of public principles like accessibility and privacy, this already exists in the telecommunications sector.

Telecommunications in Canada are transmitted via a high-quality, secure, interoperable network. It has been built without public dollars and despite the country’s many geographic and demographic challenges. In fact, Canada is on track to pass 100 per cent wireless penetration by 2015, meaning that every Canadian will have access to at least one wireless-enabled mobile device.

Where e-health has been rolled out via top-down strategic investment in a series of provincial projects and programs, telecommunications regulators have relied on “strategic forbearance”—articulating desired outcomes, defining the conditions of entry into the market and doing vigilant monitoring.

Through the Telecommunications Act (1993), Parliament established the value proposition for “incumbent” carriers — those who would be rewarded for their infrastructure investment with control of predefined service jurisdictions — and “competitive” carriers — those who only needed to build minimal infrastructure to enter the market but had to pay fees to incumbents to connect to their facilities.

The Canadian Radio-television Telecommunications Commission (CRTC) was established to safeguard public resources, ensure market entrants’ adherence to legislatively enshrined principles and to consult with the public on policy.

Parallels can be seen between the principles enshrined in the Telecommunications Act and those that govern our health care discussions. These include:

- reliability and affordability
- quality
- accessibility to Canadians in both urban and rural areas
- Canadian ownership and control
- stimulation of research and development
- privacy protection

Both the telecommunications and e-health sectors in Canada involve the management of public resources — wireless spectrum or airwaves on the one hand, the health of the Canadian public on the other. Both are managed via the same privately owned networks but according to totally different philosophies.

As a result, the e-health market is more confusing and difficult than the telecommunications market for vendors to enter and navigate, and as of 2014 pan-Canadian interoperability is not on the five-year horizon. Standards for EMRs are arcane, impenetrable and ever-changing.

Strategic forbearance has its shortcomings. While telecommunications companies have produced a quality network, the CRTC has struggled to incentivize high enough levels of competition to drive down prices. Canadians pay among the highest prices in the world for wireless services. Dissatisfaction with customer service provided by the carriers runs high, and consumers feel they have few options to take their business elsewhere.

However, the issues with forbearance, while valid, seem minor compared to the value of the telecommunications facilities put into place across Canada.

In another world, the high-level needs of clinicians, policy-makers and patients might have been clearly articulated, and vendors could find their own way to meet those needs. Intergovernmental agencies, or perhaps a public commission, could then have concentrated on monitoring the actions of vendors, listening to the public and working with both to enhance the long-term stability of the marketplace.

In another world, the EMR discussion would have been one of continuous product improvement until physicians wanted to use them, not of incentivizing the use of products that didn’t meet their needs.

Yes, the top-down approach exemplified by the creation of Canada Health Infoway is a reasonable compromise. But to act as if it was the only possible compromise reflects an overreliance on the way health care has traditionally been governed.

Conrad Amenta is a senior policy advisor on health information policy and e-health, CMA Health Policy and Research.
BIG DATA = BIG RESPONSIBILITY, DOCTORS TOLD

Marla Fletcher
Increasing the level of understanding of big data around how it impacts the profession and health care delivery was one of the main reasons the Canadian Medical Protective Association (CMPA) chose it as the topic of an information session at its annual meeting this past August in Ottawa, attended by close to 100 attentive physicians.

However, the CMPA had another important reason for raising awareness of big data: to identify the need for clear and "appropriate" rules of use for the rapidly growing repositories of shared patient information.

WHAT IT MEANS
"Big data is to the 21st century what steam power was to the 18th century," wrote Warren Tomlin — an IBM partner and leader of the firm’s Canadian interactive web portal and contact centre — in a special Globe and Mail article published Aug. 14. "It is a foundational development, a new natural resource that exists everywhere in our environment."

In a paper distributed to its members and available online, the CMPA defines big data (BD) as very large amounts of information that can be interpreted — through analytics — to provide "useful, actionable information" that is often presented as patterns and trends. For example, BD can be used to identify patients in the community who have chronic diseases in order to drive ongoing contact and care that may ultimately decrease visits to hospital emergency departments. Some of these large repositories are the electronic medical records (EMRs) where patient information collected during visits to doctors and primary care clinics is stored.

The Canadian Medical Association (CMA) has expanded on the basic definitions:

Big data in health care is often associated with the data stored in electronic medical records (EMRs), but big data may come to be understood as the clinical data in EMRs cross-referenced with other administrative, demographic and behavioural data sources to reveal social determinants of health and patterns in clinical practice ... Insights from data are used to guide decision-making.

BENEFITS AND POTENTIAL
Big data can have a big impact when organized, managed and used properly. In the Globe article, Tomlin gave this example: "Predicting and mapping... cancer treatment by analyzing longitudinal ... treatment data and cross-referencing it to the genetic makeup of individual patients can be used to find the best-case, patient-specific treatments."

Dr. Tim Ho, the physician lead for complete care with the Kaiser Permanente medical group in Southern California, described the purpose and best use of big data very simply: it can be used to describe, to learn and to improve. He told the CMPA session’s physician audience that one way his organization has benefited from it is to plumb information on health trends and care gaps from records for 9.3 million members (some 10 petabytes of data) to improve care — thus raising its score in the National Committee for Quality Assurance rankings for health plans in the US to No. 1 for Medicare plans (2012–13 and 2013–14).

Through its clinical support tools, Kaiser Permanente can also look at BD findings to identify proactive steps that medical care providers could offer specific patients, such as foot exams or diabetes health education sessions for that patient population. Electronic prompts are then sent to the appropriate clinics to schedule the followup care.

THE CONCERNS
One province moving cautiously as it employs BD analytics is Alberta. Susan Anderson, assistant deputy minister and chief information officer for Alberta Health, spoke about how her department has embraced a "consumer health strategy that brings the public (voice) into play" with its integrated health service delivery model.
Growing public and political pressure for accountability have led to an overhaul of Alberta’s Health Information Act, with amendments expected to be introduced before the end of this year. One change was the introduction in spring 2014 of new mandatory reporting requirements for privacy breaches.

Another challenge is the fact that big data information doesn’t provide context, so its findings must be carefully balanced with the human contact and interaction that takes place in physician-patient encounters.

**PHYSICIAN REACTION**

“This was kind of a rude awakening for me, because I’ve just never thought about [big data implications on medical practice] before,” confesses Dr. Charmaine Roye, CMA’s director of professional affairs and strategic health alliances and an obstetrician/gynecologist. She welcomed the CMPA session, as did several others attending, and said it has heightened her awareness of the issue. She said she hopes the session will help convince doctors to think carefully about the kinds of information they collect and store in EMRs, and called for more events of this kind to help the medical profession come to terms with the issues involved.

“Once they (physicians) do hear that there are liabilities involved... then we’ll have their attention.”

Dr. Ren Mann, an anesthesiologist based in Peterborough, Ont., is a board member with the Ontario Medical Association and has become familiar with BD through his work with the board and through other professional associations (the OMA is currently considering its approach to BD). He summarized the CMPA session as well-balanced and informative, noting: “We (physicians) all share the same sorts of concerns with respect to patient confidentiality” and the privacy of physician records.

Mann added he’s confident physicians will be involved, particularly at association and organization levels, as the parameters evolve for how BD information is collected and used to create future policies and best practices.

**WHY SHOULD WE CARE?**

The CMPA paper asserts: “Regardless of its intended use, the assurance of privacy is needed for patients and health care providers to support big data analytics.”

Dr. Patrick Ceresia, privacy officer and managing director of CMPA corporate services, noted that while privacy legislation makes it “very clear” what is considered private patient health information and how it must be protected, it’s “not at all clear when it comes to (care) providers.”

Physicians need to start considering the rules of engagement and appropriate use, Ceresia said, and be involved in the discussions that determine such appropriate use. They must examine how their practices and organizations can collect, maintain, share, protect and analyze data effectively — ensuring sufficient resources, know-how and information management capability to do so.

The CMA has also commented on the privacy and security concerns when linking biomedical data from EMRs. As more data are linked, “they become more difficult to de-identify individual patients. Furthermore, safeguards must be in place to ensure that de-identified data cannot be re-identified.”

If it became necessary to ‘re-consent’ each participant in research projects where large administrative data sets are used, those projects would probably not be feasible.

Marla Fletcher is on the editorial staff of Future Practice.

**Governance — it starts with awareness**

Physicians need to investigate how to reap the benefits of information gleaned from ‘big data’ without making themselves liable or compromising patient privacy, says Carman Baggaley, from the Office of the Privacy Commissioner of Canada.

Speaking at the recent CMPA information session, Baggaley said the discussion about ethical use of patient information is quickly evolving from “can we” to “should we”, because “with enough computer power and enough data power, we can find out almost anything.”

It’s not in the privacy officers’ mandate to work out good governance in this area, he added, so physicians must get informed and get involved.

**HIS RECOMMENDATIONS FOR A GOVERNANCE STRUCTURE:**

- shift the focus (of use of information gleaned through big data) from purpose specification and consent to appropriate use
- establish more robust risk assessment
- ensure better ways to protect patient information through ‘anonymization’, and prevent ‘re-identification’
- enact stronger enforcement powers and sanctions against privacy breaches and misuse of information
- obtain broad consent (including from patients) on what is to be considered appropriate use of personal health information in big data operations
Integrating digital literacy into medical education

Stephen G. Pelletier

AS SOCIAL MEDIA PLAYS AN INCREASINGLY IMPORTANT ROLE IN HEALTH CARE DELIVERY, a growing number of medical educators are helping future physicians develop what they call digital literacy and digital professionalism.

Dr. Bertalan Meskó, a medical futurist who travels the world consulting and lecturing on digital literacy in health care, frames digital literacy as "the way that medical professionals can use digital devices as well as online solutions in communication with patients and their peers." Meskó believes that "today's medical professionals must be masters of different skills that are related to using digital devices or online solutions" and argues that mastering those skills "is now a crucial skill set that all medical professionals require."

Dr. Bryan S. Vartabedian, an assistant professor of pediatrics at Baylor College of Medicine, suggests that because digital tools have become so pervasive in medicine, medical schools have an obligation to help medical students learn how to be smart about them and to apply professional standards in their use. The rise of social media and networked communications means that "physicians now have to learn to manage and maintain their identity in the public space," Vartabedian said.

"This is brand new. For the better part of modern civilization, physicians only had to worry about their image during a 15-minute encounter with the patient," Vartabedian said. "Now, the democratization of media has made every physician an independent publisher. That brings a whole new set of responsibilities for which physicians need to be trained. Under what context do we discuss certain items? How do we manage our online identity? What can we do and what should we not do with smartphones?"

While digital literacy is not yet part of the core curricula in medical schools, it is beginning to appear more regularly and more formally as extracurricular learning.

At the University of California, Irvine, School of Medicine (UC Irvine), for example, medical students can take the elective Health 2.0 + Digital Literacy. Designed to fill a gap in student understanding about emerging trends in health care technology and social media, the course focuses on such topics as how to manage requirements for the Health Insurance Portability and Accountability Act (HIPAA), data security, health record protection and the emerging importance that digital tools have in patient-centred health care.

The school periodically offers short training sessions on digital literacy. "We catch students at their first-, second- and third-year orientations and again before they graduate," said Dr. Warren Wiechmann, associate dean of instructional technologies at the school. "We talk about the basics of social media and professionalism, and also cover newly emerging technologies like Google Glass and 3-D printing. We’ve also put on a session about how to curate content on the Web."

In addition, he said, the school offers workshops on what qualifies as a good website or smartphone app. Other sessions look more broadly at topics in health information technology, including the business of technology and how the startup market works.

At Baylor, Vartabedian developed a course called Digital Smarts, which helps medical students develop a professional, safe and intentional strategy for their interactions with social media. Like UC Irvine, Baylor takes a longitudinal approach.

"Digital Smarts aims to prepare our students for the realities of the digital age," Vartabedian said. "We effectively touch our students at three or four points over the course of three or four years. At orientation, we cover..."
very broad issues about students’ online identity and topics like the permanence of digital messaging. When they hit 18 months, right before they go to the ward, we talk about more specific clinical scenarios they will face, such as what you should and shouldn’t do when communicating with patients on platforms like Twitter.” For fourth-year students, the focus switches to such topics as how students can build a digital footprint and how they can present themselves online as they advance into residency and start to groom themselves for new jobs.

Under the aegis of the AAMC Group on Information Resources, Vartabedian and Wiechmann collaborated with Dr. Katherine Chretien, an associate professor of medicine at the George Washington University School of Medicine and Health Sciences, and Dr. Neil Mehta, an associate professor of medicine at the Cleveland Clinic Lerner College of Medicine at Case Western Reserve University, to develop a digital literacy toolkit for educators and learners. Available online through the AAMC, the toolkit includes case studies and guidelines on the use of social media, educator notes and other resources.

“The concept behind the toolkit was to put together a set of materials that any faculty member, from the most junior faculty member to a dean, can use to host a meaningful discussion about social media, digital literacy and digital professionalism,” Wiechmann said. “You don’t need to have an expert on campus or in a program to be able to have these discussions.”

Vartabedian said that because social media “now represents the modern means of both sharing information and communicating,” tomorrow’s physicians need specific training that can help them be professional in their use of digital tools. “The public presence of the physician is something that needs to be taken very seriously,” he said. “I might even go further to suggest that medical schools have a civic if not a moral obligation to be preparing our students for how to maintain themselves in the public space. Medical schools have a responsibility to help students understand where the limits are.”

This article is reprinted from the July/August AAMC Reporter. For more information about the Reporter, visit www.aamc.org/reporter.

Social media and digital medicine: my future

We asked some medical student leaders in Canada about their views on this article, and how they see the digital world impacting their education and future practice. Here’s what they said.

**DIGITAL PROFESSIONALISM MUST BE TAUGHT**

Ali Damji

**IF YOU ASKED EVERYONE IN MY MEDICAL SCHOOL CLASS, YOU WOULD BE hard-pressed to find any student who does not use any form of social media.**

There is a lot of value in social media. It provides future physicians with an avenue to engage in health promotion, education and advocacy with the communities we serve outside of hospitals, clinics and other traditional institutions.

At the same time, there is a considerable danger that comes with venturing into the developing territory of digital professionalism. Just as there are professional expectations placed on us for interacting with patients face-to-face so there are professional expectations that apply to the behaviour of trainees and physicians in the digital world.

Recently, the University of Toronto faculty of medicine instituted a policy entitled “Guidelines for Appropriate Use of the Internet, Electronic Networking and Other Media” which details the professional expectations of medical students and trainees in the digital world, echoing a similar policy from the College of Physicians and Surgeons of Ontario.

While students must read this policy before starting medical school, there is no formal curriculum at the University of Toronto or at several other medical schools to teach us digital professionalism.

This is in stark contrast to the ongoing education we receive on other types of professionalism, such as appropriate face-to-face communication with diverse patient populations. This seems like a missed opportunity, as social media and electronic communication are increasingly pervasive in medical student culture and will be even more important in our future practice.

There is also significant interest from medical students to learn more about digital professionalism. The Ontario Medical Students’ Weekend 2013 theme was Health is Social, with many of the 700 students participating in one of several dedicated interactive sessions on digital professionalism.

We need a more formal curriculum on digital professionalism in medical schools, because policies and guidelines alone cannot promote understanding and true learning.

Ali Damji is a second-year University of Toronto student and an Ontario regional representative for the Canadian Federation of Medical Students.
MEDICAL STUDENTS EXISTING IN TWO WORLDS

Nina Nguyen

SOCIAL MEDIA ARE REDEFINING how trainees learn and practise.

The digital era has brought to the medical world a wealth of free, open-access resources and an expanding community that knows no physical boundaries.

As medical students, we are thankful for this because knowledge is now available instantly at our fingertips. This widespread availability of knowledge does not limit itself to diagnostic criteria and treatment algorithms, because doctors and doctors-in-training are now part of that information that patients and their communities can seek in the digital world.

It used to be that doctors only worried about their reputation during the 15 minutes they were interviewing a patient. Now, the pervasive — and archival — nature of social media makes control of public image hard, not only for celebrities, but also for any professional who is interacting on a daily basis with a community.

Publishing outlets and social media are a revolutionary way to instantly share snippets of our daily lives with close and not-so-close friends through words, pictures and videos. We have been extensively warned by our respective medical schools to not post anything that our grandmother, mother or any so-called morally strict family member should not see — but what if our patients might have different values than our acquaintances?

This discrepancy between what we think is acceptable and what our patients might think makes the control of our online presence much more challenging.

Avoiding the use of any media, including private platforms like Facebook and Twitter, is not the solution, since we are also told that personal branding is essential for establishing a career. This dilemma calls for greater awareness of the mechanisms of media, especially social media, and how medical students can benefit from that power instead of fearing it.

Every year, around the time that applications to medical school or to residency programs open, many students change their social media handles to more anonymous ones and tighten their security settings in order to make their online footprint less visible. However, many forget that any previous publication that was once in the public domain may be cached somewhere, making it harder to hide questionable content from admission committees.

Medical students don’t necessarily need to be taught new skills: as proud millennials we are well-acquainted with the world of media, but not so familiar with the hidden curriculum of medicine. Some attending physicians — who may or may not choose to accept us to residency — still disagree on topics that we thought were settled, such as homosexuality and interracial dating. Sometimes our opinions on issues such as palliative care, use of therapeutic marijuana or abortion are frowned upon by both physicians and patients — without us knowing. We need to be clear on what is acceptable within the standards of our profession.

Unlike many of my peers, I choose not to withdraw completely from all media platforms. The need to establish an online reputation is now inevitable: if I don’t do it myself — and have some degree of control over it — someone may do it for me.

Being able to exist in two different realms is exciting and worrisome at the same time. Medical students, instead of being urged to avoid excessive exposure to the online world, should be schooled on how to build a public image, both online and off.

Nina Nguyen is a third-year student at the University of Sherbrooke, Sherbrooke, Que., a freelance blogger and a frequent user of social media channels.

EXPLORING WHERE DIGITAL FITS INTO PRACTICE

Mimi Lermer

MEDICINE HAS EVOLVED WITH THE growth of digital and communication tools, not only in terms of computer-based office systems like the electronic medical record, but also in terms of the medical resources at our fingertips.

Medical students are seeking out resources ranging from online search engines for journal articles and textbook chapters to mobile apps that can calculate a patient’s risk of stroke or heart attack, quickly help us with the dosing or interactions of a medication, or look up codes required for certain limited prescriptions.

Students today have grown up with social media platforms like Facebook and Twitter, and it’s often second nature to use these as communication tools. Where do the lines blur between personal and professional use? Is there a place for social media in medicine?

We are asking these questions and are interested in exploring the answers. In response, the Canadian Federation of Medical Students (CFMS) produced a document on online professionalism for students that has been integrated into lectures and small group sessions by medical faculties across Canada.

Whether or not a school hosts a lecture on social media, the digital era is being addressed in medical education out of necessity. Discussions on professionalism inevitably include the technology we use with and for patients. Similarly, as we move through residency and into practice, we will continue to use these tools and others to help us best meet the needs of our patients.

Mimi Lermer is immediate past vice-president of communications for CFMS, and a PGY-1 Neurology at McMaster University, Hamilton, Ont.
Medicine X: an academic medical conference for everybody

Colleen Young
After a busy, even overwhelming, work year, Mike was seeking a place where he could find content, people and connections to recharge not only his “social media passion, but also my passion as a physician.”

Medicine X describes itself as “the world’s premier patient-centred conference on emerging technology and medicine.” In his opening address to over 650 delegates, Dr. Larry Chu, executive director of the conference, said: “Medicine X is a place where all stakeholders can come together to change health care. You belong here. Everyone belongs here.”

This year, “relationships” and “empathy” were dominant themes that resonated throughout presentations, panels and hallway conversations. Innovative health care is reaching beyond mere connections to finding ways to actively build trust and develop relationships — relationships with oneself, between providers and patients, peers to peers, patients to pharma, and even with technology. Why? Because better and more empathetic relationships improve care in health.

RELATIONSHIPS FOR WELL-BEING AND THE INTERCONNECTED SELF
With the opening keynote “Interpersonal Connection, Self-Awareness and Well-Being: The art and science of integration in the promotion of health”, Dr. Daniel Siegel (@DrDanSiegel) dove right into the subject of relationships not only as they apply to the practice of medicine but for overall personal and connected well-being.

Siegel maintained that to revolutionize medicine and transform the traditional patterns of care where professional tells patient, we need to focus on relationships. Relationships, he said, are interpersonal connections that build the foundation of self-awareness and wellness. He underlined that self is not isolated within the body but comprises the person along with all his/her interconnections to people and environment. In each person there exists the differentiated self — the ‘me’ — and our multifaceted networked connections — the ‘we’. Thus, the differentiated ‘me’ plus the differentiated ‘we’ equals an integrated identity he called “mwe.”

When our integrated identity is made visible we experience kindness and compassion and build empathetic relationships. “Our relationships give us the feeling of being seen, of feeling felt, of being connected. Those are the fundamental ways that we create well-being.”

RELATIONSHIP BETWEEN PATIENTS AND PHARMA
Siegel’s statement was echoed by Sarah Kucharski (@AfternoonNapper) in her impassioned ePatient Ignite talk — nay performance — titled “Summertime.” She ended with a plea to the pharmaceutical industry to: “See me, hear me, feel me and include me.”

Jamia Crockett (@MamaSissyKat) led a panel of ePatient scholars, pharma representatives and a doctor of pharmacy to explore the relationship between patients and pharma in a session called “The New Pharma.”

Traditionally, direct communications between pharma and patients are limited due to tight regulations on the industry. Pharma can no longer afford to treat patients merely as raw materials in a supply chain. Kucharski contends that while patients and pharma may not always have the same goals, each must open themselves to discovering differences and finding ways to resolve them.

Editor’s note: Medicine X is a unique conference that allows health care providers and patients to meet as equals to discuss and debate health care issues involving social media and digital health. Future Practice invited two Canadian delegates to provide their views on this year’s conference.
PERSONAL RELATIONSHIPS WITH TECHNOLOGY AND SELF-TRACKING

Speaking as a patient and a designer of change behaviour programs, Dr. Kyra Bobinet (@DrKyraBobinet) talked about personal relationships to devices designed to help people track disease and wellness. Self-tracking is more than data collection. “We underestimate the emotional aspects of self-tracking. Self-tracking is hard, even with scientific and physician training,” she said. Often people get discouraged and abandon the technology because the self-tracking creates shame and self-dislike and enhances failure.

Bobinet reflected that technology might be more accepted if it acted as a “humble servant.” She proposed developers and designers take an experimental, curious approach to self-tracking rather than setting simple binary goals that perpetuate the win vs. lose scenario. Wearables and tracking tools need to include the emotional layer of the user in their design. Bobinet went so far as to anthropomorphize technology — suggesting it must evolve with the patient, the way any successful long-term relationship does, recovering from misses or disconnect. “Devices come across as arrogant. I’ve never seen tech apologize before, but why not?”

When asked “what can physicians do with self-trackers?” Gary Wolf (@agaricus), seen tech apologize before, but why not?” “Devices come across as arrogant. I’ve never seen tech apologize before, but why not?”

When asked “what can physicians do with self-trackers?” Gary Wolf (@agaricus), co-founder of Quantified Self, encouraged medical professionals to shift their thinking. They should consider people with chronic conditions as astronauts and explorers, and not just the beneficiaries of scientific discoveries. They are invested in discovering advances, not only for themselves but also for others.

PEER-TO-PEER RELATIONSHIPS ONLINE

The value of online communities was another common conference theme. On the last day, Pam Ressler (@pamressler) moderated a panel titled “Communicating the Experience of Illness in the Digital Age: Reaching beyond the Keller/Adams controversy.” As Susannah Fox (@SusannahFox) observed, the Internet has democratized publishing. The social web gives us access not only to information but to each other and that, the panellists agreed, is the most exciting innovation of the connected health era.

However, beyond merely connecting, it is the formation of communities that reveals the value of the social web. Meredith Gould (@MeredithGould) pointed out that a group of people commenting online is not automatically a community.

Self-disclosure is an essential part of creating community. I agreed with my fellow panellists, underlining that behind every successful community is a dedicated person or team creating the space that welcomes self-disclosure and ensures that it gets reciprocated. Community managers know that self-disclosure conversations create stronger connections, build trust and develop relationships that deepen the sense of community. People frequently look at growth and activity as success metrics, but establishing and maintaining a profound sense of community is the hallmark that distinguishes the ones that work.

One audience member admitted she doesn’t share her patient or caregiver story publicly for fear of losing professional credibility. She hopes that eventually, through gatherings like Medicine X where patients are included and valued, individuals will be more comfortable publicly self-identifying as a patient, where appropriate, and to grant that identity its valued position within complex, multifaceted identities.

During the pre-conference conversation, Paul Wicks (@PaulLikeMe) commented on my blog post TMI? Or gold for online communities and their managers? He stated: “Technology is not the whole answer. Ultimately the answer is social... We need to get to the point... where disclosure of TMI (too much information) that benefits others is seen not as a weakness or a failing but as a donation to the world, a gift that can never be repaid.”

Quoting Dana Lewis (@danamlewis), Fox declared “we are not waiting” for everyone to understand the power of the social web. “We’re more than 15 years into being able to share openly online, and people still aren’t ready for it. She asked, “How might we spread the word of the power of connecting for health online and make this look less like witchcraft? How might we thank the brave people who share online and help others?”

And Mike Sevilla, did he find the inspiration he was looking for? Given that he wrote four reflective blog posts about the conference, Medicine X certainly recharged his social media passion. With so many thought-provoking presentations, panels and other conversations that continue online, it’s very likely his passion as a physician has been re-energized too.

Colleen Young was a panellist at Medicine X and is manager of engagement and social innovation, ELLICSR, Princess Margaret Cancer Centre, Toronto.

“Quality improvement and lower costs in health care all hinge on better relationships. Relationships matter. We’re going to make the social web work.”

— Dr. Mike Evans (@docmikeevans)
Medicine X: the wizard(ry) of X

Javed Alloo

WHEN THE GLITTER BALL STARTS
strobing neon lights across the conference hall to the beats of dance-hall music, I’m not quite sure what to make of it all.

The spotlight falls on Dr. Larry Chu, the Stanford, Calif., doctor out to transform the way health care services and devices are conceived and delivered, at a conference he calls “Medicine X” (the ‘X’ is for intersections, and all that’s still to be discovered).

As he speaks passionately about promoting patient-centred care to cross the gulf between patients, health care providers, technologists and designers and his love of glow-in-the-dark wristbands, I begin to realize that the magic behind the success of this particular brand of collaborative medicine gets more impressive with each revelation and example.

The first insight comes in seeing how Medicine X holds a mirror up to itself, striving to embody the very principles and learnings it hopes to share with diverse conference attendees. Amid the showmanship and sportscaster introductions, there’s a real authenticity. The event is demonstrating how to advocate for collaboration while encouraging the psychological, organizational and social factors needed to promote and sustain change.

There are patients present for nearly every moment onstage — a conscious expression that health care can’t be effectively conceived without keeping its purpose (health for patients) as the central focus. Sometimes this atmosphere makes conversations difficult. I fear that the pressure to be politically correct might prevent honest discussions about the barriers to delivering the desired kind of care. Still, it’s a testament to the maturation that has occurred on all sides in recent years that the conversation tries to honestly reflect needs and impediments while looking for ways to deliver on core health priorities. There’s real bravery, a willingness to face challenges, to humanize the other and the goals of medical interventions, to disclose, be hurt and yet remain engaged. That’s a lot of emotion for a scientific conference. But, as front-line health care providers and patients have always known, medicine is an emotional business that keeps the common goal — the “why” of health care — front and centre.

Now in its third year, Medicine X shares new concepts, experiments and tested initiatives for better collaborative health from providers and organizations of every stripe and technology, pharmaceutical companies and patient peer-to-peer support organizations.

Moving beyond its origins of starry-eyed optimism that health care could be saved with technical advances alone, Medicine X now has patients and other panelists asking: “What good is a better pill or pill dispenser if I can’t afford my medications?” The conference also projects an awareness of social determinants of health and begins to ask questions about marginalization, race and gender — even the embarrassing bits that still linger in any modern conference or initiative.

As a family doctor, I find it’s the real-world insights that make Medicine X so compelling. For example, acknowledging the urgent need for solutions that effectively connect health providers and communities while tackling systemic, technological and perceptual barriers to building a health system that supports providers in delivering care for patients in the ways they need.

And then there’s the glowing wristband (the kind college kids wear to clubs and raves) that you’re instructed to share with other conference-goers and speakers who’ve shared an exciting or impressive idea with you. It takes two people, one holding each end, to make the band begin to glow. The effect is surprisingly affirmative, enlisting emotion and psychology to bolster thought leaders and change-bringers who can often feel isolated out in front of their teams and organizations. It’s about sustaining the people and factors that bring change to our health system.

Medicine X also demonstrates unrivalled use of social media, widening the conversations and aiming for the democratization and dissemination of health planning discussions. Becoming one of the top trending topics on Twitter, Medicine X shows that talking about health in progressive ways is something that brings people together in ways that few other topics can match.

In the end, that’s what Medicine X is about: a conference designed to facilitate change, not just by delivering knowledge but involving you — the care provider, patient or policymaker — in a way that’s already different from the way you’ve conceived of health care transformation before.

Are you ready for this? Is Canada ready for ‘MedX, eh’?

Dr. Javed Alloo (@javedalloo) is a Toronto family physician keenly interested in supporting adaptation and change for patients, organizations and their communities.
An accountability manifesto

Ewan Affleck

ON OCT. 19, 2012, GOVERNOR GENERAL OF CANADA DAVID JOHNSTON addressed the Royal College of Physicians and Surgeons of Canada on the occasion of the organization’s annual convocation. He challenged Canadian physicians to make a “gift to our country for its 150th birthday” by taking steps “to make the highest level of professionalism an explicit, living creed for all who practise medicine in Canada.”

With the 150th anniversary just two years away, there is still time to develop concrete strategies to meet the Governor General’s challenge.

A Canadian physician is born of a robust series of steps: rigorous undergraduate education and equally demanding postgraduate training are followed by national and specialty examinations. Successful candidates proceed to provincial or territorial licensure and health authority credentialing before being freed to provide independent patient care.

Thereafter, the life cycle of the Canadian physician becomes a little more obscure. Although a scattering of health services employ evaluation tools aimed at assuring longitudinal physician competency, this is not the norm. Professional colleges offer membership to physicians for a fee and when attaining benchmarks of continuing medical education, but do not assure measures of the quality of care provided by their members.

In my case, after almost a quarter of a century as a Canadian physician I have never had the quality of my work evaluated, even in a cursory manner. Am I using evidence to inform my clinical decisions? Do my efforts result in improved health or diminished suffering in my patients? Is my care timely, effective or efficient? Do I provide care safely and equitably to all I treat? Is my care centred on the best interests of the patient?

Who knows?

Certainly not my employer or college, nor my licensing body, nor most importantly the patients I care for. None have any concrete measure of the quality of my work. Nor do I imagine my patients know that the quality of my care has never been evaluated since the completion of my training. Faith in my clinical competence is blind — and I am not an exception among my peers.

This suggests there is an accountability deficit in the medical profession and raises the important question: how can Canadian physicians, as a self-regulating profession, assure the quality of patient care or, in the Governor General’s terms, deliver on the “right granted to physicians by the state to control standards and competence”?

Although the stated purpose of the health care industry is the delivery of quality care, we in the medical profession have not traditionally had ready means of measuring the quality of our product. This creates a concerning paradox.

In part, the lack of accountability lies in the difficulty of establishing robust measures of quality, both in definitional and functional terms. The advent of digital information systems offers realistic opportunities to measure health service performance, and nascent quality indicators. The promise is that health analytics will permit us to evaluate the quality of our work and direct the health care system to appropriate or quality care. Certainly the premise that we must as a profession begin measuring and being held accountable to the quality of our work is unimpeachable. The only question is how to do it.

We must embrace the foundational value of health analytics, which still lacks currency among front-line physicians. A measure of this lack of engagement is the poor representation of health analytics training offered to medical students entering the profession. A scan — albeit cursory — of the curricula of the 17 Canadian undergraduate medical schools reveals scant mention of health analytics. This reflects my personal experience as a preceptor of medical students and residents from a variety of Canadian medical schools, who invariably report little attention is given to health analytics during their course of study.

Canadian physicians must address this accountability deficit by embracing the importance of self-evaluation and tracing the consequences of our daily clinical decisions. Health analytics, although still developing, is the practical tool that can be refined to drive accountability, promote self-regulation and help renew professionalism.

Although analytics need to become an expectation of every medical practice, what better place to start on this path than with our youth, our future, by making health analytics a cornerstone of medical training? Just as the Governor General challenged all Canadian physicians to embrace the highest level of professionalism, I am challenging our medical schools to help reach this goal by placing health analytics in its rightful place, as a robust core component of medical education.

We must embrace the foundational value of health analytics, which still lacks currency among front-line physicians.

Dr. Ewan Affleck is a physician in Yellowknife, NWT, and a member of the Future Practice editorial advisory board.
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