Patients supplying advice to Alberta as it builds Connect Care system

BY DAVID VEITCH

Ryan Magnussen has used Alberta's healthcare system hundreds of times since a debilitating spinal condition forced him to retire 15 years ago.

The former bank manager and businessman says, over that time, the key to improving healthcare quality and safety became clear to him.

"Every little mistake that happens in healthcare seems to come back to problems with information and communication," says the 56-year-old Calgary man.

"So if you fix those two things, I think you can eliminate a lot of these errors."

Wanting to make a difference, Magnussen accepted an invitation from Alberta Health Services (AHS) in 2013 to volunteer his time as a patient advisor, providing health leaders with advice, direction and the patient perspective on decisions related to policies, programs, services and facility design.

AHS is Canada's largest province-wide health system with more than 100,000 staff, physicians and volunteers, including about 800 patient advisors.

About 80 patient advisors, including Magnussen, are currently embedded in all levels of planning and design work for Connect Care, a mammoth undertaking that aims to consolidate and digitize the health information of 4.3 million Albertans. This information is currently stored in about 1,300 independent electronic systems, in addition to paper-based systems.

The foundation of Connect Care is a common clinical information system that will allow healthcare providers a central access point to patient information, common clinical standards and best healthcare practices.

The first phase of Connect Care is expected to launch in Edmonton this fall.

"We are catching up and digitizing the

Ryan Magnussen, right, is playing an active role as a patient advisor with Alberta's Connect Care system.

healthcare workplace. All of it. Every aspect of it," says Dr. Robert Hayward, Chief Medical Information Officer with AHS.

"Closed-loop medication management. Full digital documentation. Team relationships and communication. The way tasks are managed. All of that is moving from paper and various other media into one single integrated environment.

"Not only will Connect Care help Alberta continue to lead as a health information systems innovator but, with an integrated record that spans the entire continuum of care, Connect Care will create a foundation for health informatics innovation, allowing us to further explore how health technologies can improve health outcomes. It's really extraordinary."

Patient advisors have been involved in this 'extraordinary' project every step of the way. One or two patient advisors sit on each of more than 30 major Connect Care governance committees and councils.

"We need the voice of patients and families to guide us, help with some decision-making and provide a perspective to broaden our thinking and make sure we're staying as patient-focused as we intend," says Barb Kathol, Senior Program Officer, Connect Care Operations.

"Connect Care is being designed by the people who will be using and benefiting from it: frontline healthcare staff and physicians, as well as the patients they care for. This way, the system is being designed and built with the people using it in mind, as well as the people we care for."

Magnussen stresses the involvement of patient advisors is anything but a token gesture.

"From Day 1, I've been treated like a respected partner," he says.

Magnussen has full voting privileges on the 33-member Connect Care Executive Committee that reports directly to the AHS executive leadership team. Among

other tasks, this committee assessed proposals from seven vendors and selected Epic Systems Corporation in 2017 as AHS' partner on the project.

Magnussen also co-chairs the Connect Care Patient and Family Advisory Group comprised of about 20 patient advisors who provide recommendations to any and all teams involved in the project's planning and design. This advisory group was recently tapped to provide advice on how to best manage patient consents through an electronic system, and how quickly test results should be made available to patients.

"Any committee or any council can go to them for consultative advice," Dr. Hayward says of the Connect Care Patient and Family Advisory Group, "or (patient advisors) can insert themselves and raise a red flag if there's an area where they think more input is needed."

Patient advisors are also embedded with clinicians and operational leaders on more than 20 area councils that are examining how Connect Care can best support specific clinical areas, such as cancer, surgery, primary care and continuing care.

AHS Chief Information Officer Penny Rae says patients bring a much-needed outsider perspective to Connect Care planning and design. "They're not biased to AHS," she says. "They're biased to what's good for patients."

Magnussen is quick to note patient advisors bring a diversity of backgrounds and experiences to the table, and don't always agree with one another.

"We can have quite (pauses) … fruitful discussions," he says, laughing. "It's not just a rubber stamp, that's for sure."

Magnussen spends about 15 hours per month volunteering as a Connect Care patient advisor. He considers this work the third act of his professional career.

"This is something I take great pride in," he says.

BC's Digital Technology Supercluster revving up on healthcare projects

BY ZENA RYDER

The trial and error process of finding the right drug, at the right dose, is frustrating for both patients and doctors. As we now know, many medications are ineffective or harmful because of an individual's genetic makeup.

Canada's Personal Genome Project reported in 2018 that over 23 percent of the people whose genomes they sequenced turned out to be "at risk for severe potentially life-threatening adverse drug reactions" because of their genetic makeup. [http://www.cmaj.ca/content/190/5/E126]

The BC-based Digital Technology Supercluster [https://www.digitalsupercluster.ca/] is addressing this problem with their Pharmacogenomics Project. The Supercluster is a group of 600+ businesses, organizations, and institutions that are collaborating on projects involving the collection, storage, analysis, and

use of digital data in various sectors, including healthcare.

Supercluster CEO Sue Paish explained that when the Pharmacogenomics project is complete, doctors anywhere in Canada can order cheek swab kits to be mailed to their patients. Each patient will then send their swab sample away for genetic analysis.

Based on that patient's unique genetic profile, as well as on factors such as age, medical history, and medications they're taking, the patient will receive a detailed report on how they're likely to respond to hundreds of different drugs – a number that's growing as researchers discover more drug interactions.

This information will become part of that patient's electronic medical record (EMR), so that when they need a prescription, their doctor can immediately access drug recommendations – improving patient safety and convenience.

Through this project, as well as other Supercluster projects, the expertise of

small and medium-sized enterprises (SMEs) can reach all Canadians by collaborating with larger companies and organizations.

Paish said, "Each Supercluster project must have at least three organizations involved, and at least one of those must be a small or medium-sized enterprise."

GenXys and LifeLabs are the SMEs involved with the Pharmacogenomics

> **One of the Supercluster's health sector projects is a teledermatology system that includes artificial intelligence.**

project. The other collaborators are Telus Health and the non-profit research organization, Genome British Columbia.

Over the next five years, the federal government will invest a total of $950 million in the five superclusters across the country that successfully applied for

the funding. In November 2018, the Digital Technology Supercluster formally launched with an announcement that it will receive federal funding of $153 million to get started.

Across various projects, federal funding will be matched by Supercluster members. The Supercluster has initiated seven projects, which was to be officially announced in February 2019. Three of the projects are in healthcare. In addition to the Pharmacogenomics project, the others are the Dermatology Point-of-Care Network and the Secure Health and Genomics Data Platform. [https://www.digitalsupercluster.ca/wp-content/uploads/2018/12/Supercluster-Project-Summaries-docx.pdf]

How will the Dermatology Point-of-Care Network help Canadians? Doctors and patients are all too familiar with the current situation – a lengthy and time-consuming process.

A patient who is concerned about a

e-Health 2019: A bold new conference experience, coming to Toronto in May

If you have made professional development a priority for 2019, the e-Health Conference and Tradeshow is an event to include in your activities for the year. The 19th annual e-Health Conference and Tradeshow is Canada's largest congregation of digital health professionals, offering proactive, top-quality learning and an opportunity to network with organizations and people that value quality health information.

This May, e-Health will continue to deliver in-demand keynote presenters, expert panelists, networking opportunities, social events and leading-edge vendors.

The 2019 conference is shaping up to deliver on another successful event. Come Celebrate, Grow & Inspire Bold Action in Digital Health in Toronto, Ontario from May 26 to 29.

What's New at e-Health 2019? Whether you are an e-Health veteran or a first-time delegate, all attendees can look forward to a refreshed and modernized conference experience.

Let's start with the tradeshow floor. e-Health 2019 is literally breaking down walls and moving toward a completely open concept space. By removing barriers between the tradeshow floor, sponsors, exhibits and plenary rooms, delegates will be able to move freely between conference sections and ensure they don't miss a thing. All attendees will re-

The 2019 conference is being held at the Beanfield Centre, one of Canada's greenest conference spaces.

ceive wireless headsets to tune in or tune out of presentations and truly customize their experience.

The 19th annual conference is being held at the newly updated Beanfield Centre, one of Canada's greenest conference spaces, which boasts 160,000 square feet of 100% green power from renewable sources and incorporates today's most advanced technological innovations.

Sunday, May 26, 2019
New Sunday Workshop
Partnering to Design Together –
An Innovative Workshop with Patients

More and more the healthcare industry is leaning on the experiences and expertise of patients to find innovative approaches and solutions for healthcare improvements. With that in mind, this year's conference is kicking off with 'Partnering to Design Together', a full day workshop that will connect digital health innovators with patients to explore new techniques and resources through 'design thinking'.

Design thinking approaches complex problems with the philosophy that solutions should be created with, and not just for, end-users. Guided by the Hacking Health team, participants will adopt a design thinking mindset, as they identify problems, create innovative solutions and present ideas to the Hacking Health panel to be developed.

Plenary Speakers: e-Health always brings in an impressive roster of speakers for its plenary program and this year is no different. To date, Michael B. Decter, President and Chief Executive Officer of LDIC Inc., and Globe and Mail health columnist Andre Picard have been confirmed to speak at e-Health 2019.

Michael B. Decter, a Harvard trained economist, served as Deputy Minister of Health for Ontario and Cabinet Secretary in Manitoba. Michael is a well-recognized expert on healthcare policy. He was the founding Chair of the Health Council of Canada. He continues to serve as the Chair of Medavie Inc. and Patients Canada. He is also a Trustee of Auto Sector Health Care Trust and Chair of its Finance, Audit and Investment Committee.

He has authored *Healing Medicare: Managing Health System Change – The Canadian Way* (1994); *Four Strong Winds – Understanding the Growing Challenges to Health Care* (2000); and *Navigating Canada's Health Care*, co-authored by Francesca Grosso (2006). In 2004, Michael was awarded The Order of Canada.

André Picard is the health columnist at The *Globe and Mail* and the author of five books, including *Matters of Life and Death: Public Health Issues in Canada*, and The *Path to Health Care Reform: Policies and Politics*. He also has a large Twitter following at @picardonhealth.

André has received much acclaim for his writing, including the Michener Award for Meritorious Public Service Journalism and the Centennial Prize of the Pan-American Health Association, awarded to the top health journalist in the Americas. He is also an eight-time finalist for the National Newspaper Awards – Canada's version of the Pulitzer Prize.

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Improving throughput in radiology

to extract the data you need, as the data could be housed in six or seven different production systems. There again, investments must be made into integration engines and interfaces. And, of course, the data itself could be wonky. "The data you extract is sometimes not trustworthy," said Dr. Chang. "Too many times, people grab every data element and use it."

But despite these challenges, creating business intelligence and analytics systems is still possible. It helps to think about it in a new way, though, said Dr. Chang.

"BIA isn't something you buy, it's something you do," he said.

He noted that at his own institution, the University of Chicago Department of Radiology, doctors and residents are encouraged to spot problems. And when they do it, they're urged to let the IT department know.

Indeed, IT is seen as the solution, rather than additional staff. "We don't throw additional FTEs in to solve problems," he said. As he mentioned, adding staff can compound problems, as people tend to make mistakes, and more people can make more errors.

Instead, the goal is to re-design processes and to automate them, as much as possible.

On a practical note, Dr. Chang advised his audience that when pitching management for funding to improve processes, never position them as "quality" projects. That's because quality is seen as a "floormat".

And floormats, when you buy a car, he explained, are expected to be free. "When I pitched a project to the C-suite, and called it a quality project, they said great, go find

a grant." Things changed when he re-packaged it as a productivity effort. "When I called it a throughput project, I got the funding immediately," said Dr. Chang. "It did double our throughput. And it also raised quality. But management thought the quality part should come free."

BC's Supercluster

skin mole phones for an appointment with the family doctor, or waits to see a physician at a walk-in clinic. The doctor orders tests. The patient visits the lab, waits for test results, and then makes another doctor's appointment once the results are in.

If the patient is referred to a specialist, they may wait weeks or months for an appointment – because there is a national shortage of dermatologists.

This back and forth is time consuming, involves time off work or school, and is especially difficult for those who face additional barriers, such as the elderly, disabled, mentally ill, and those who live in remote, rural areas.

It would be better if, as Paish puts it, "The healthcare system could come to the patient," instead of the other way around. She says technology is now available to make "point-of-care" patient access a reality in dermatology.

Technology can increase the geographical reach of each doctor, enabling

a BC patient to access the expertise of a dermatologist in Ontario, and vice versa. Paish didn't want to reveal too many details before the February announcement, but the Supercluster's website says the project aims to "reduce time to diagnosis and help improve patient care with teledermatology and telepathology imaging, both of which will be augmented by artificial intelligence." [https://www.digitalsuperclus-

> **Paish is aiming for a world leadership role with the Secure Health and Genomics Data Platform.**

ter.ca/wp-content/uploads/2018/12/Supercluster-Project-Summaries-docx.pdf] Seven organizations are collaborating on this project: BC Cancer, Careteam, Change Healthcare, MetaOptima, Providence Health Care, Telus Health, and the University of Victoria.

The Secure Health and Genomics Data Platform also reduces geographical barriers. Currently, a doctor in New

Brunswick, for example, can access patients' genetic data collected in New Brunswick. So, if their patient has a rare disease, a doctor might find information about a couple of other NB cases, learn how they were treated and what the outcomes were.

But that's very little to go on. Paish says, "There's currently no Canada-wide system for collecting, analyzing, and securely storing health and genetic data." If the NB doctor could access data from across Canada, they would be better informed when they provide treatment. This project has the potential to make Canada a global leader in this field. Paish says she's received letters of international support telling her, "If the Supercluster builds this platform, they will use it".

Collaborators on this project include household names such as Microsoft Canada and Deloitte. Other partners are Genome British Columbia, LifeLabs, DNA Stack, Molecular You, UBC, and the BC Provincial Health Services Authority.

Sue Paish is proud of the Supercluster's momentum. She says, "Organizations across Canada have quickly recognized the potential of being involved."