

S4E3 - Thousands of handprints

Transcript

Man: [00:00:04] What in part sparked the need for a CPSI or indeed the WADE panel was the fact that – and I'm quoting here from the US report, which basically said there's the equivalent of a 747 a day dying due to avoidable patient adverse events. And so the challenges that were huge remain significant. But I guess that was the driving force is the recognition that we had to do better.

Narrator: [00:00:39] Canadian Patient Safety Institute presents *Patient*, a nonfiction medical podcast about the people trying to fix health care from the inside out. I'm your host, Jordan Bloemen [ph]. For the three or so years that we've been making *Patient*, we've started just about every episode the same way: "Canadian Patient Safety Institute presents *Patient*." On August 25th, it was announced that at their respective board meetings, both the Canadian Patient Safety Institute – the organization behind this show – and the Canadian Foundation for Health Care Improvement had voted to pursue amalgamation. On October 1st, two of Canada's largest quality and patient safety organizations legally amalgamated into something new. It's always good when you get to the end of something big to look back and reflect on what it is you've done. In the 17 years since its inception, CPSI has helped change the face of patient safety in Canada. They have changed how the medical system thinks about its relationship with patients. They've changed how we report incidents of patient harm. They've changed how we approach patient safety on a national level. This being, I suppose by definition, the last Canadian Patient Safety Institute presents *Patient*, we thought it would be a good time to reflect on the history of the group that brought you this show, the sea change that they helped usher in patient safety, and the future of this really interesting field. Like anything, we're going to start at the beginning. Here's Dr. John Wade, CPSI's first board chair and CEO, and Wendy Nicklin, former board chair.

Dr. Wade: [00:02:39] About 2001, the Royal College got very concerned. And Bernie Langer, who is the chief of surgery at the University of Toronto, but then-president of the Royal College of Physicians and Surgeons of Canada, called and he said, "We've got to do something. The Americans have come out with "To Err is Human." They were showing that 48, 98,000 people a year died from adverse events in the US, and we thought it might be similar in Canada. So we formed the national steering committee, which I chaired.

Wendy: [00:03:12] And we got together and said, "What are we going to do about patient safety for Canada? What kind of map do we need to create? How can Canada move ahead in this

important issue that we're now paying attention to?" So we developed a paper called "Building a Safer System," which was published, I believe, in 2002.

Narrator: [00:03:33] The steering committee published the "Building a Safer System" report, which recommended, among other things, the creation of CPSI. Bill Foale, former CEO of Health Care Can, explains.

Bill: [00:03:44] It had 19 recommendations and by my count, 16 of the 19 recommendations have been fully implemented, and the other three or four are well on their way. And of course, the first recommendation in the report was to create the Canadian Patient Safety Institute, which was announced in December of 2003.

[0:04:06] Well, Canada has what David Naylor calls this chronic condition. It's called NIH syndrome, and that doesn't stand for National Institutes of Health; it stands for not-invented-here syndrome: this idea that we are the sum of our parts, not greater than the sum of our parts. So CPSI was born out of this recognition that we needed to learn from one another, that we owed it to patients in Canada, across Canada, to not repeat the same lessons at their expense.

Narrator: [00:04:35] One of the first major milestones in CPSI's history came in 2004 with the publishing of the Canadian Adverse Events Study. The document revealed some pretty startling realities of health care in Canada. Dr. Ross Baker, professor at the University of Toronto, explains.

Ross: [00:04:52] I think the important thing about CPSI is it came into an environment where there had really been very little knowledge and very little experience of patient safety. And then with Peter Norton and a group of other colleagues, we published the Canadian Adverse Events Study in 2004, and all of a sudden people discovered that one in 13 patients in Canadian hospitals was unintentionally harmed as a result of a patient safety event.

Narrator: [00:05:18] As Ronald Hughes [ph], chair of the Board of Directors at CPSI and Sandy Cozy, CPSI's senior director of strategic partnerships and priorities explained, the document was not necessarily received in the spirit in which it was published.

Ronald: [00:05:32] You know, the number of people harmed on an annual basis, the number of fatalities on an annual basis, is just devastating. When we released that information, we thought that the media would jump all over it, and not necessarily CPSI for maybe not doing our job, but the health care providers, the health care system. We thought that there was going to be this

tsunami of controversy, and how could we say such things and how could you report such statistics? It was quiet. It was too quiet.

Sandy: [00:06:01] You know, when we released numbers around unintended health care harm being the third leading cause of death in Canada, people didn't pay attention. They still didn't pay attention. There's people's lives behind every one of those numbers. When we say every 13 minutes and 14 seconds, somebody in a Canadian hospital or receiving home care services dies as a result of unintended health care harm, those are people.

Narrator: [00:06:27] Those are people. CPSI needed to give a voice to those people. If they wanted the media and health care system to take notice, they needed those patients to have an autonomy that was un-ignorable. Their answer? Patients for Patient Safety. Patient advocates Maryann Murray and Linda Hughes explained.

Maryann: [00:06:46] We're a group of about 70 volunteers, most of whom have experienced harm in the health care system. A small group of us formed way back in 2006 after experiencing harm, thinking that we needed to do something to try and improve patient safety in Canada. So we, as part of that program, helped build tools for patients and public to know how to communicate effectively during their medical care, how to understand what's happening to them. And some of those tools are used nationally now; some are used internationally. And I think it's a clear example of how important it is to include the patient perspective and those patient stakeholders in every area of the health care system.

Narrator: [00:07:38] Centring patients didn't just give those patients a voice; it also exposed providers to a perspective they may be assumed that they understood, but in reality didn't fully grasp. Catherine Galton, CEO of Health Care Insurance Reciprocal of Canada, and Phil Hassan, former CPSI CEO, explain.

Catherine: [00:07:58] One of the biggest movements, I think, is actually having patients be part of our team. We would have thought, "Of course they are part of our team," and yet, they were not. We always felt we were doing the best thing for them as opposed to the best thing with them.

Phil: [00:08:17] Clearly, we have to understand these things from the patient's perspective. Patient Safety is about the patient, and suddenly gave permission to staff to understand that they could engage the patients into this kind of effort. And when they did, they found out that they learned a lot.

Narrator: [00:08:37] Right in the middle of that relationship between patient and provide is this question of disclosure. When harm in the health care industry occurs, how do you handle the discussion that follows? Can you formalize it in some way, instructed by research, to make it more beneficial to both and to prevent further harm? When we look at the timeline and the achievements of CPSI, the work done on this subject, the subject of disclosures is pretty important. Kristina Kruse, CEO of B.C. Patient and Quality Council, and Glen McRae, executive director for Interior Health Quality Patient Safety, explain.

Kristina: [00:09:14] I would say two of the most pivotal moments that Canadian Patient Safety Institute has had in this country has been the publication of national guidelines for disclosure and the National Safer Health Care Now campaign. So disclosure is really about providing an accurate understanding to patients, to families, to caregivers when harm occurs in their care.

Glen: [00:09:40] When I started teaching disclosure, you know, 15 years ago, formally as a patient safety manager, our conversation was around convincing people that they should disclose and why they ought to and all the reasons why they should. We don't have to have that conversation anymore. We're not convincing people to do it; we're convincing people that there's a way to do it well and to share some advice and experience. So that's a huge change from trying to protect a story to ensuring the patient or family gets that most accurate understanding of the care they received.

Kristina: [00:10:14] So those guidelines really outlined what the aims are of an effective conversation, but also how do you do it and how do we ensure that people really know what happened in their care and get that apology? And then also, how do we then advance care so that it doesn't happen again? And those guidelines really form the foundation for policies, for approaches across this entire country, and sort of level set so that we all could ensure that Canadians have that experience when harm occurs.

Narrator: [00:10:46] The laundry list of major milestones and projects undertaken by CPSI could reasonably fill this episode, could fill a feature-length documentary, which it did, which is where we're getting a lot of our audio for this episode. It's called Building a Safer System, and you can find it on CPSI's YouTube page. There's Safer Health Care Now, a series of interventions for frontline health care workers; there's CPSI's national strategy. But I think that our time might be better spent looking at maybe the big-picture stuff, the cultural shifts that CPSI helped spark, that changed how we talk about patient safety, how we tell stories about it, how patients interact with health care, and how providers interact with patients. We're going to talk about that impact and culture after this break.

Narrator: [00:11:35] Silence can be confusing. During your virtual medical appointment, silence could indicate to your health provider that you have nothing to... even if what you really want to say is... and... oh, and... Always speak up whether you are online or on a phone call. Conquer silence for your health. This message brought to you by the Canadian Patient Safety Institute. ConquerSilence.ca

Donna: [00:12:04] The most significant accomplishment for CPSI, from my perspective, is actually spending time and energy on listening to the voices of the patients, or as I call it, the customers. So it's the Patients for Patient Safety. It's the health care workers delivering patient safety. It's the public who demand patient safety. So when we put customers or patients or families, health care workers, in the centre of everything we do, that really speaks to what patient safety is all about. And CPSI has done that beautifully.

Doug: [00:12:46] The issue, I think, was listening to people who we are serving. So the cultural change is actually awareness, wanting to listen and shifting from, "This is all about me who happens to be a doctor doing something," to, "You as a patient for whom I am doing something where I'm offering something that's relevant to you, that's respectful of you, and is appropriate for whatever your medical need is." That's the cultural change.

Narrator: [00:13:18] That was Donna Mernihan, dean of nursing at Thompson Rivers University, and Dr. Doug Cochrane, former board chair, CPSI. This all brings us to storytelling. When we look at CPSI's impact, it's the narratives, the lived experiences of patients who experienced harm in health care that played such a significant role, probably because they remind us that on the far side of all those startling and important statistics, there are real people. Those people's stories represent a powerful tool for advocacy and change. CPSI's CEO Chris Power; Senior Director of strategic communications Cecilia Bloxham; and Dr. Ward Flemons, medical director, Health Quality Council, told me about those stories, the kind of stories that we've tried to tell on this show, the kind of stories that CPSI has been telling for years.

Chris Power: [00:14:12] I think probably one of the biggest things I've learned is the power of story, to just listen to what individuals have to say to you. When we listen to patients who've been involved in harm, unintended harm from the health care system, when we listen to providers, those who are providing care, who have unintentionally harmed people, it is so powerful and we learn so much. And it really helps guide us to what we need to do to improve patient safety.

Cecilia: [00:14:42] To be able to spend time with people who have lost a loved one due to harm in health care or they themselves have been harmed, it immediately reminds you why we do the

work that we do. And to be able to be exposed to the vulnerability, the courage, and the hope that each of those members of Patients for Patient Safety Canada shared with me will be something that I'll take with me for the rest of my career.

Ward: [00:15:07] Patient stories are actually the fundamental groundwork. And you have to be able to tell them. Even when they're challenging, even when they're tragic, you have to be able to talk about them.

Chris: [00:15:16] You know, when they tell their story to politicians, when they tell their story to people who are working in health departments across this country, it touches their heart. It's not just something they're reading or it's not just data or information. This is real. So it's so, so powerful. And it's become such a major part of what we do at CPSI.

Narrator: [00:15:37] An important part of the work done at CPSI. Any discussion of storytelling always raises the question of audience. CPSI has a lot of built-in audiences: there is health care providers, policymakers. But a big shift came in expanding the scope of that audience. Chris Power explains.

Chris: [00:15:57] So I would say one of the most significant contributions – and you know, there's so many that have happened – but one of the ones that really sticks out for me is we had the privilege to develop a new strategic plan for CPSI. And we knew that what CPSI had been doing over the last number of years was amazing work, but it wasn't getting us far enough; it wasn't raising the bar on patient safety. So we took a bold new direction and we decided that we needed to continue to do some of the things we were doing, but also branch out and to do some different things. And so one of the things that we did is we branched out and we went public. Our work before had been primarily with care providers within the health care system, but we thought, “You know what? We need to do more than that.” So we reached out to patients. We'd always worked with patients, but this time broader, to the public, to really awaken them to what the state of patient safety was in this country. We reached out to policymakers, to regulators, to politicians, so in a very different way. For me, that was a significant contribution and something that I think will set patient safety in really great stead as we move forward on our journey.

Narrator: [00:17:14] There's a tricky issue at the heart of storytelling and patient safety, and it concerns data. You see, most data covers issues and instances of harm in the health care system. But as Dr. Glen Macrae and Virginia Flintoff, manager, central management team at CPSI, explained, safety is more than just the absence of harm. And generating data on the presence of safety presented some interesting challenges that CPSI had to overcome.

Glen: [00:17:44] So one of the things I'm most proud of is some of the current work we are doing with CPSI around the measurement and monitoring for safety framework. As someone who's been working in the patient safety field for years, formally for the last 16, we struggled to have this conversation about what patient safety was and what it wasn't. And we likened it always to the idea that health is more than the absence of illness, so safety has to be more than the absence of harm. But the data we had easy access to was all harm data. And so what we were able to do by participating in the most recent MMSF work – measurement and monitoring for safety framework work with CPSI – is we were able to do two things. One is we redesigned the whole way we describe safety up to the board through our senior executive using the dimensions in the MMSF, which is more than just past harm. And we also then took that same model and had local teams using it in the operating room or even in our concerns management work. And the reason I'm proud of it is it allows us to start bringing the patient voice, the narrative, the storytelling that we've all been talking about for so long as being critically important to understanding quality, and it gives us almost a permission to stand and tell it.

Virginia: [00:18:57] What measurement and monitoring of safety did? We introduced it at the bedside with a core team of frontline worker, middle manager like a head nurse, a physician, and a senior leader. And those four people would come, learn the concepts of measurement and monitoring of safety, and take it back. Once we told them and convinced them not to rush this, and they became familiar with how to implement the conceptual model of measurement and monitoring, it changed the way the staff took responsibility.

Narrator: [00:19:46] Which brings us to today and the organization's next steps.

Woman: [00:19:51] The amalgamation with the Canadian Foundation for Health Care Improvement, to me, is absolutely the natural next step. We are two very small organizations. There have been three federal reports. All three of them said we shouldn't be standalone. Work is hugely important, but too small to really make an impact in the kind of way that we should. I know that with the combined strength of these two organizations and combined resources, we can be so much better. The impact can be so much greater than we can alone.

Narrator: [00:20:24] We wanted to wrap up this last episode of Canadian Patient Safety Institute presents *Patient* by looking forward to what comes after Canadian Patient Safety Institute. As we mentioned at the top of the episode, CPSI and the Canadian Foundation for Health Care Improvement are going to be amalgamating. What they will be called, their first order of business, all of this is up in the air. But what we know is that the well-being of the patient, their safety, is going to continue to be the foundation on which this national group's efforts will be built.

[0:21:03] I want to wrap up with a thank-you to CPSI for empowering us to tell these stories across the three seasons of this show. And I think I want to give the last word to former CEO Hugh MacLeod because I think he captured really beautifully how we should think about the impact that CPSI has had and the impact of what comes next.

Hugh: [00:21:25] Our imprint, the CPSI imprint, is not a single imprint from a single board member, a CEO, or a single director; our imprint is thousands of handprints on the patient safety landscape in Canada. I would hope in the future the combined organization will be a thousand fingerprints of the staff of CPSI, the staff of the existing organization, and whatever comes next.

Narrator: [00:22:03] Thanks for listening.