

OSSU UPDATE

Ontario SPOR SUPPORT Unit Newsletter



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Complex Care for Kids helps families navigate care



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"Let's ask," is the approach of the Complex Care for Kids Ontario research project that aims to help fragile children with complex medical needs. The OSSU-funded IMPACT Award will evaluate what works in caring for these high-need children by asking those involved in their care, from families to health care providers and government policy-makers.

Children with medical complexity make up 0.7% of Ontario's pediatric population but use $\frac{1}{3}$ of all child health resources. They are at risk of sudden hospitalization for life-threatening conditions and account for 49% of hospital days, 75-92% of health technology assistance and sadly, 43% of child deaths.

The Provincial Council for Maternal and Child Health is implementing Complex Care for Kids Ontario to improve province-wide access to integrated medical care for medically complex children. The research team will evaluate the impact of a key worker, who tailors personalized care plans for each child-family and works with the family to connect them to the right care, in the right place, at the right time.

"We hope to provide a highly robust scientific evaluation of what is working for children and families and to work with policy-makers to make this sustainable,"

says principal investigator **Dr. Nora Fayed**, Queen's University, Kingston, Ontario. "Essentially, we need to figure out what's working and generate the evidence to keep it sustainable."

The researchers hope to improve children's health while reducing the burden on caregivers and on Ontario's health system.

"We have a comprehensive evaluation framework (which includes looking at cost effectiveness from all stakeholder perspectives) made up of outcomes related to the child's health, the caregiver's health and the overall experience of care and cost," says Dr. Fayed.

"This is a group defined not by diagnosis but by health situation and their perspective matters. Instead of us deciding what is the criteria let's ask them about what outcomes are important," says Dr. Fayed.

The program has started in Toronto, Ottawa, Hamilton and London with satellite sites and outreach to less urban regions.

The research could benefit approximately 6300 kids in Ontario. "So much is riding on this strategy," says Dr. Fayed. "We took the time to figure out what effectiveness means for each of these stakeholders and then we put it into practice, the practice of research."

NEWS



OSSU's co-Scientific Director **Dean Fergusson** has been appointed President-Elect of the international Society for Clinical Trials, a multidisciplinary group focused on improving health by advocating for, and educating researchers in, clinical trials.



Simon Denegri, NIHR National Director for Patients, Carers and the Public in the UK and a member of OSSU's Relevance and Scientific Advisory Committee, was awarded the Order of the British Empire (OBE) for services to 'NHS, Public Health and social care research'. He received this honour in June at the Queen's Birthday Honours.

'I am thrilled to receive this honour. As well as it meaning a great deal to me personally I am delighted that patient and public involvement is also being recognised in this way. One of the highlights of this in recent years for me has been to work with OSSU and other international partners. Long may it continue.'



John Lavis, Director of The McMaster Health Forum, an OSSU research centre, has been named a Distinguished Visiting Professor at the Africa Centre for Evidence (ACE), University of Johannesburg. He was also appointed co-chair of the Registered Nurses' Association of Ontario (RNAO) and the Nursing Quality Indicators for Reporting and Evaluation® (NQuIRE®) International Advisory Council.



Watch for OSSU's redesigned website, www.ossu.ca, in the fall.

Fertile ground for ideas

Gardening and nephrology may sound like an unlikely pairing for hemodialysis research. For over 100 people, including 14 patient partners attending the "Gardener's Grove" conference, it was a creative approach to engaging participants in discussing future kidney research.

Using rocks, plants, soil and decorations, participants created gardens as part of "Plant-Nite," a team-building exercise to instill a mindset of planting ideas and nurturing growth. This mindset helped generate advice and feedback for researchers to 'grow' ideas about how to develop innovative clinical trials that focus on patient-oriented research. Patients, caregivers, researchers, nurses, nephrologists, administrators and students enthusiastically participated in this event that broke down barriers between the various players in nephrology research.

The conference, sponsored by CIHR's Strategy for Patient-Oriented Research



Patient partner Charles Cook (centre) "plants" ideas with other participants at the Gardener's Grove conference

(SPOR), included patient-oriented research training, ethics considerations for trials, open discussions with patients and caregivers, over 10 investigator trial pitch sessions and more.

The event was led by **Dr. Amit Garg**, principal investigator for MyTEMP, a clinical trial and OSSU IMPACT Award. MyTEMP

involves more than 7,500 hemodialysis patients at 80+ centres across Ontario to determine whether cooler, personalized dialysis temperatures can prevent heart attacks, strokes, and death. It is setting the foundation for future large-scale registry trials with input from patient partners, trials which were discussed during the conference.

"As a patient partner I felt welcomed and acknowledged at the conference. I felt that my thoughts, opinions and personal experiences were listened to and valued. I am thankful for having had the opportunity to attend and participate in the conference. I would definitely do it again if given the opportunity." — Patient Partner

Accolades

Congratulations to the successful Ontario applicants of the CIHR SPOR Innovative Clinical Trial (iCT) Multi-Year Grant. This initiative aims to build capacity and increase the intensity of iCT research.

- **Dr. Jeremy M. Grimshaw**, Ottawa Hospital Research Institute, Ottawa
- **Dr. Noah M. Ivers**, Women's College Hospital, Toronto
- **Dr. Jonathon L. Maguire**, St. Michael's Hospital, Toronto
- **Dr. John C. Marshall**, St. Michael's Hospital, Toronto
- **Dr. Subodh S. Verma**, St. Michael's Hospital, Toronto
- **Dr. Aristotle N. Voineskos**, Centre for Addiction and Mental Health, Toronto

CAHSPR Conference

Patient-engagement was a thread running through the Shaping the Future of Canada's Health Systems 2018 conference hosted by the Canadian Association for Health Services and Policy Research (CAHSPR). OSSU was well represented by researchers, patient partners and our Executive Director **Vasantha Srinivasan**, who spoke about the value of patient and family engagement in health research, providing examples and learnings from across OSSU.



CAHSPR ACRSPS

OSSU Tweets Retweeted
Bernard Leduc @b_leduc · May 29
Excellente discussion sur l'engagement des patients et familles @ACRSP 2018
@AccredCanada @Leslie_Thompson. @DumezVincent @Vasantha_Srinivasan
@OSSUtweets @hopitalmontfort

Christopher McCabe Retweeted
Stirling Bryan @StirlingBryan · May 30
Thank heavens for: (1) Ontario Ministry for H<C for its bold policy initiatives in hospital payment, and (2) @wwodchis and team for thoughtful and rigorous realist evaluation. Seems that bundled payments work, for some programs.
#CAHSPR2018

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