

Use of Patient Reported Outcome Measures for symptom management

Ontario Health
(Cancer Care Ontario)

Ontario, Canada



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Summary

Ontario Health (Cancer Care Ontario) is the primary cancer advisor to Ontario's government. Its mission is to equip health professionals, organizations and policy-makers with the most up-to-date cancer knowledge and tools to prevent cancer and deliver high-quality patient care. Since 2007, it has been collecting Patient Reported Outcome Measures (PROMs) data to enable patients to report symptoms in real time, improve clinical response and engage patients in self-care. With the largest PROMs dataset in Canada (as of January 2021), Ontario Health (Cancer Care Ontario) is using analytics to inform care improvements on a patient and population level. The data is also used to inform policy and planning at the system level, including development of patient and clinician symptom management resources, and patient education and self-management tools.



The key problem that required a solution

Natalie Coburn, Clinical Lead for Patient Reported Outcomes and Symptom Management, described the need that catalyzed interest in this project: "Around 2005, there was a report looking at palliative services and how well we were supporting cancer patients through their cancer journey. We recognized that we were not doing as good a job with symptom management as we wanted to do." This was echoed by Christine Peters, Regional Oncology Lead for Patient-Centered Care: "We asked ourselves, 'how do we shift the system to be responsive to that need, that experience and the symptom burden of patients?'" This recognition led to a pilot study in the southeast region of Ontario that looked at PROMs as a way to screen patients for symptoms and point them to the right services. Based on the success of that pilot, Ontario Health (Cancer Care Ontario) initiated a rollout across the 14 Regional Cancer Programs in the province.

Aims of the new system

Ontario Health (Cancer Care Ontario) identified an opportunity to bring the patient's voice into decisions about care pathways and symptom management. PROMs provided a scientifically tested, robust method to systematically screen patients and encourage conversations with their clinicians about relevant symptoms and how to manage them. Standardized collection of PROMs data across the province allows Ontario Health (Cancer Care Ontario) to aggregate information at a hospital level and share this back with each of the 14 Regional Cancer Programs. This way, hospitals can learn about their patients' symptom burdens and share insights with each other.



Innovation description

Context/background

In 1943, the Province of Ontario created the Ontario Cancer Treatment and Research Foundation, which was transformed into Ontario Health (Cancer Care Ontario) in 1997. Now part of Ontario Health, the organization aims to collect and analyze data about cancer services, combine it with evidence and research, and share this with the health care community in the form of guidelines and standards. It also monitors and measures the performance of the cancer system across Ontario, ensuring that patients and their families are engaged in its design, delivery and evaluation.

Innovation components/approach

Ontario Health (Cancer Care Ontario) required adequate infrastructure to support the collection of PROMs data across the province. The data collection system had to be built internally to meet the organization's specific needs. "It's our patient data, and it has their personal health information. That was one of the big decision factors in terms of building our own system. We wanted to own our data and make sure that we were responsible for the privacy and security components of the tool," said Colleen Fox, Director of Person-Centered Care. The system they built for this purpose is the Interactive Symptom Assessment and Collection (ISAAC) platform.

Patients from the 14 Regional Cancer Programs are asked to input their data into ISAAC prior to each encounter with the care team. They can do this via an onsite kiosk or tablet, or from their personal device through a recently launched URL link. The data is shared with the patient's care team for discussion during the visit, either electronically or through a printed sheet.

The data is also collected centrally by Ontario Health (Cancer Care Ontario). Aggregated PROMs data moves from ISAAC into a central analysis hub, the Activity Level Reporting (ALR), where all patients' records from the 14 Regional Cancer Programs are also stored. PROMs are processed within ALR by Ontario Health's (Cancer Care Ontario) analytics team. "Each patient has health card information (i.e., health card number ID), ISAAC information. This means that PROMs data ultimately can be linked to other tables available in that data structure and also other administrative databases," said Narges Nazeri Rad, Team Lead & Methodologist.

Ontario Health (Cancer Care Ontario) also manages the process of trialing and adding new PROMs to the screening tool. Richard Smith, Director of Product Management, described this process: "First, there would be a clinical team that works with us to understand the benefits of including another PROM. That would really be clinically driven; typically, by our provincial clinical leads. There could be a small team that is

representative of the type of PROM that is under consideration, who would provide input on it. Quite often, the new PROM is generated by evidence, meaning that it could be in use somewhere else. Looking at publications and research documents, the clinical team determines that it might be something that would be good for us to collect as well in Ontario. There definitely needs to be a use case, either supported by evidence or by a physician's need to collect this information, which would be related to improving the outcome of a particular patient. That definitely needs to be part of it before we would even look at it and engage the technology team. After that, we would implement the technical changes to actually include the PROM in the screening tool. And then the provincial clinical leads would work with the community to actually roll it out and encourage its use."

PROMs inform clinical practice, enhance person-centered care and are used in health services research, performance management and quality improvement. Specifically, the collection, processing, storage and management of PROMs data by Ontario Health (Cancer Care Ontario) has enabled improvements at the individual, hospital and system level. At an individual level, PROMs have been used to enhance communication between clinicians and patients about symptom management and health-related quality of life.

At a hospital and regional level, aggregate PROMs data is used to monitor and compare patient outcomes, and can help identify patients in need of further support. Data used at the hospital and regional level also informs local models of care to support symptom assessment and prioritization. At a system level, Ontario Health (Cancer Care Ontario) uses PROMs data for performance management and quality improvement, with the ability to compare outcomes across regions and settings. Data is also used for performance management on its cancer system scorecard.

PROMs data has allowed Ontario Health (Cancer Care Ontario) to influence policy through evidence-based insights, leading to system-level improvements for clinicians and patients. Guidelines on symptom management have been updated using information from PROMs data, and patient education and self-management resources have been developed. Furthermore, the dataset is made available for research, leading to dozens of academic publications on the use of PROMs for symptom management.

Target population

Ontario Health's (Cancer Care Ontario) purpose in collecting PROMs is to encourage conversations between clinical teams and cancer patients about symptom management. The expectation is that this will lead to improved care and quality of life for the patient, and reduced symptom burden.

Key stakeholders

There are many stakeholders involved across the system in the development, collection and analysis of PROMs data for symptom management. Key stakeholders include the following:

- ▶ Patient and family advisors (PFAs)
- ▶ Ontario Health's Ontario's Person-Centered Care team
- ▶ Ontario Health's Product Management team
- ▶ Regional vice presidents, regional directors and oncology leads for Person-Centered Care across the 14 Regional Cancer Programs
- ▶ Analytics, informatics and IT teams (including ISAAC and ALR teams)
- ▶ Legal, Privacy and Data Security teams



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Evidence of impact

There is wide evidence in the secondary research that symptom management can improve patient care and outcomes. For Ontario Health (Cancer Care Ontario) specifically, the impact of this program is demonstrated by an improved patient experience, better matching of needs and services, and wider adoption of PROMs beyond cancer care.

At a patient level, the adequate use of PROMs for symptom management can significantly improve the experience of care. Joanne MacPhail, cancer survivor and PFA representative, recounted how, one day when she was feeling particularly bad, she flagged this in the questionnaire: "I answered 9 across the board - the highest score you can give is a 10, which is the worst possible situation for you. Due to entering this high score, my oncologist and nurse promptly addressed my concerns and got me some help for the extreme pain I was in at the time."

An example of better matching of needs and services was found in head and neck cancer patients. "Head and neck cancer patients were showing very high symptom burden through the scoring on our PROMs. That helped us to establish some organizational guidelines and standards on minimum care requirements. For example, all head and neck patients should have access to a dietician and should have access to a speech language therapist.

Having that data and being able to use it has actually enabled changes to the care that's provided to patients," said Colleen Fox.

Further evidence of Ontario Health (Cancer Care Ontario) success in using PROMs is that areas outside of oncology, such as hip and knee replacement surgery, have implemented similar programs and look to Ontario Health for guidance and implementation support.

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Colleen Fox
Director, Person-Centered Care



Key challenges

Ontario Health (Cancer Care Ontario) has faced multiple challenges in developing, launching and maintaining its PROMs program for symptom management. These challenges include meeting patient's expectations, securing staff buy-in, regulation, funding, accessibility, development time and data security.

- ▶ **Meeting patient's expectations:** Joanne MacPhail described what happens when patients feel they are reporting important data but it's not changing their care: "To me, when the doctor doesn't pay attention to it, I feel like he's discounting me, he's not listening to me, and I feel discounted and frustrated. I think that a number of patients feel that way. They figure 'why am I taking the time to come to the cancer center early and complete this if the doctor's not going to pay attention to it?'"
- ▶ **Securing staff buy-in:** this was identified as the main, continued challenge that the Ontario Health (Cancer Care Ontario) team faces in the use of PROMs data for symptom management. If staff do not use the insights from the screening, patients may become frustrated with a system that is not responsive to the symptoms they are reporting, as identified above. Interviewees for this case study identified several challenges to staff-buy-in, including limited flexibility of PROMs, varying views on the value of the tool and a lack of local ownership.

Because PROMs are a validated tool, there isn't scope for changes or personalization of the measures in each center. "You've got to use the PROM as the PROM is written, and no one likes the PROM as it's written. Everyone wants to say, 'well, can we just add this, or take away that, or change this word?' When you pick a PROM and you want to put it across the entire population so that everything is comparable, you've got to get everybody to like the same PROM, and that is impossible. Some center is not going to be happy, or some group of physicians is not going to be happy," said Natalie Coburn.

Once PROMs are rolled out, there are varying levels of uptake from clinicians. "I hear different things, some heavily rely on it. Others tell patients not to do it. They feel that they are able to capture the patient's experience without the use of this data. Definitely I would say uptake from the clinicians can be a challenge, and I know outside of PROMs, most clinical screening tools aren't well received. Clinicians generally feel like they have those skills. I would say that's a major challenge," said Christine Peters.

Finally, Natalie Coburn believes that the top-down approach to rollout may have led to issues in frontline staff's sense of ownership and buy-in: "Because it was a top-down initiative,

you didn't get that grassroots desire to do things, and the centers don't have the same feeling of ownership over the program because it came top-down. The same thing that makes it successful is also one of the biggest problems with it."

- ▶ **Regulation:** Colleen Fox described the hurdles Ontario Health (Cancer Care Ontario) had to overcome in the initial phase of this program: "In the early days, from a regulation perspective, we did have to go through many hoops to be able to actually collect, acquire and use the data from a privacy and legal perspective. Within Ontario, we are governed by the Personal Health Information Protection Act. We had to work within that and show all of the safeguards that we were putting in place. It was a challenge just in terms of actually being able to collect all of this data and put the systems in place at the sites. But we have a dedicated privacy team who worked closely with us to help us through that challenge."
- ▶ **Funding:** all interviewees agreed that funding is always a challenge. Recently, Ontario Health (Cancer Care Ontario) was integrated into the Ontario Health agency, which led to some internal resource realignments.

Programs such as PROMs can highlight the need for support services that are often deprioritized when funding is stretched. In Natalie Coburn's view, "If you have to choose between funding a drug or funding psychosocial support, you will have to go with the drug because it's going to cure the cancer, and then psychosocial support always is going to be like the poor cousin. It's not going to get the top-tier support like provision of the surgery or the radiation, or the drug, and there's a limited funding bucket here, so it's difficult to make those decisions. I think to Ontario Health's (Cancer Care Ontario) credit, they do think really holistically about how they're supporting the patients to get these things, despite the funding difficulties."

- ▶ **Accessibility:** Ontario has a very diverse population, with a mix of urban and rural locations. Cultural differences, language barriers, travel distances and differences in digital skills can lead to access limitations for certain groups. "For ease, we started with English and French. From a patient perspective, having more languages and making it more accessible is one of the things that I think could have been helpful earlier on. We have quite a diverse population, especially in certain areas of Ontario. If it's only available in certain languages, that's challenging. We do have paper copies available in other languages and they can be uploaded on the backend by the hospital, but I think that's an ever-present challenge: trying to consider health equity and what we can try to do to make sure that the system is built for everyone," shared Colleen Fox. The team has also found that there are gaps in data reported by the LGBTQ community and Indigenous populations.

- ▶ **Development time:** as with many innovations in health care, the time to design a pilot and assess efficacy has been a challenge. "In Ontario, a [PROMs] pilot will often take two years, and I think that can be a frustration for the regional leads. We see this great opportunity but often it takes a two-year pilot, and of course you want to do it right, but I think finding that balance between being responsive to the needs of the system and perfecting the system, it can be a tough balance. I think that can lead to some frustration from leadership," said Christine Peters.
- ▶ **Data security:** due to the sensitive nature of PROMs data collected by Ontario Health (Cancer Care Ontario), it is of paramount importance that the data remains secure at all times. Richard Smith explained: "You need to make sure that the data is secure. Once you have it stored and it's secure, when it's being used for analytics, you need to make sure that it's properly de-identified and used for a specific purpose. There's a lot of responsibility that comes with using tools and collecting highly sensitive patient information." Furthermore, security needs to be considered when data is shared back with sites in the form of reports. Patient IDs and cancer center locations are sometimes not reported correctly in the data that Ontario Health (Cancer Care Ontario) receives. Narges Nazeri Rad suggested that the organization must be very cautious about ensuring that data is only reported back to sites if it is relevant to their own patients, as reporting errors could lead to privacy breaches.

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Richard Smith
Director, Product Management

Key enablers

Ontario Health (Cancer Care Ontario) has taken key steps to ensure the success of PROMs use for symptom management. These include providing staff support, securing leadership buy-in, engaging patients, multidisciplinary collaboration and a robust information governance system.

► **Providing staff support:** to address some of the staff buy-in challenges, the clinical team for PROMs visit the sites and try to address their concerns. Natalie Coburn described her approach: “If there are issues, if there is a cancer center that says, ‘we really don’t like this, we find it is a burden, we don’t think that this is important, we’re not going to do it anymore,’ then I will go sit down with them and say, ‘OK, well, let’s talk about it. What are the problems? What are the structural issues that you’re having, getting patients to utilize this?’ And sometimes it’s something as simple as, ‘we don’t have a printer in the right place.’ For many years, we would go out to the centers and say, ‘well, let’s look at how you’ve got everything laid out. Let’s look at how you’ve got check-in. Let’s look at who’s advising the patients on using this.’ A lot of times, it’s just a matter of going out and talking to them and saying, ‘OK, well, we’re not collecting this data for hoarding purposes. Really, the purpose is for you to sit down and have a conversation with a patient, and here’s how

it helps. We have randomized controlled trial data that shows that if you intervene on these symptoms, patients live longer.’ It’s just having someone go out and talk to the providers and the nurses is usually all that it takes.”

► **Securing leadership buy-in:** Ontario Health (Cancer Care Ontario) benefited from clear and supportive leadership in its development of the PROMs program. Colleen Fox describes how this helped the development and how they used the patient voice to engage leaders in their vision: “You need to get buy-in from leadership. It’s fine for me to stand up and say, ‘we need to do this because patients have a high symptom burden and we need to manage it.’ It’s very different when you hear a patient come up and tell their story, and explain the series of events that they’ve gone through and how it’s impacted them. When they say either, ‘this could have benefited me,’ or, ‘this system was in place and this is how it helped me,’ that’s been very powerful for us, for leadership buy-in.”

Once buy-in had been achieved from the top, visible frontline leadership helped launch the project and create a shared vision among staff. Christine Peters describes one particular leader from the initial phase of the project: “We had a provincial head who oversaw a few programs, most

prominently nursing, and she really was a driving force for this. She was in a leadership role. She saw the importance of it. She talked to patients, who were certainly also a part of that driving or championing role. She really was a rallying force, not only internally in the organization to get something set up, but also more forward-facing with the hospitals that are delivering cancer services.” They now have clinicians and leaders across the organization who are champions of the program and continue to drive this vision.



- ▶ **Engaging patients:** the success of the PROMs program begins with patients taking the time to fill out the screenings ahead of their consultations. Without patient buy-in, the program would collect no data. Ontario Health (Cancer Care Ontario) is acutely aware of this and has included patients at all levels of development of the program. Joanne MacPhail described how patient engagement was a key success factor for Ontario Health (Cancer Care Ontario) more broadly: “I think it’s their engagement of patients and families, caregivers, right from the get-go and continually having our input. There is no initiative, no committee that does any work without at least two patients and caregivers at the table. They’re always sending updates. They’ve added, in recent years, Your Voice Matters, and that gives us an opportunity to answer questions regarding our experience and our care.”
- ▶ **Multidisciplinary collaboration:** Colleen Fox described the multidisciplinary nature of the stakeholders involved in the PROMs program: “It involved a lot of other people, our legal team, our privacy team (to make sure we could actually collect, store and use this data), the technical services team (who developed the ISAAC product and run it), and our data and analytics team (who then get the data and do all of their wonderful work with it to help us with our system planning). A lot of internal teams really had to come together in order to roll out PROMs and ensure it continues to be sustainable within our system. From a frontline perspective, we involved regional leadership to ensure that we had their buy-in. We did a lot of work with clinicians as well, not only from a training perspective, but also making sure that they understand

the reason for collecting PROMs.” To ensure that all voices are heard, Ontario Health (Cancer Care Ontario) has also established multiple advisory committees, such as the Ontario Cancer Symptom Management Collaborative and the Patient Recorded Outcomes Advisory Committee.

- ▶ **Robust information governance:** Ontario Health (Cancer Care Ontario) has the status of prescribed entity, which allows it to use personal health information for planning purposes. This allows it to use PROMs data to inform policy and planning decisions, but requires adherence to strict data management and security protocols. This includes establishing a robust information governance structure to ensure that there is accountability for the collection and use of PROMs data. Ontario Health (Cancer Care Ontario)’s accountability agreements with each hospital describe exactly what data fields are collected and why.

Ontario Health (Cancer Care Ontario) also follows strict protocols for any changes made to the system. When a new PROM is introduced, for example, it goes through a risk assessment, a privacy impact assessment, and several other checkpoints and procedures. This means the process takes longer, but it ensures that data is secure and used appropriately.



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Future plans

While the original intent of the PROMs program was to encourage conversations between patients and clinicians, its success has led to a valuable data asset accumulated over time. “I think it’s a phenomenal program. It’s an amazing amount of infrastructure that was set up to get the same question asked of all patients across an entire population, and I think we’re just beginning to realize the potential of what we can do with it, in terms of looking at how we’re supporting patients and where we should put better supports,” said Natalie Coburn.

The team also identified opportunities for the use of data analytics in the wake of the global pandemic. Richard Smith highlighted opportunities to use linked datasets to understand the impact of the pandemic not only on COVID-19 patients but also on other areas such as mental health and cardiovascular conditions. Colleen Fox stated that the move to virtual care is having a direct impact on how patients submit their PROMs data: “The transition to virtual care really changes how the visits are taking place, but then also how patients can even screen for their symptoms. We do have a URL that you can access from home, but historically, it’s always been done in the center when you’re seeing your clinician.

Most cancer care is done in person, not virtually. There’s a big shift in moving to that virtual care environment. We need to try and be emboldened and meet that challenge.”

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Natalie Coburn
Clinical Lead for PROMs



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- ▶ Narges Nazeri Rad, Team Lead & Methodologist, interviewed on 19 November 2020
- ▶ Joanne MacPhail, Patient and Family Advisors representative, interviewed on 20 November 2020
- ▶ Christine Peters, Regional Oncology Lead for Person-Centered Care, interviewed on 20 November 2020
- ▶ Richard Smith, Director, Product Management, interviewed on 23 November 2020
- ▶ Natalie Coburn, Clinical Lead for Patient Reported Outcomes and Symptom Management, interviewed on 25 November 2020

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