



In conversation with

Shelly Jamieson

Ken Tremblay

With some \$240 million in Federal funding over five years, the Canadian Partnership Against Cancer (CPAC) is a unique approach to achieve a pan-Canadian vision and to accelerate strategies that optimize the effectiveness and efficiency of cancer care in this country. Central to its mandate and 30-year vision, the Partnership's goals are to reduce the incidence of cancer, lessen the likelihood of dying from cancer and to enhance the quality of life of Canadians living with cancer. Leading the charge to impact a population health challenge as complex and prevalent as cancer is the Partnership's CEO Shelly Jamieson, a veteran of executive leadership, public policy and change management. Her diverse career has spanned geriatric care, leadership with Extencicare Canada and the Ontario Nursing Home Association, Ontario's Health Services Restructuring Commission (HSRC) and Government, including Deputy Minister of Transportation, Secretary of Cabinet, Head of the Ontario Public Service and Clerk of the Executive Council. She wears governance hats with High Liner Foods, the 2015 Pan Am

/ Parapan Am Games and Health Quality Ontario. A Queen's Diamond Jubilee Medal winner and inductee of the Hall of Fame of Canada's Top 100 most powerful women, Shelly holds a degree in Urban Studies from the University of Toronto and is a graduate of the Executive Management Program from the Ivey School of Business at Western. HQ's Ken Tremblay caught up with her this summer.

HQ: You have to admit – that's an impressive CV?

SJ: My husband says I can't keep a job! I mentor a lot of young people and talk to them about career planning. People did that for me and it was very helpful. I'm a firm believer that there seems to be two groups of people: those who have a plan and know exactly what they're going to do in their career; and, the others who are like me. When I was a young, I didn't know that the jobs I ended having even existed and it's been a delight. Over my journey I have learned to keep my mind and eyes and ears open; it's often been other people who recognized that I might

be a candidate for a position I might not have considered. Then I have to regroup: why I would be good for this job; would I like it; or, is this organization also good for me? I always encourage people not to be afraid of something completely different than what they're doing currently.

HQ: Why the move to disease management from executive leadership?

SJ: I've had the privilege of having two really large jobs in my career: one where I had 18,000 employees as president of Extencare; and, the Ontario Public Service with 68,000 employees. When I finished with Ontario Public Service, I was looking for something different and made a conscious choice to consider smaller organizations. But I also was looking for a direct connection between my work and what actually happened. When a search firm contacted me about the CPAC job, the more I dove into the model, the more I realized that I had not seen anything like it before. It was easy for me to be passionate about cancer because, like all Canadians, it's touched my life through family and friends. I liked the idea that I was going to be part of something important to the country.

I had not seen this focused approach to align the players in a particular disease and I liked the idea of mobilizing on a national scale the efforts of people who were already experts in cancer. I never intended to be the cancer expert – that was something I had to sort out when I was considering this job. But CPAC and our network across the country are full of people who dedicate their careers to the cancer field. What they needed was someone to spread the scope and impact of the mandate on a national scale and I felt I could bring my experience to the table.

HQ: Achieving relatively consistent performance across Canada in any healthcare endeavour has its challenges. How do you see the CPAC model being different from approaches of the past? Is its governance structure a means to an end?

SJ: A couple of things help us stand together. We don't have any sticks and no one has to work with us. But, we do have carrots, money does help make things happen. There are many jurisdictions that simply don't have the money to spend the time, for example, to study the attributes of a [successful] cancer screening program. So people have to want to work with us.

The unique aspect of the CPAC model was that it resulted from about 700 experts across the country spending a decade trying to figure out how to work differently together. CPAC was not created [first] and then had to beat a path to ensure that people would work with them; it was the reverse. They were already on board. They wrote a national cancer control strategy, submitted it to government and, in 2006, the federal

government made the decision to create this organization and have a pen on a national cancer control strategy. They deliberately set up the governance of the board to be reflective of those 700 experts and various subgroups that wrote the original plan. People had skin in the game from the beginning and as we go forward. There isn't anything we do in this organization that doesn't already have the approval and endorsement of our partners. We don't set the agenda; we set it together.

HQ: How does CPAC transcend the jurisdictional tensions and barriers that have often complicated disease management strategies and delayed consistent clinical care and outcomes in this country?

SJ: It's all about relationships: it's one thing to have a process, tools and even the money. But, if you don't have trust and respect between the parties, it just doesn't work. In our first five years, we spent a lot of time bringing people together who had just simply not been in a room before to talk about cancer control issues.

While that was important, we had to build the groundwork to work together. Just getting together to talk where nothing changes is not going to have a systemic impact. In our second five years, we've been more focused on integrating and brokering knowledge, catalyzing efforts, seeking that sweet spot where there's consensus in the room. We share knowledge, invest in ideas and integrate and harmonize, for example, standard methods of collecting data. It's been a very effective and unique way of working.

We have a bit of an advantage because cancer is so pervasive. It's not hard to get people across the country to recognize the importance of working together. I feel blessed to work with professionals and experts that are quick to understand that we are better off when we work together.

We have many initiatives underway and the provinces and territories have the right to opt in and out depending on their resources or priorities. We're always looking for a critical mass in the country on initiatives and who might work together now or later on. Some might adopt a best practice in something that we've developed as a group and catch up on others later or, they might just choose to be outside that effort – that's just fine. Over time our credibility as a group is increasing: we're getting things done; we're evidenced based; we're trusted. There's a sense of value in the time we spend and the work we do together.

HQ: CPAC's vision speaks to making cancer a disease almost like polio – a thing of the past. Is that achievable by 2037?

SJ: There are three goals (buckets) in our mandate: to reduce the burden of cancer; to have fewer people being diagnosed with

cancer (we can achieve that); and, to improve the quality of life for those who really have been touched by cancer.

In Canada right now there are over 1 million cancer survivors. Yet we're not really good at survivorship. You finish your active treatment and then you're kind of punted back out into life away from the cancer system. We're finding many people need more support than that, both emotionally and physically.

I would frame it a little differently and say that after 30 years there might be a different distribution in those buckets than there is today. Cancer is about 200 different diseases and to imagine their elimination after a period of time, even if it's decades, is wishful. There's a lot of fundraising in the cancer field and the hope that something is going to eradicate cancer.

HQ: Your organization contemplates four key methods to galvanize approaches to cancer care with its partners: convene, integrate, catalyze and broker. Which approach(es) hold the most promise? Which might be the most challenging?

SJ: Catalyze is where we're having the most fun right now. We did do a good job of convening [the system]. For example, if we put out a call for experts in cervical cancer in this country, they show up because they want to be part of what we're doing.

Regardless of how the health system or cancer control services are organized in a province, how can we cut through or across all the jurisdictions to get something done? We're finding enough commonality that we can fund initiatives (e.g., best practice) where people can still play within their system and retain their identity.

It turns out that mobilization or brokering of knowledge is easier to say than achieve. While there's a lot of talk about knowledge transfer and information exchange, what does that mean and what does it look like? There are not a lot of sophisticated ways of measuring and understanding true impact of knowledge transfer but we're trying. I go back to "convening" – if you come up with really good practices, how do you know that anybody applied them with some level of impact? How are we measuring those things [downstream]?

It was a bit of a surprise to me to find out that there aren't as many good practices out there as I thought there were. We can have great ideas about best practices and good evidence but good evidence with low compliance is not going to change the data, right? Even though we issue system performance reports every year and continually develop metrics and outcome measures, it's still early days. We have to see where we're actually having an impact and where we aren't and that's easier said than done.

HQ: In the short term, cancer management still follows the pattern of disease prevention, early detection and screening, rapid response to effective

therapy, survivorship and, when needed, palliation. How do you envisage CPAC altering the course of a cancer diagnosis in this country?

SJ: We need a better understanding of what personalized medicine is, where we could anticipate either the type of cancer somebody might get or the type of treatment that would work best for them. That would be a game changer. The example that we're very proud of is colorectal cancer. There is more screening for colorectal cancer than ever been and because of our collective efforts, we've detected cancers earlier: if you don't have polyps you'll never get colorectal cancer. If everybody were truly screened for colorectal cancer there wouldn't be any more colorectal cancer. That's awesome but not the same for many cancers.

"The Emperor of All Maladies" is an awesome book about the history of cancer. If you're a systems thinking geek like me, it's rich with examples and lessons over time where someone with a bright idea hasn't been enough to change the course of cancer. Yet, when there's been a medical breakthrough, political will or someone like a Terry Fox, elements converge and we've been able to get things done. As a systems thinker, how many of these things have to line up to make a difference with cancer? And that's the trick and what the cancer control community is trying to do in Canada. We have resources provided by Health Canada. We have good will. We have champions. We have advocates. We have science. How do we get enough alignment to actually change how we do things today? That's another thing easier said than done.

HQ: Successful disease management, particularly at the population health level, requires robust health informatics. How are you leveraging those resources and possible investments with your mandate? What is the key indicator you are using to make sure that CPAC is making a difference?

SJ: First, I want to be clear that we try really hard to ensure that we're not duplicating anybody else's work. When I talk about the sweet spot I'm looking at things we could do that no one else is doing. We rely heavily on information and data collected by others and we partner with them to harvest [information] we need. So, we work with key partners like the Canadian Institute for Health Information and Statistics Canada. We're fortunate in that cancer has registry data; many other diseases don't have that. We're trying to maximize the use of registries and in tumour banks to help us assess if we're doing the very best.

If we're going to be driven by evidence, we have to make sure that we are asking and studying the right questions as a society or community of providers. To the people who hold the databases, we say we don't want to do what they do. But we also ask that

they not ask the next question in cancer because that's what we do. We marshal the cancer control community to talk about what's next. What could we do next to really make a difference in this piece of the disease whether it's prevention, treatment or outcome? We're working with the many Pan-Canadian organizations to make sure that they're not spending time or resources coming up with the question that might be either already answered or planned further down the road.

HQ: CPAC funds CAREX Canada, a means to provide occupational and environmental carcinogen exposure surveillance information and tools to Canadians. With its reports on known, suspected and potential carcinogens, what are your expectations about how the incidence of cancer will change in this country?

SJ: CAREX is one of the tools available to jurisdictions and Canadians to better understand what these things could be doing to us and where they exist. It is quite an impressive piece of work. It can drill down to any postal code in Canada and is linked to international standards on acceptable limits in terms of these different carcinogens. It's certainly there to be mined by any jurisdiction, municipal, provincial, federal, different advocacy organizations, etc. and they consider it quite a gold mine. And in fact it's in demand in other parts of the world. CAREX staff actually helped design the service so that they can extract the information they need.

All of these things lead us to a better understanding about why some people develop cancer and some people don't. We're sure that some people have genetic predispositions while others develop cancers from environmental exposure. We know this to be true; we're not as sure about how much, how long, how often and what we can do about it to interrupt that. So CAREX is a very powerful tool.

HQ: Clinical trials have and will continue to play an important role in changing the prognosis for cancers. How does CPAC plan to improve the cancer research landscape in Canada?

SJ: One of the legacy pieces of this organization. One is the Canadian Partnership for Tomorrow project, a population health research platform and largest of its kind in Canada. It's so large that it's globally significant and it has received attention from outside of the cancer community.

This is a classic example of without CPAC's involvement there would have been small regional cohorts (data sets) across the country. But we were able to bring the resources and parties together to develop a national data set. What's awesome about this project is that 300,000 Canadians (between the ages of

35 and 69) have enrolled in this study. It involves about an hour and a half online survey sharing their personal living style and key elements about their life and some 130,000 have also given bio samples (e.g., blood and toenails samples). They've agreed to share and link their information through their adult lives with their health database. This means is we're going to be able to provide in Canada and probably around the world accelerated access to testing questions to either prove or disprove theories about certain kinds of cancer. A scientific panel will assess projects and those approved will be given quick access to needed data sets meaning we're going to get through these research questions quickly. That's pretty exciting.

HQ: While your central mandate functions at national policy and system delivery levels, cancer is a suite of diseases where patient-centred approaches and experiences are pivotal to success. How do you bridge patient experience, primary care, survivorship and palliative/end of life care issues with providers using a national lens?

SJ: End of life and palliative care are the least well organized of the cancer continuum and it's incredible that they are as well organized as they are because they have tended to be unstructured, supported by leftover funding and have been achieved through a lot of good will by hardworking people. We've just formed a palliative and end of life network with representation from across the country. It's been very welcomed by jurisdictions because people are doing some awesome things in this country but they are not sufficiently organized to know each other and to share information and resources.

The other thing that I want to highlight is that the patient and/or family voice has become embedded in everything we do. Even on our most technical committees, we ensure a patient voice is there. That's how palliative and end of life care became so important because patients and families will tell you how they feel neglected. Clinicians, researchers and academics often have interests in other parts of the cancer control continuum, although some of them do specialize in palliation. We have patients on our board and they are a great reminder that we need to be grounded in the very real experience of the cancer journey which can diminish your quality of life and can indeed lead to palliation and end of life care.

HQ: Which country(ies) are outperforming Canada in terms of cancer care? What lessons learned will be important for this country to implement?

SJ: We've been in touch with other jurisdictions around the world through the Union of International Cancer Control. Dr. Heather Bryant, Vice President of Cancer Control at CPAC,

is an elected member to that board, the organization which sponsors the World Cancer Congress.

We speak frequently to folks in the United Kingdom, New Zealand, Ireland and France. But I would say our closest relationship is with Australia where there are many similarities with our [national] journey where we are each ahead or behind in certain parts of the journey. The countries I just named have national cancer control strategies so they have some similarities with us. Australia has a federated health system, a small population spread over a vast area and they have a First Peoples population with unique needs. That is very interesting and important to us because a big part of our work here is for Canada's First Peoples.

HQ: Perhaps tangential, we're approaching the 20th anniversary of the HSRC's work in Ontario. Thoughts: what did it get right or not get right?

SJ: I have stayed in touch with two of my colleagues from that time, Dr. Duncan Sinclair and Mark Rochon. Going back to "The Emperor of All Maladies." I wished I had read that book before I joined the commission because that mandate was about system reform, about disruption in the system and inertia in the system although such reform was driven by evidence. Duncan often mused that if the man on the moon landed in Canada and you had to explain our hospital system, what would you say? You wouldn't be able to say that hospital locations and the programs they offered were driven by the evidence that the more often you do something the better you get at it. I feel privileged to have been part of that team. I also learned valuable lessons about the role of the public service, the role of politicians and in the role of an arm's length independent agency.

I believe our work was helpful in at least drawing attention to the fact that we needed to think more as a system. When you look back over the last 20 years, you see a lot of mergers

and rationalization of services resulting from, perhaps pushed by the fact that the commission was given fairly extraordinary powers at the time. I can't believe that was almost 20 years ago – I must be old!

HQ: Any sense of what you want your legacy to be at CPAC?

SJ: When I joined CPAC three years ago, I felt the board's support in making sure that the breadth and depth of our impact as an organization was maximized. The people who had been on the first five-year journey had done an awesome job of building a foundation. What was needed next was to make sure the country knows about CPAC (the model and its activities), what resources are here and what we can achieve together. We've come a long way on that in three years.

The second piece is making sure that we have evidence and that, if we're an organization that's driven by evidence, we're in fact making a difference. I feel confident that we have evidence about what we're doing together is working and that there are some things where we need to recalibrate. It seems to me that there is enough evidence for a third mandate of five years in 2017. The model is becoming more sophisticated, our outcomes are being achieved in a more accelerated fashion and, because we're doing it over and over, it's getting easier. There's lots of work to do here and I want to set us up in the best position to move into a third mandate.

On a personal note, I've worked in many different jobs working with First Peoples where I have had varying degrees of success and failure. I'm so proud of the work that we do here with First Nations, Inuit and Métis partners. I will come away from this job having learned an enormous amount about tone and style and listening versus directing. We have incredible First Nations, Inuit and Métis partners. Together we're getting stuff done and I'm very proud of that.

HQ: Thank you.

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