

OSSU Launches Comprehensive Patient-Oriented Research Collection

Does engaging patients in research projects improve health? A comprehensive collection of 17 innovative OSSU-funded demonstration projects – covering youth involvement in mental health services, suicide prevention, Indigenous health, children with complex medical needs and more – highlights the value of patient engagement in research.

Engaging Patients in Health Research: the Ontario Experience, a special patient-oriented research supplement in CMAJ (*Canadian Medical Association Journal*), features in-the-trenches experiences, tips and challenges from Ontario health research projects.

The collection, perhaps the first of its kind, is a practical resource to help researchers conduct this innovative research and informs the growing approach of engaging patients, caregivers, family members and communities as partners in health research. Available online and in print, the supplement includes an infographic and podcast with researcher/patient partner conversations.

“The innovative, collaborative approach of these projects underscores Ontario’s role as a leader in putting patients first and in seeking ways to improve patient health and health care delivery,” says Dr. Adalsteinn Brown, Chair, OSSU’s Board of Directors. “We expect that IMPACT projects will live up to their names, impacting how we deliver health care in future, from emergency services to mental health, hip fracture care to heart failure care and more.”

Across the projects, patients helped determine study outcomes, create plain language materials, advised on recruitment and more. Challenges included keeping patients engaged, ethics boards delays, regular communication and ensuring patients had the tools and skills



to fully participate. Practical tips include flexibility, need for a variety of patient roles, compensation and for researchers to understand and respect patient experiences.

Select highlights:

- **An essential medicines list** – to ensure diversity in this project to develop a list of free essential medicines, researchers canvassed people on the streets of Toronto as a novel recruitment strategy to attract participants.
- **Transporting patients with C-spine injury** – patient involvement helped identify broader outcomes including pain and discomfort, time spent in the emergency department and radiation exposure concerns.
- **First Nations diabetes project** – partnerships with Indigenous communities were critical, with Chiefs of Ontario as project co-leads, placing ownership and control of community data with the communities themselves.

“Engaging patients as partners makes them active, rather than passive, participants whose experience and ideas can enrich research projects,” says Frank Gavin, patient partner and OSSU board member. “We hope this publication will be a resource to anyone interested in conducting patient-oriented research.”

NEWS



Thank you to **Michael Decter** for his significant contributions to OSSU over the past 5 years as Chair of both the Board and the Strategic Advisory Committee.

“We are grateful for Michael’s vision and commitment in guiding us as inaugural Board Chair on our journey to make patient-engagement in research part of Ontario’s health research culture,” says Vasanthi Srinivasan, Executive Director, OSSU. “His leadership gave OSSU a successful start.”



Congratulations to **Dr. Michael Green** for induction into the prestigious Canadian Academy of Health Sciences (CAHS) Fellowship. Dr. Green,

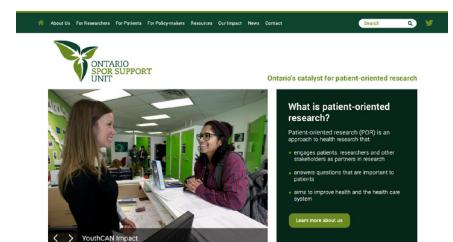
head of the Department of Family Medicine at Queen’s University, also leads the INSPIRE-PHC research program, an OSSU research centre, and received an IMPACT Award for research in Indigenous health.



After being asked to review a clinical update on adverse drug reactions submitted to *The BMJ*, **Frank Gavin**, a member of OSSU’s Board, Strategic

Advisory Committee and Patient Partners Working Group, was asked by the journal to turn it into an opinion piece published online November 6, 2018. Congratulations Frank!

New OSSU website – coming soon!



The Health Researchers' Sex and Gender Toolkit



The Health Researcher's Toolkit: Why Sex & Gender Matter

A new toolkit aims to help researchers enhance their work to include sex and gender considerations. Developed by Women's Xchange, an OSSU research centre, the Health Researchers' Sex and Gender Toolkit contains seven practical e-learning modules to help researchers.

Most research to date hasn't adequately represented women in health studies. Some diseases, such as heart disease, present differently in women. Caregiving, a role usually provided by women, is a gender issue that can impact health.

"I think it's essential because sex and gender has moved from something that people like to talk about to a must do," says Dr. Paula Rochon, lead of Women's Xchange. "The toolkit provides researchers with practical guidance."

As funders now require a sex and gender perspective in research, the toolkit is a practical way to enable this, from grant writing to publication and dissemination of findings. Patients were also engaged in the project – partnering on content, design and presentation.

"We want to make sure all research is thinking about sex and gender so that the findings are valuable for everyone and adds new insights to current research. It will give us so much information on things we haven't even thought about," says Dr. Rochon.

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A View From The North



Brimming with energy and enthusiasm, patient advisor Keith Taylor, a member of OSSU's Patient Partners Working Group, is tackling patient engagement in research at Thunder Bay Regional Health Sciences Centre. A volunteer for the past nine years, Keith is driven by commitment to patient partnership in health care, and now health research.

"I really believe in it and have passion for it," he says. "It's a fuzzy warm thing to do."

Keith has recently been involved with the Working Group's 'Ladders of Engagement' activity, a patient-developed, led- and delivered- project highlighting the different needs and wants of patients, caregivers and family members when engaging in research projects.

"It's unbelievable how hard it is to get patient engagement in research,"

he says. "It is so much harder than acute care."

Despite challenges, he sees progress: the hospital's research institute has assigned a staff person to focus on patient-oriented research.

"For anyone to change their philosophy, you need to prove there is a benefit," says Keith. "We did that in acute care. Now this is what we have to do with researchers which is harder. Projects are much longer and researchers are very different from clinicians."

He sees OSSU playing a critical role in advancing patient engagement in research with its resources, training and network of expertise.

"OSSU is leading the way in Ontario – I'd like to see patient-oriented research centred there. If I can go to OSSU for resources, it is easier."

National SPOR Summit



SPOR Summit 2018
Mapping the Progress of
Patient-Oriented Research in Canada

Conférence de la SRAP 2018
Le point sur les progrès en recherche axée
sur le patient au Canada



OSSU initiatives were in the spotlight at the recent 2018 CIHR SPOR Summit, "Mapping the Progress of Patient-Oriented Research in Canada", held in Ottawa. Several conference sessions celebrated Ontario's patient-oriented capacity building successes, featured

researchers from OSSU IMPACT Award projects and centres as well as several patient partners discussing patient engagement experiences.

Thank you to all patients and researchers who represented OSSU at the national Summit.

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