

## Ottawa: a patient partnership engine

An OR Black Box® to improve surgical outcomes, a patient navigator for Francophones and a matchmaking service for researchers and patient partners show that Ottawa is 'walking the talk' in patient partnership in research. Home to two OSSU Research Centres and more than half a dozen OSSU-funded research projects, Ottawa is a hotbed of patient partnerships in research. Read the highlights in this latest OSSU update and the full stories [online](#).

### Out-of-the-box thinking

An innovative project that brings aviation expertise to the operating room engaged patients from start to finish to ensure success.

Just like on airplanes, The Ottawa Hospital now has a "black box" in a surgical operating room that records conversations, captures video, monitors patients' vital signs and more. The research project, led by anesthesiologist [Dr. Sylvain Boet](#), aims to determine how to make surgery safer and more efficient by understanding where errors occur.

**"We are lived experience experts and it's that expertise that is important"**

The Ottawa Methods Centre, an OSSU [research centre](#), worked closely with Dr. Boet's team, providing expertise in patient engagement, recruitment, grant review support and more.

Laurie Proulx, a patient at The Ottawa Hospital, became involved in the OR Black Box® project while recovering from surgery in late 2017.

Imagine being a patient, nervous about surgery, who hears that your surgery may be recorded. How do you explain this to a patient? That's where Laurie and the other patient partner in the project came in: they helped the research team determine the best way to explain the black box to surgical patients.

"The research team had done interviews with 15 surgical patients and coded results then presented the information to us," explains Laurie. "They wanted to leverage the experience of a patient having surgery: you are nervous, what do you really



Dr. Sylvain Boet using OR Black Box® technology

The Ottawa Hospital

want to know? We came up with key messages – short, simple materials such as



Laurie Proulx, patient partner

The Ottawa Hospital

your data is safe, this is the technology, your information is confidential, we will use the information to improve surgery, and there is always the option to opt out for both patients and staff."

She also helped design an information pamphlet and poster for patients, ensuring they were relatable and clear. Laurie is also a patient engagement ambassador, presenting at the SPOR Summit and the Surgical Safety Network about the value and practice of patient engagement.

"We are lived experience experts and it's that expertise that is important," says Laurie. "Researchers have experience but we do as well because we have lived medical experiences that have gone well and some not so well with errors. I hope to bring those positive and negative experiences to research."

[Read more.](#)

### Francophone patient partners bring insights to health system navigation

Simone Dahrouge, from the Bruyère Research Institute in Ottawa, is the primary investigator on an [OSSU IMPACT Award](#) assessing how patient navigators may help Franco-Ontarians access community services and achieve their health goals. Simone spoke to us about the value patient partners bring to her research.



*"Although we've all been patients or caregivers, we need to involve that group in our research because that's not the hat we wear at the table. We think of things from our professional perspective. It's the patient partners' role to bring the service users' perspective. They have rich lived experiences, and bring diversity to the table. Their insights in shaping our navigation program definitely contributed to its success."*

*"Not having services in your language of choice is definitely problematic. This is the reality for many Franco-Ontarians. You can miss the nuances, and this can compromise care. The more the care you need relies on communication, such as in mental health, the bigger the barrier. There is also a cultural component. There is a sense of belonging when getting services in your own language; it's easier to form that rapport with the provider. If you are sick and not in your comfort zone, it can be especially stressful. Our patient partners bring this valuable perspective to the research."*

### Blood cancer trials benefit from patients' lived experience



Drs. Manoj Lalu and Dean Fergusson, GO CAR-T cell clinical trial investigators

A novel approach to clinical trial design that integrates patient partners with leukemia may help Canadians with blood cancer. [Read](#) about how the GO-CART clinical trial protocol for life-saving therapy at The Ottawa Hospital — and an OSSU EMPOWER award recipient — partners with patients for success.

# It's in the DNA



**Like threads in woven fabric, patient engagement** is becoming firmly entrenched at The Ottawa Hospital.

"It is becoming part of the hospital's DNA," says Dean Fergusson, head of the Ottawa Methods Centre, OSSU's Scientific co-Lead and a key advocate for patient engagement in research at The Ottawa Hospital who has championed this cultural shift.

Central to this culture change is CIHR's Strategy for Patient-Oriented Research (SPOR) [framework](#), combined with OSSU's leadership in moving the bar for researchers.

"SPOR provided a formal structure for patient engagement at the Ottawa Hospital Research Institute," says Zarah Monfaredi, SPOR Program Facilitator, Ottawa Methods Centre. "OSSU and SPOR gave the foundation for us to support research teams engaging with patients for the first time. When teams are looking for examples of engagement in practice, OSSU's IMPACT awards are fantastic case studies to share."

A key partner is Claudia Hampel, the hospital's first full-time patient engagement manager. She and Zarah work together to break down silos, integrating patient engagement into clinical and research activities, using a framework codesigned by the Patient and Family Advisory Council (PFAC) along with Zarah and the previous manager.

Support at the senior level has been critical to the team's success.

"We also had full senior leadership approval of the program with board approval of the patient engagement framework," says Claudia. "Everyone is dedicated to it at the senior level."

Over the next two years, Claudia will support staff to adopt SPOR principles, with patient and family advisors helping staff to become comfortable with engaging patients in research. There is this incredible support system in our province and we are so lucky to have it," says Zarah.

Read the full [article](#).

## CHEO's matchmaker



Michelle Quinlan, CHEO "matchmaker"

**A matchmaker between researchers** and community members is how Michelle Quinlan describes her role at CHEO.

Since November 2017, Michelle has been the inaugural Research Family Leader Program Co-ordinator, a position created by the [Ontario Child Health Support Unit](#) (OCHSU), an OSSU Research Centre.

Charged with embedding patients/family members as Family Leaders on research teams, she is clearly having success. As a service for researchers, she ensures that screens in the hospital feature messages asking, "do you want to have family members involved in your research?" She then determines needs for the type of patient engagement on the research project, such as a Research

Project Reviewer or a Research Project Advisor.

In 2019, 54 engagement requests have been completed or are in the queue, including the Care for Rare genetics program, mental health, robotics and research, complex care and more.

There is a waiting list for researchers to present to the [Patient and Family Advisory Council](#) (PFAC) for advice on their projects. "There is an obvious appetite for researchers to come to PFAC for advice, and the feedback from research teams on the value of these consults is always positive," says Michelle.

Perhaps because CHEO is a children's hospital, youth are keen partners in patient engagement.

"A surprise that I would call a success is the interest from youth," says Michelle. "The appetite from youth with lived experience is really interesting, perhaps some have an interest in medical school and some want to give back. We have 16, 17, 18-year-olds who are either patients with recent experience at CHEO or some whose siblings have been involved in research."

Read [more](#).



Dr. Denise Harrison, lead researcher, and Yiyian Zhou, patient partner in the OSSU-funded ONesIE study who were matched by Michelle

## NEWS



Congratulations to **Dr. Diana Urajnik**, the new director of the Centre for Rural and Northern Health Research ([CRaNHR](#)), an OSSU research centre.



Kudos to McMaster University's **Dr. Michael McGillion**, Associate Professor, School of Nursing and a champion for patient partnership with OSSU's Research Centre at [PHRI](#). He was named a 2019 McMaster University Scholar in recognition of international impact in research and excellence in innovation in teaching and learning.

Congratulations to three new Tier 2 Canada Research Chair (CRC) recipients in the OSSU family!



**Dr. Nav Persaud**, St. Michael's Hospital, who leads an IMPACT Award on [essential medicines](#), is a CRC in Health Justice.



**Dr. Tara Gomes**, lead at OSSU research centre [Ontario Drug Policy Research Network](#), St. Michael's Hospital and an ICES scientist, is a CRC in Drug Policy Research and Evaluation.



**Dr. Noah Ivers**, an IMPACT Award recipient and researcher at Women's College Hospital, is a CRC in Implementation of Evidence-based Practice

## Clinical trials boost

Congratulations to the Ontario recipients of CIHR SPOR Innovative Clinical Trial (iCT) Catalyst Grants. This [initiative](#) aims to build capacity and increase the intensity of iCT research.

- Dr. Lora Marie Giangregorio, University of Waterloo, Waterloo
- Dr. Paul Karanicolas, Sunnybrook Research Institute, Toronto
- Dr. Cynthia Lokker, McMaster University, Hamilton
- Dr. Jonathon Maguire, St. Michael's Hospital, Toronto
- Dr. Nicole Obeid, CHEO Research Institute, Ottawa
- Dr. Patricia Parkin, Hospital for Sick Children, Toronto
- Dr. Jennifer Stinson, Hospital for Sick Children, Toronto

## Upcoming Events

### Sep 9 – Nov 25

Virtual Masterclass, McMaster Health Forum, via Webex

### Jan – Mar, 2020

Virtual Masterclass, McMaster Health Forum, via Webex

### Oct 3 – 5, 2020

1<sup>st</sup> North American Conference on Integrated Care, Toronto

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