

THE 20SENSE REPORT

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Making sense of Canada's
specialty pharmaceutical market

SPOTLIGHT ON THE CANADIAN
SPECIALTY PHARMACEUTICAL MARKET

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Patients are talking. Are we listening?

Today's patients are connected via apps, publishing blogs, answering surveys, and ensuring their voices are heard. Their words are a mirror to our industry, showing us what we're doing right—and what's missing.

In a 2018 survey by the Canadian Partnership Against Cancer (CPAC), up to one in five surveyed cancer patients reported that nobody discussed different treatment options with them.¹ Along the same lines, up to 25% maintained their health providers did not take their travel constraints into account when planning for treatment, and similar percentage were underwhelmed with the emotional support they received during outpatient cancer care.

At the same time, the industry is going through some turbulent times, with rumblings of a national pharmacare program² and increased government oversight. The Patented Medicine Prices Review Board (PMPRB) is working on

drug pricing reforms^{3,4} that, while well intentioned, may discourage innovation. Recognizing the need to contain costs, specialty drug manufacturers face difficult choices about what to include in their patient support programs (PSPs), which raises concerns that patient experience could suffer.

We cannot let this happen. Satisfied patients keep the specialty pharmaceutical industry healthy and vibrant. As one analysis has found, "pharmaceutical companies with the best results regularly monitor, evaluate and optimize their programs through ongoing research with key stakeholders"⁵—which should, first and foremost, include patients.

In fact, many in the industry are making it their business to put patients first. Abbvie Canada, for instance. Not only have they incorporated Care Coach Calls (phone calls to patients by trained coaches) into their PSP, but they've measured their impact. As it turns out, patients who received the calls

were 72% less likely to stop treatment – an impressive figure by any standard.⁶

In support of this approach, a recent webinar including PSP leaders from across the globe on "the next-generation PSP" predicts that, while patient care and services are currently fragmented, "as data becomes richer and more available, the care and delivery to patients will be improved."⁷

We agree. Data is key, real-world data is even better, and PSPs give us a perfect opportunity to discover what makes our patients tick. Here's a thought: what if we simply asked them? What if we built patient experience questionnaires into our processes for managing specialty drugs? It's only through front-line feedback from patients that we can align our PSPs with their needs.

Here's another thought for our rapidly changing times: it's no longer good enough to think about patients. We need to think like patients. **Are we up to the challenge?**

Patient-Centred Innovation in Our Midst

While our industry still has progress to make in connecting with patients, there's also a lot we can be proud of. Throughout the country, creative stakeholders have been working to make life easier for patients living with chronic and complex diseases. We've highlighted how thinking like a patient makes all the difference.

Case 1: Hospitals and community partnerships

Oral cancer therapies rely on patients to fill prescriptions, take medications as prescribed, and report side effects – but life happens. To help keep patients on track, the Southlake Regional Health Centre in Newmarket, Ont. launched a bold program with few precedents: partnering with a specialty pharmacy to support cancer patients as they transition from the hospital into community care. In the voluntary program, patients receive follow-up phone calls from an oncology pharmacist at the specialty pharmacy. The pharmacist asks questions to find out if the patient is following the regimen, experiencing any side effects and help them with their therapy.

This program illustrates how hospitals and specialty pharmacies can work together to patients' benefit. "Delivery of drugs to patients by specialty pharmacies and coordination with community clinics is very convenient for several reasons," says

Dr. Stephanie Snow, a medical oncologist at the QEII Health Sciences Centre in Halifax. "Leveraging resources outside of the hospital is often positive for a patient's experience. They can stay in the community instead of coming to the hospital setting and have quick access to counselling and education via their specialty pharmacy or clinic. As a physician I feel confident that my patients are receiving the utmost care as I stay in close contact with the clinic nurses and specialty pharmacists."

Let's put a face on it: a 56-year-old woman, on medication for metastatic breast cancer dispensed at her own pharmacy, enrolled in the Southlake program. The oncology pharmacist gave her a call and learned she was experiencing nausea, throbbing in the head, weakness in the legs. The pharmacist relayed this information to the healthcare centre, a nurse from the centre followed up to get more details, and the patient was subsequently admitted to the centre for cardiovascular management. A big win for patient care.

Case 2: Piloting home-based treatment options

There's no place like home, especially when you're sick – and need to take an infused medication. At the same time, home infusions have complex protocols and pose some risks, which is why infusions of specialty medications have typically been administered in the clinic or hospital setting.

Undeterred by the challenges, the manufacturer of a myeloma medication took the bold step of piloting home infusions in its PSP in the name of patient-centricity. That's because the patients served by the drug are often very sick and may struggle to walk, let alone travel long distances to receive their medication. By removing the access barrier and bringing infusions into the home, the manufacturer achieved its overarching objective: improving the quality of life and health outcomes for patients.

There's a financial benefit as well: by reducing hospital stays and hospital-acquired infections, home infusions save money overall for the healthcare system. Indeed, a 2017 review found home infusion to lower costs with savings between \$1,900 and \$2,900 per treatment course, compared to infusion in medical settings.⁸

The myeloma patients enrolled in the pilot program have nothing but praise for the service. In one patient's words: "The service and explanation of the program [by my nurse] was second to none." →

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**Case 3:
Customizing services based
on individual needs**

Patients living with Hepatitis in rural communities can face challenges accessing specialized care. Fortunately for patients in Prince Albert, Saskatchewan, a specialty pharmacy with expertise in hepatitis C medications has stepped up with a pioneering program that connects the patient with Shelley, a local Hep C nurse. Through a validated questionnaire, the program identifies patients at high risk of non-adherence – and supports them with customized strategies to promote treatment success.

By talking to each patient before therapy begins, the program can identify and address barriers that might otherwise slip under the radar. “The in-depth research they [the pharmacy] do on every single medication [a patient may be taking] is remarkable to me,” says Shelley, adding that “they help me facilitate the best possible care.”

Arguably most important of all, the program helps draw patients out of their isolation. Nobody explains this better than Hep C patient James: “For the past 25 years, it felt like I had nobody on my side. Since I was approved and [transferred to the program], I have so many people in my corner... I wake up and I’ve got a smile on my face. That hasn’t happened in years.”

**Case 4:
Innovative therapies at the local level**

The best medicines do more than alleviate symptoms: they change lives. Isaiah, who has lived with atopic dermatitis (the most common form of eczema) for as long as he can remember, can attest to this reality.

While the disease often subsides with age, Isaiah’s condition kept getting worse. “My skin would shed like crazy,” recalls Isaiah, now 18, adding that simple showering caused him near-unbearable pain. Bullying from classmates, meanwhile, left him emotionally battered.

Having tried every product imaginable, to little effect, Isaiah had all but lost hope – until a breakthrough biologic medication received Canadian approval in early 2018. The medication’s PSP helped Isaiah secure coverage and assigned a nurse to support him through treatment. The PSP also enabled him and his mother, Sherry, to receive injection training at a local pharmacy. The family appreciated this convenience, which minimized their waiting time, and felt reassured that a specialty-trained pharmacist was providing the training.

After just two injections, Isaiah noticed a dramatic improvement in his disease. No longer driven to scratch his skin all the time, he even began enjoying showers. What most struck Sherry, however, was the boost in his confidence and well-being.

As Isaac’s case makes clear, innovation matters. While new policies may be putting cost pressures on the specialty drug industry, we can’t afford to sacrifice pharmaceutical innovation. Nobody knows this better than Sherry, who says: “I finally have my son back.”

- ¹ Living with cancer: a report on the patient experience. Canadian Partnership Against Cancer 2018. <https://bit.ly/2zxt5vW>
- ² Government of Canada launches Advisory Council on the Implementation of National Pharmacare. Health Canada, June 20, 2018. <https://bit.ly/2trGEsb>
- ³ Patented Medicine Prices Review Board (PMPRB) explores possible changes to how it conducts business. PMPRB News, Dec. 11, 2017. <https://bit.ly/2N3vNwz>
- ⁴ New PMPRB rules could impact patients with rare diseases: study. Benefits Canada, August 30, 2018.
- ⁵ Evans H, Martini J. Patient support programs that deliver results. ZS 2015. <https://bit.ly/2DH1jBg>
- ⁶ Marshall JK et al. Impact of the Adalimumab Patient Support Program’s Care Coach Calls on Persistence and Adherence in Canada: An Observational Retrospective Cohort Study. Clin Therapeut 2018; 40:415-29.
- ⁷ Simms P. Eye for Pharma webinar: the next-generation PSP. <https://bit.ly/2xH7lw7>
- ⁸ Polinski JM et al. Home infusion: Safe, clinically effective, patient preferred, and cost saving. Healthc (Amst) 2017; 5:68-80.
- ⁹ The Commonwealth Fund (2012), International perspectives on Patient Engagement: Results from the 2011 Commonwealth Fund Survey.
- ¹⁰ Deshpande PR et al. Patient-reported outcomes: A new era in clinical research. Perspect Clin Res 2011; 2: 137-44.
- ¹¹ Palmer K, Tepper J. Patient engagement a new frontier for drug makers. Healthy Debate, April 17, 2017. <https://bit.ly/2pqTCX3>
- ¹² Healthcare system needs to catch up to the requirements of the Google Generation. Canadian Medical Association, August 14, 2018. <https://bit.ly/2w9QpwY>





Anatomy of a Patient-Centric Patient Support Program

In April 2017, Erin Truax was diagnosed with multiple sclerosis (MS) and her life changed forever. She recently sat down with us to share what it's like to be part of the specialty drug ecosystem and give us a close-up view of her PSP.

Q: Tell us about your MS journey.

In addition to shock and confusion, I felt embarrassed when I got the diagnosis. I guess I was concerned with how people would view me. At the same time, I resolved to keep living, and the following week I went on a planned trip to the Arctic. I've continued to live life to the fullest, and on good days I forget about my MS. On bad days, the support of my family and friends – and let's not forget my dog! – reminds me that everything is going to be OK.

Q: Tell us about your experience with MS medication.

I'm taking an injected medication, which decreases the frequency of flares and delays the progression of the disease. It's proven to be the right drug for me.

Q: Does the medication have a PSP and has it helped you?

Yes. The PSP provides injection equipment, a symptom diary, and even a travel cooler since the drug needs refrigeration. My primary interaction with the PSP is through "nurse Judy," who is worth her weight in gold.

Q: Did you have any challenges accessing and paying for the medication?

Access was seamless, and I've been able to pay for it through a combination of my work benefits package and support from the manufacturer. Judy helped me with everything: whom to call, all the paperwork, who would pay for what. Needless to say, this was invaluable. The pharma company gave me one month of free drug, so I could get started right away.

Q: How has she helped you?

Judy came to my condo and taught me and my sister to do injections, tailoring her instructions to our learning styles. The medication comes with a machine that automates injection, which makes things a lot easier. And the needles don't hurt that much! Judy also calls me if she thinks I may be out of needles or just to see how I'm doing. She's gotten to know me as an individual.

Q: Do you think your PSP is "patient-centric"? What about the industry in general?

Absolutely. Judy has been a friend all the way, and knowing she's there has been a huge comfort to me. If other people are getting the same kind of treatment as I'm getting with Judy, I'd say the industry is definitely on the right track.

Q: Is there anything else you'd like to see in a PSP?

I think an online chat group would be great, and perhaps videos of patient experiences, such as experiences with needles. Before starting my medication, I looked for such videos online and found them enormously helpful.

Q: Any thoughts you'd like to impart to specialty drug manufacturers?

I would encourage industry to dig deeper to get the "real goods" from patients. Industry has an incredible opportunity to use real people like me, with our real-life experiences, to gain insight. If you want to know what's working and not working, have those conversations with patients. Honest feedback is powerful!

Q: Any final thoughts for our readers?

I'm inspired by the work that's being done to support MS. I was initially reluctant to talk about my experience and even avoided discussing it with my parents, but now believe that the more people talk and share, the more and better research will happen, so we'll eventually find a cure.

Canadian Patients Show Their Power

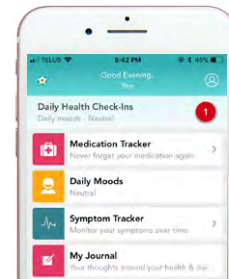
Tell me what to do, doctor. This attitude made perfect sense in the pre-digital era, when patients had little access to information. Today's patients wear health apps on their wrists and trade health tips online. They seek greater control over their health—and are willing to take responsibility for it.⁹

These winds of change have blown through the world of medical research, and today's clinical trials routinely feature “patient-reported outcomes” among their endpoints.¹⁰ The pharma industry has also taken note: while compliance still requires the industry to keep some distance from patients, many pharma manufacturers now communicate more directly and authentically with patients in advisory board meetings and clinical trials.¹¹

Here are a few examples that showcase this new era of patient engagement – right here on Canadian soil. Such initiatives are changing the landscape of healthcare and giving fresh opportunities for pharma stakeholders to improve the patient experience.



PHOTO: MEGHAN TANSEY WHITTON



1. Patients reaching patients:

Welcome to Sickboy, a podcast series that aims to dismantle the stigma of living with chronic disease – using humour, silliness, and the occasional swear word. The brain-child of a young man with cystic fibrosis and two of his friends, Sickboy has touched a wide and varied audience. In one of the podcasts, a cranked-up guitar riff segues into a Q&A with a 24-year-old woman who describes how, on some days, her juvenile rheumatoid arthritis makes her feel 80. In another, a woman with a brain tumour talks about the healing properties of weed while conceding that “nobody is in control of this.”

This series is too good to miss. New to Sickboy? We recommend starting with these episodes:

[It's either Hodgkin's or it ain't: Hodgkin's lymphoma.](#)

[Feeling like I'm 80: Juvenile rheumatoid arthritis.](#)

[The birds & the bees & a brain tumour.](#)

2. Patient-centric innovation:

Remember house calls? Thanks to a company called Mediseen, they're back in style – with a new twist. A cloud-based digital platform enables patients to access quality health care in their homes or offices, rather than commuting to clinics and sitting in waiting rooms. For people who sometimes have trouble walking across the street – like the company's founder, who lives with Crohn's disease – the service is pure gold. Hundreds of health providers have already signed on. Along similar lines, a service called Maple lets patients chat with Canadian doctors online, as well as get prescriptions and notes excusing them from work.

[Mediseen: Bringing Back the House Call](#)

[Maple: Online Doctors, Virtual Health & Prescriptions in Canada](#)

3. Data power:

Recognizing that “patients will drive the future of health innovation,” a company called Self Care Catalysts has set itself the dual goal of promoting self-care and collecting patient data to support drug research. The company's mobile platform serves as a one-stop health-tracking system that yields real-world insights for physicians and industry.

In tandem with these efforts, patients have gone public, crafting YouTube videos describing their health challenges, evaluating their doctors online, and posting testimonials of their treatments. This trove of information makes it easier than ever for industry to find out what patients actually want – an invaluable asset when designing a PSP. And another thing: younger patients love technology.¹² Use it or lose them.

[Self Care Catalysts: Real World Health Experience & Behavior](#)

What We're Reading

We find that the following articles provide great insight into the specialty pharmaceuticals market. Follow us on LinkedIn where we're sharing our thoughts on these topics and many more.

[Healthcare system needs to catch up to the requirements of the Google Generation](#)

[Webinar: Patients & the Next Generation Patient Support Programmes](#)

[Impact of the Adalimumab Patient Support Program's Care Coach Calls on Persistence and Adherence in Canada: An Observational Retrospective Cohort Study](#)

[First Baby, then Breast Cancer | Breast Cancer Vlogs](#)

[Sometimes Patients Simply Need Other Patients](#)

[Patients get floor at Canadian Medical Association's inaugural health summit in Winnipeg](#)

[Party Pooper: I thought I was dying – then they told me I had Ulcerative Colitis](#)

Upcoming Issues

In upcoming issues of *The 20Sense Report*, we'll take a deeper dive into:

- Specialty pharmaceuticals and data, key areas for insight maximization
- Patient support programs: exploring opportunities for outcomes-based agreements
- CAR-T therapies

Is there an issue you'd like us to address? Do you have a question you'd like us to answer?

We welcome your suggestions for topics you'd like *The 20Sense Report* to cover.

Are you looking to make better sense of the specialty pharmaceuticals market?

Contact us at:
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20Sense helps pharmaceutical manufacturers and specialty service providers more effectively enter and compete in Canada's complex specialty pharmaceuticals market by optimizing data, insights and programs that deliver better outcomes for patients and value for payers.

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