

OSSU 2023 Research Day Conference Summary

Date: Thursday, September 28, 2023
Venue: Sheraton Centre Toronto Hotel

Abbreviations

CIHR	Canadian Institutes for Health Research.
EDI	Equity, Diversity and Inclusion.
ICES	Formerly known as the Institute for Clinical Evaluative Studies (www.ices.on.ca).
LHS	Learning health systems are healthcare systems in which knowledge generation processes are embedded in daily practice to improve healthcare.
OCAP	Ownership, Control, Access, and Possession Principles for First Nations data governance (https://fnigc.ca/what-we-do/ocap-and-information-governance/)
OCHSU	Ontario Child Health SUPPORT Unit (www.ochsu.ca).
OHIP	Ontario Health Insurance Plan
OSS	Office of Spread and Scale (https://www.wchwihv.ca/our-work/the-office-of-spread-and-scale/) – an OSSU Initiative focused on digital health & implementation science.
OSSU	Ontario SPOR SUPPORT Unit (www.ossu.ca).
POR	Patient-oriented research (https://cihr-irsc.gc.ca/e/41204.html) is about engaging patients, their caregivers, and families as partners in the research process.
SPOR	Canada’s Strategy for Patient Oriented Research (https://cihr-irsc.gc.ca/e/41204.html).
SUPPORT	Support for People and Patient-Oriented Research and Trials
TCPS 2	Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (2022) (https://ethics.gc.ca/eng/policy-politique_tcps2-eptc2_2022.html).

Contents

BACKGROUND/INTRODUCTION	3
About OSSU	3
Meeting Objectives	3
SUMMARY OF PRESENTATIONS.....	3
Welcome and Introductions	3
Healthy Debate: Engaging Community to Reduce Disparity: The Power of Data Linkage When Used Responsibly.....	4
The Learning Health System	7
The Value of Patient Engagement in Child Health Research and The Impact of Patient-Oriented Research on Practice and Policy in The Context of Provincial Child Health Priorities	9
Winning Strategies for Patient-Oriented Child Health Research: The CHILD-BRIGHT Experience	12
A Whirlwind Tour of Implementation Science and Practice	13
The COACH Trial – Comparison of Outcomes and Access to Care for Heart Failure	14
A Pragmatic Strategy Empowering Paramedics to Assess Low-Risk Trauma Patients with the Canadian C-Spine Rule and Selectively Transport them Without Immobilization	15
Patients as a Virtue	15
Patient Engagement in Clinical Research: Key Learnings and Reflections	16
Strengthening Patient Engagement in Clinical Research: The CanVECTOR Network Experience	17
Tools, Strategies and Approaches to Anti-racism in Patient/Public Partnership in Research.....	18
Graduate Student Presentations	19
Closing Remarks.....	20



BACKGROUND/INTRODUCTION

About OSSU

The Ontario SPOR SUPPORT Unit (OSSU) is a network of 14 leading health Research Centres and 8 Research Initiatives, supported by a Coordinating Centre located in Toronto, that engages researchers, patients and other partners in patient-oriented research (POR) to improve the health of Ontarians and the health care system. Jointly funded by the Canadian Institutes of Health Research, the Government of Ontario and partner Ontario-based hospital foundations and institutes, OSSU provides supports such as expertise, infrastructure, training and resources to people conducting POR to help implement Canada's Strategy for Patient-Oriented Research (SPOR) in Ontario. The mandates of OSSU are to help transform and support patient-oriented health and health service research and to support the uptake of research evidence to improve the health of Ontarians.

Meeting Objectives

One of OSSU's objectives is to disseminate and promote POR supports, training and knowledge/evidence to health and health services researchers, patients and caregivers, providers, policy and decision makers, and other stakeholders. As part of its knowledge dissemination strategy, OSSU hosts Research Days designed to: (1) showcase the impact of POR and patient partnership in Ontario; (2) network and engage the OSSU POR community to share research learnings and best practices; and, (3) foster the growth of POR research collaborations and partnerships across Ontario.

On Thursday, September 28, 2023, OSSU hosted its first hybrid Research Day event with 75 in-person registrants and 237 virtual registrants.

This report provides a substantial summary of each presentation at Research Day. For more details, click on this [link](#) to view the presentations.

SUMMARY OF PRESENTATIONS

Welcome and Introductions

Dr. Vasanthi Srinivasan (Executive Director, OSSU)

Dr. Srinivasan opened the meeting by welcoming the participants, offering an acknowledgement of the land, and introducing Dr. Catherine Zahn, Deputy Minister of Health for Ontario.

Dr. Catherine Zahn (Deputy Minister of Health, Ontario)

[Session 1, 00:03:24] Dr. Zahn expressed her deep commitment to research across the entire spectrum, from fundamental science to health system studies, given that our future as individuals and as populations depend on an efficient and effective healthcare system. She is also committed to patient and community involvement in research and believes that value accrues when patients and partners are involved at the front-end helping researchers understand the questions that are interesting and important to patients. Upfront involvement of all stakeholders can only lead to positive experiences and outcomes, stronger health care delivery, and more robust health systems. Accordingly, continuing the Ministry's collaboration with OSSU and SPOR, is important to advancing patient-centred research and that OSSU's Policy Roundtables are a great illustration of the impact of this work. Ontario is committed to supporting education and knowledge exchange toward promoting evidence-based decision making and shares the goal of a



continually evolving and improving learning health system. OSSU's aims to engage and connect with patients to enhance research and accelerate knowledge translation are tightly aligned with the Ministry's priorities that are detailed in the Health Act.

Ontario maintains its commitment to supplement federal funding to increase the impact of SPOR and to support OSSU's projects. There are so many examples of the impact our joint research efforts have achieved such as the use of health system navigators, studied in an OSSU IMPACT project led by Dr. Simone Dahrouge, to assist Francophone patients in accessing health services. This model will be extended to other populations whose first language is not English, across Ontario. Also, this partnership led to the design and delivery of specialized training in POR evidence to enabled senior decision makers at the Ministries of Health and Long-Term Care to support their decisions with patient informed evidence. Overall, this collaboration for innovation and knowledge sharing is a touchstone for an integrated, accessible, and responsive healthcare system for Ontario.

Dr. Dean Fergusson (OSSU Scientific Lead, Ottawa Hospital Research Institute, Ottawa)

[Session 1, 00:08:45] Dr. Fergusson provided some housekeeping instructions for the meeting, noted that the meeting videos will be posted on the OSSU website, and introduced Mr. Frank Gavin, chair of the OSSU Board of Directors.

Mr. Frank Gavin (Chair, OSSU Board of Directors, Patient Partner)

[Session 1, 00:11:03] Mr. Gavin presented an overview of OSSU's mandates and work. OSSU seeks to help transform and support patient-oriented health and health service research in Ontario and to support the uptake of health and health services research evidence. The SUPPORT Unit has made great strides toward achieving its mandate by bringing patients and researchers together with health system stakeholders such as policy makers, decision makers, clinicians and others to develop high-relevance POR evidence designed to improve health care in Ontario and achieve the quintuple aims of reducing costs, improving population health, improving patient care experience, improving health care provider well-being; and, advancing health equity.

Today's program includes some very interesting presentations on topics such as: how data is helping to shape a better health care system for Ontarians; progress that has been made in Ontario's learning health system; how patient engagement is strengthening child health research; and, the patient's experience with engagement. All these sessions include speakers who are researchers and patient partners actively engaged and contributing to the work of health research.

Healthy Debate: Engaging Community to Reduce Disparity: The Power of Data Linkage When Used Responsibly

Dr. Seema Marwaha (Healthy Debates)

[Session 1, 00:15:04] Dr. Marwaha, Editor in Chief of Healthy Debate, a health publication that publishes on Health Research and Health Policy, served as moderator for the session. The future of health data research is a huge topic, so this panel will narrow the focus to data enabling community engaged research and help us understand and identify health inequities. This session will describe the true power of data linkage, when used responsibly.

Dr. Charles Victor (IC/ES, Toronto)

[Session 1, 00:17:15] Dr. Victor, Senior Director for Strategic Partnerships and Digital Services for ICES, provided a quick overview of the development of the OSSU Data Platform and highlighted its potential to enable community engaged research in the future. The OSSU Data Platform was launched in 2014 through the Data and Analytical Services (DAS)



offering. These services were expanded in 2017 with the capacity to link external data with ICES data sets. In 2018, ICES launched its Public Advisory Council which provides input into ICES operations and research, and in 2019, the Data Platform formally became part of the Health Data Research Network (HDRN), which is the CIHR SPOR-funded Canadian Health Data Platform. Access to high-performance computing to support machine learning and artificial intelligence in health research began in 2021.

During the development of the Data Platform, ICES enabled remote access to both ICES and non-ICES researchers, across Ontario, 40% of which come from outside of the Greater Toronto Area. Where there were 14 active projects in 2014, the Data Platform now supports over 100 active projects each year and has completed over 1,000 requests since 2014. Availability of research datasets has grown from 33 in 2014, to over 76 datasets in 2023.

The OSSU Data Platform doesn't support just researchers, it also supports many different clients, stakeholders, communities, and knowledge users enabling access to the data. The Data Platform of course, also provides access to ICES scientists, many of whom work on SPOR funded research projects and clinical trials.

For the future, the Data Platform will be working with the Information and Privacy Commissioner of Ontario to enable ICES to operationalize the collection and use of intersectoral data; data that will, when linked with health data, enable incredible research into the social determinants of health. This includes data on social services, housing, transportation, justice, etcetera. For phase II of OSSU, ICES will expand its holdings with a focus on community engaged research and equity, diversity, and inclusion. ICES will expand its work with indigenous data sovereignty as well as its work with sex and gender, and Francophone health research. The ICES Black Health Equity Group will help answer questions around health access for black Ontarians. Similarly, ICES will work with the transgender community to help support research looking at health access for transgendered individuals.

Dr. Jennifer Walker (McMaster University, Hamilton)

[Session 1, 00:26:34] Dr. Walker introduced herself as a Haudenosaunee member of the Six Nations of the Grand River and a member of the Wolf Clan, and a health services researcher and a core scientist and indigenous health lead at ICES. Dr. Walker spoke about the development of indigenous data platforms in Ontario since 2014, the current state of those platforms in terms of how far they have come, and what further development is needed such as including groups that are currently missing and what data is potentially missing from the health and health care experiences of First Nations, Inuit and Métis people in Ontario. A lot of work has been done to build these platforms with indigenous communities, indigenous leadership support, and strong indigenous governance.

There are multiple indigenous data platforms at ICES that reflects the diversity of existing indigenous governance structures for First Nations, Inuit and Métis nations in Ontario. Formal data governance agreements have been established with Chiefs of Ontario, Grand Council Treaty 3 and Kenora Chiefs Advisory that help to provide access for First Nations to their own data, but also provide protection to ensure that the work is being done in ways that honor the perspectives, knowledges, and governance of First Nations. Formal data governance and partnership agreements have also been established with the Métis Nation of Ontario which has allowed for the linkage with the Métis citizenship registry in Ontario.

Engagement with indigenous communities is foundational to research in Canada. This includes research in which indigenous identity or membership in an indigenous community is used as a variable for the purpose of analysis of research data. Ethical standards and indigenous principles around data governance are clearly described in the TCPS 2 (2022) – Chapter 9 Ethics Standards for Research Involving Indigenous Peoples of Canada as well as in the First Nations Principles of Ownership, Control, Access, and Possession (OCAP) for data governance. ICES now has tools and pathways

to guide the way these projects are done and to ensure that these strong principles and ethical requirements are met. So rather than creating barriers, they really create pathways to ethical community engagement and research.

Dr. Paula Rochon (Women’s College Research Institute, Toronto)

[Session 1, 00:33:35] Dr. Rochon introduced herself as a geriatrician, the founding Director of Women's Age Lab at Women’s College Research Institute and Professor at the University of Toronto. Ontario has amazing population level data for the more than two and a half million people who are older adults and there is a great opportunity to look at issues related to older people and women. If we don't look for differences between people using disaggregated data by age and sex, then they will be completely missed. For example, the diagnosis of type 2 Diabetes occurs more frequently in older populations. However, with the data disaggregated for sex, men have a higher frequency of diagnosis than women for each age group which is unusual given the women tend to have a higher frequency of diagnosis in most chronic conditions.

In partnership with OSSU, the Women’s Age Lab created an online module, entitled “What Gets Counted Counts”, to help early career researchers (and others) think about the importance of looking at sex and age disaggregated data. OSSU patient partners informed the development of this module and created a webinar to promote this resource to researchers and other patient partners. The module demonstrates the importance of thinking about sex and age disaggregated data which fits with the idea of the sex and gender-based analysis plus that researchers are encouraged to do in all their research and that CIHR is requiring as part of their grant process.

Dr. Peter Tanuseputro (Ottawa Hospital Research Institute and Institute Savoir du Montfort, Ottawa)

[Session 1, 00:40:06] Dr. Tanuseputro introduced himself as a public health physician, a practicing family doctor, and a health services researcher using the data at ICES. Language as a health determinant is important for health care (diagnosis, treatment plans, building rapport and supportive counselling) as well as a reflection of a person's culture (values and beliefs, goals of care, and circles of care). There are roughly 25 datasets at ICES (including home care and long-term care data) that contain a language variable. Dr. Tanuseputro studies language and language concordance between patients and physicians throughout healthcare encounters using Ontario Health Insurance Plan (OHIP) data to see if there is a difference in health outcomes. His research also considers the language of the facility or long-term care home (eg: French language ethnic-specific facilities) to see if that makes a difference in outcomes. In terms of health disparities of long-term care residents across six commonly reported quality indicators, Francophones living in designated bilingual or French language long-term care homes scored better on indicators such as antipsychotic medication use than in non-designated language long-term care homes. In a recently published paper in CMAJ¹, Dr. Tanuseputro and his team found that frail Allophone (people who spoke neither English nor French) home care recipients admitted to hospital and treated by a language-concordant physician had lower risk of harm (eg: falls, medication errors, surgical infections, etc), shorter length of stay and lower in-hospital mortality than Francophone counterparts.

In conclusion, the importance of language is often forgotten. It's one of those health determinants that really make a difference, not just for communication, but for culture, and all the things that make a person, a person.

Dr. Arjumand Siddiqui (University of Toronto, Toronto)

[Session 1, 00:48:26] Dr. Siddiqui, an Epidemiologist trained in the United States, offered some perspectives from an international context on large-scale, secondary data analysis on health inequities and community partnered research. Using the WHO framework on Social Determinants of Health, which arguably can be used as a framework on all health,

¹ CMAJ July 11, 2022 194 (26) E899-E908; DOI: <https://doi.org/10.1503/cmaj.212155>



Dr. Siddiqui proposed the importance of linked data to study the myriad of ways that health is expressed, and that large population and sample datasets would be useful to yield generalizable results.

Canada is somewhat distinct from the international community in its commitment to community partnered research. Again, using the WHO framework, one can see the merits of doing community partnered or community-based research, for if research affects communities, then you would want researchers to engage those communities. But there is another way to look at this framework that suggests some fundamental science can also occur on health equity, that is perhaps not ready for rollout to communities and that perhaps isn't in the domain of partnered research. Dr. Siddiqui noted that W.E.B. Dubois, known as the father of all sociology, did a lot of work to document the state of black people in the United States during the time of slavery and beyond. He is considered one of the foundational theorists and empiricist in the field, and his work was not partnered research. Dr. Siddiqui also noted a number of major health equity scholars who used big data, linked data, administrative data and/or survey data to understand health equity without using community partnership. Some of these scholars include: David Williams, a major race and health scholar; Nancy Krieger, a major scholar in health equity; and, others such as Sherman James, Lindsey Bailey, Ana Diaz Rue, and Amani Allen. Again, these are not scholars who by and large are using community engaged research, but they are producing some phenomenal basic fundamental science on health equity.

Based on this backdrop, Dr. Siddiqui made a number of provocations:

1. It is absolutely the case that many of the main contributions of our time to understand social determinants of health internationally, the literature used to understand health inequities, was done using large datasets without community engagement.
2. Will Canada concede that there is room for work in this area that is community led, driven, and partnered, AND, that there's room for work that isn't, because it's not actually ready for translation or politically too sensitive.
3. Or is Canada staking a claim for another path, which is that everything should be partnered, irrespective of what it is, and that everything is ready for so called Knowledge Translation, and that there is no value in scientific questions in and of themselves that don't have partnerships? ...and are we ready for the implications of that?

Research should be deliberate and very cognizant of the choices and understand that, as wonderful as community engagement can be, if you look at the larger landscape, you may see that it doesn't necessarily behoove us to have everything community engaged for the protection of the science, but also for the protection of communities.

The Learning Health System

Dr. Robert Reid (Trillium Health Partners, Mississauga)

[Session 2, 00:04:04] Dr. Reid presented a new action framework for Ontario's learning health system (LHS) with a reminder that an Ontario-appropriate definition of the LHS is the combination of a health system and research system that at all levels is: 1. Anchored on citizen needs, perspectives, and aspirations; 2. Driven by timely data and evidence; 3. Supported by appropriate decision supports and aligned governance, financial and care delivery arrangements; and, 4. Enabled with a culture of, and competencies for, rapid learning and improvement². The LHS is a natural evolution from our traditional thinking around the brokering of evidence through knowledge, translation and exchange to one where evidence is embedded directly into health systems and integrated by patients, providers and system leaders to improve day-to-day care. It drives rapid-cycle learning within and through the different layers of the system starting with patients

² Lavis JN, Gauvin F-P, Reid R, Bullock H, Wodchis W, Hayes A. Rapid synthesis: Creating a rapid-learning health system in Ontario, Hamilton, Canada: McMaster Health Forum, 31 March 2018

and providers and progressing through healthcare teams, organizations, local systems, and at more senior levels of regional, provincial and national layers. It is also a partnership between three groups: health and social services delivery; research; and, patients, caregivers, and citizens. This three-pillar 'wobbly stool' needs greater support in lifting the voices of patients, caregivers, and citizens throughout the learning health system process.

The Learning Health System Action Framework is presented as an engine with variety of learning gears, with patients, caregivers and providers at the centre, driving a larger production cycle centred on the quadruple aims and equity. These underarticulated gears are where different types of evidence and expertise comes together to produce learnings in the cycle. Certain fuels and accelerants (such as funding, partners, networks, data, expertise, leadership, etc) are constantly needed to drive the gears and the engine of the system. There are also moderators and brakes for the system (such as capacity, priorities, regulations, governance, accountabilities, etc) that provide direction and forward seeking.

Details of this action framework can be found on the OSSU website (<https://ossu.ca/resources/learning-health-system/>) and be published shortly.

Ms. Maureen Smith (Director, OSSU Board of Directors, Patient Partner, Ottawa)

[Session 2, 00:15:02] Ms. Smith discussed the patient, caregiver and community member's perspectives on the Learning Health System. Patients have a variety of questions such as: is the LHS just the newest buzzword; what does it mean in practice; how do we move beyond the three-legged wobbly stool; what does this mean for patient care outcomes and experience; who rotates those gears; and, how can patients be part of this system? Patients are more than just data donors in the LHS. A recent scoping review found very few articles discussing the level of patient involvement in Learning Health Systems and there is no common language or tools to support their involvement. There also does not appear to be a lot of sharing between local systems - you could be in a learning health system and not know it. While there is a big role for patient-centred research, CIHR's grant system is not really suited to building sustainable engagement capacity that is essential for this to work.

There are several recommendations to consider for the path forward. (1) Communicate clearly to patients, caregivers, and communities about how their feedback and data is used to improve patient care with concrete examples of impact. (2) Ensure that your health system has the capacity and infrastructure to nurture continuous, impactful and goal-oriented engagement. (3) Increase the level and extent of patients, caregivers, and community involvement in health system improvement activities. Patients, caregivers, and community representatives want to be involved and can help shape learnings through sharing their experiences.

Dr. Kerry Kuluski (Trillium Health Partners, Mississauga)

[Session 2, 00:19:31] Dr. Kuluski noted that patients, families and communities sometimes express immense frustration at sharing their health and care experiences and then not getting a response. This occurs across the system for a variety of reasons such as not knowing what to do with the information or sometimes the data is not actionable. A recent scoping review was done to see what other health systems are doing to better collect and action patient experience data. Across the globe, this is something that many health systems struggle with. This scoping review identified four key domains of activities that form a strategy to improve how we collect and action patient experience data to improve care.

1. Optimize engagement with populations and communities to ensure people feel comfortable with sharing what does and what doesn't work for them in the healthcare system.
2. Optimize data collection and sampling strategies to ensure questions yield relevant, valuable and actionable data.
3. Consider the various ways in which patient experience data is collected and how it can be brought together in a useful way.



4. integrate patient experience data to allow patient-provider teams to co-design quality improvement initiatives.

These domains are currently being explored at Trillium Health Partners to understand how each can yield actionable patient experience data. Three key messages were revealed from patient and caregiver partners working on this project: (1) Focus on the patient care journey (ie: measure experience at different times); (2) Build accountability mechanisms to ensure something is done with the data; and, (3) be mindful that many factors will shape how people want to share the experience (if at all).

The Value of Patient Engagement in Child Health Research and The Impact of Patient-Oriented Research on Practice and Policy in The Context of Provincial Child Health Priorities

Dr. Colin Macarthur (OCHSU, The Hospital for Sick Children, Toronto)

[Session 3, 00:00:40] Dr. Macarthur began the session with a description of the Ontario Child Health Support Unit (OCHSU) which is one of the research centres in OSSU. The vision of OCHSU is to build capacity in patient-oriented child health research to improve the quality, relevance and uptake of the research, leading to the tagline for the Unit, which is "*better research, better care, better outcomes*". OCHSU provides a suite of services to researchers across the province in methodologic support, clinical trials, health economics, data management and support, patient and family engagement, and training and education in POR.

To date, OCHSU completed more than 1,300 methodologic consultations which has led to around \$30 million in new research funding. The Unit has supported child health projects within some SPOR chronic disease networks, CIHR SPOR innovative clinical trials, and some health economic work with the Choosing Wisely Health Quality Ontario initiative. Over 100 child health data sets are posted on the OCHSU and CIHR websites which have been accessed over 5,000 times. From a training and education perspective, OCHSU has hosted more than 120 training sessions on POR and child health and its webinars, workshops, and presentations have reached more than 700 participants each year that the unit's been in operation. OCHSU was also involved in the development of the Patient Oriented Research curriculum in Child Health (PORCH). The PORCH curriculum has been integrated into the onboarding processes for Family Advisory Committees at hospitals across the province, the SickKids Summer Student Program, and partner onboarding process in the CYSHCN, which is a US-based multi-site research network focused on children and youth with special health care needs.

The remaining presenters will highlight the value and impact of patient engagement in concussion and in-hospital pediatric care research.

Dr. Nick Reed (University of Toronto, Toronto)

[Session 3, 00:08:34] Dr. Reed began his session with an outline of pediatric concussion care and research. Concussion can have a significant impact on a child's ability to do the things they need, want, and love to do in life such as playing the sports they love, or going to school and learning, driving or learning to drive the family minivan, or jumping on a trampoline with buddies. Concussion affects about 1.2% of Ontarians every year which is the highest rate that has ever been reported and children are at highest risk within the population for this injury. About 30% of young people that experience a concussion are going to have a prolonged recovery beyond a month, usually a few months but can be years. There is also a significant risk for mental health issues, psychiatric hospitalization and self harm in this population.



The objective of the PedCARE study was to determine if the introduction of early physical activity would help with recovery. The approach was a randomized clinical trial across three academic pediatric emergency departments and 456 participants were randomizing within the study. The study found that early exercise was helpful for those young people that adhere to the exercise prescription. Some of the patient engagement approaches used included qualitative interviews in advance of the study with youth, caregivers, teachers and sport coaches to better understand their opinions on the current standard of concussion care, their comfort with exercise, the proposed study intervention, and the selection of research outcome priorities. Also, in advance of the project, existing patient engagement platforms were consulted, in particular the Holland Bloorview Kids Rehabilitation Hospital Research Family Engagement Committee, regarding the survey questions, data collection processes, wording use and study recruitment approach. Finally, following the study, research participants and their families were asked to provide perspectives on a range of topics which informed the next phase of the project and the knowledge mobilization strategy. From a value and impact perspective, the study found: patients received improved evidence-based care and were engaged throughout the project to ensure that the findings are as relevant as possible; healthcare providers can deliver improved evidence-based care; Health systems and policy makers can use this evidence to inform decision making, change protocols, programs and funding. An exciting part of this project was putting this evidence into practice through the PedsConcussion Living Guideline for Pediatric Concussion Care.

The Concussion Priority Setting Partnership is currently trying to address the need for concussion research across multiple domains including funding and priorities. Using a James Lind Alliance methodology, the initiative conducted a research priority setting study to identify a tangible list of the top 10 research priorities from the perspectives of patients, caregivers and clinicians. The process involved four stages: (1) National survey to Gather Unanswered Questions; (2) Generating Summary Research Questions and Evidence Verification; (3) Interim Prioritization Setting Survey; and, (4) Final Priority Setting Workshop. Consensus was reached on the final ranking of the top 10 unanswered research questions in concussion³. From a value and impact perspective: patients and providers should be involved in prioritizing research that is going to affect patients and providers; at the system/policy level, this top 10 list should influence funding priorities and justify investing energy, momentum, and resources dollars to conduct this research in the best possible way.

Ms. Francine Buchanan (The Hospital for Sick Children, Toronto)

[Session 3, 00:24:12] Ms. Buchanan (SickKids) presented on behalf of herself and Kimberly Courtney (CHEO) on the work that the Ontario Child Health Support Unit (OCHSU) has done on patient engagement in the child health research area. The unique aspect of this work is that both programs are embedded within the respective hospital systems. The goal of this work is to address the challenges facing patient engagement (such as awareness & education, quality, uptake, sustainability, equity & accessibility, and tokenism) by taking all the research that a lot of the researchers in this room are doing and putting it into practice.

The Family Leader Program at CHEO offers opportunities for parents and caregivers to engage as Research Project Reviewers (sharing perspectives on short summaries of our research projects) and/or as Research Project Advisors (as a member of a research team sharing experience to helping to solve issues that come up during the project). CHEO has established both a Family Council and a Youth Directed Family Council to support the research projects and embedded a lot of their engagement into their processes such as Family Leaders as grant reviewers on all internal CHEO delivered grants. They also provide a Smart Start Program where early career researchers are matched with patient and family advisors so that they can learn, firsthand, the value of patient family engagement from the beginning. CHEO also provides training for researchers, staff and Family Leaders.

³ <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2805754>



SickKids has established the Patient Engagement in Research (PEER) program that offers a full suite of supports around matching family advisors with researchers, research document reviews (eg: applications, consent/assents, recruitment materials, and dissemination materials), engagement evaluation support, training and consultation support. They have also established a Research Family Advisory Committee (RFAC) to provide input on research studies, grant and proposals. RFAC is also embedded in the training of clinician fellows through the Clinician-Scientist Training Program.

Recognizing that there is a lot of benefit in sharing ideas about practices and challenges, OCHSU invited other engagement practitioners to form an informal network referred to as OCHSU & Friends. The group meets bi-monthly and serves to support and network practicing patient engagement specialist working within complex healthcare systems.

SickKids has embedded patient and family engagement and POR into its strategic plan and patient and family engagement has been embedded in some of the clinical networks such as the Pediatric Inpatient Research Network (PIRN).

Dr. Peter Gill (The Hospital for Sick Children, Toronto)

[Session 3, 00:38:41] Dr. Gill, a general pediatrician at SickKids, presented on the Canadian Pediatric Inpatient Research Network (PRIN) and how patient priorities and health systems data has been used to help design and inform future research projects within the network. The aim of PIRN is to work with children and families to generate evidence that improves care and outcomes for hospitalized children in General Pediatric Inpatient Unit (GPIU) settings. GPIUs represent the largest inpatient unit at many children's hospitals and over 65% of children are cared for in community hospitals. In general, regarding GPIU research, there is a lack of high-quality randomized controlled trials, significant number of barriers to research due to the variety of conditions under care, and a lack of patient and family involvement.

Once PIRN was launched, the network began a two-pronged approach to determine which areas to focus research on. With funding from a SPOR Catalyst Grant, PIRN undertook a research priority setting exercise with patients, caregivers, providers, and clinicians, using the James Lind Alliance methodology. A top 10 list was created that focused, not on specific disease, but on processes and areas of care. PRIN also used a data-driven approach to look at areas of high health system burden and cost. Using the data resources available at IC/ES, the top 25 most costly conditions were identified to focus research on. Importantly, the study also found that over 2/3rds of the conditions are cared for in community hospitals. The finding demonstrates that a huge proportion of hospital care occurs in community hospitals which is not generally represented in much of the research.

Dr. Sanjay Mahant (The Hospital for Sick Children, Toronto)

[Session 3, 00:48:31] Dr. Mahant presented on how PIRN research is influencing practice and policy. PIRN research is patient oriented and follows the framework of outcomes research which focuses on outcomes that patients experience in the real world to generate information to improve decisions, healthcare policies, and patient outcomes. Using Bronchiolitis as an exemplar condition, one of the most common and cumulatively expensive conditions in hospital care, PIRN conducted a multicenter randomized clinical trial involving academic and community hospitals on the prolonged or intermittent (every 4 hours) use of pulse oximeters. The study found that intermittent use of pulse oximeters led to similar patient outcomes, length of stay, safety, parent reported outcomes and better nursing satisfaction due to reduced workload. This study was followed by a multicenter qualitative study to understand how best to de-implement prolonged pulse oximeter use in practice, including both patient and clinician perspectives on practice change. This information is informing national guidelines and international practice guidelines, hospital quality improvement, policy, and bedside practice.



Poor feeding and the need for fluid therapy is the most common reason for hospitalization in infants with bronchiolitis. There are two options for care, nasal gastric feeds or intravenous fluids. Research has shown that both are effective, however, providing breast milk or formula via nasal gastric tube results in fewer intravenous pokes, better nutrition and less hunger. Dr. Gill is leading a PIRN multicenter, academic and community hospital-based study to understand how we can improve shared decision making in fluid therapy choice in bronchitis.

Finally, a population-based ICES study of over 2 million children in Ontario at 141 hospitals showed that while hospitalization and mortality rates were the same, there was a dramatic increase in ICU use and costs over time likely due to overuse of a newly introduced respiratory support intervention called High Flow nasal cannula. This study has informed efforts to reduce unnecessary High Flow nasal cannula use and look at appropriateness of ICUs in bronchitis care. Other studies include a multicenter qualitative study to understand how we can improve care in those whose preferred language is other than English; and a study looking at how we can co-design tools to support shared decision making in children with medical complexity.

Winning Strategies for Patient-Oriented Child Health Research: The CHILD-BRIGHT Experience

Dr. Annette Majnemer (Co-Director, CHILD-BRIGHT; McGill University, Montreal)
Carrie Costello (Patient Partner and Parent Liaison, CHILD-BRIGHT)

[Session 4, 00:00:50] The CHILD-BRIGHT Network⁴, is a SPOR-funded research network focusing on children with brain-based disabilities. Ms. Costello began the session with a video describing how not to engage youth in research.

Many of the problems seen with child and youth engagement are linked to power dynamics. Proper training and capacity building are important considerations in youth engagement, however, it is also about ensuring the right environment is in place to support engagement. Creating a supportive environment takes time and should be specifically assigned to someone as their job. When creating a research team, consider who would have the appropriate skills and demeanor to work with youth and parents. Patience and support are also important considerations to foster positive engagement. Ensure that the environment is always open to ideas and suggestions from youth and parents - don't say no or justify why something cannot be done a certain way. Just listen and consider. Ask questions to get below the surface of an issue. Try not to use leading questions with youth. Allow youth the opportunity to explore their responses using open-ended questions. Consider how to make patients part of the whole project (not just the parts you think you need them for).

Dr. Majnemer briefly summarize some of the strategies CHILD-BRIGHT is using to promote patient engagement. These strategies involve aspects of structures, processes, outcome measurement and raising awareness. In terms of structures, patient partners are fully engaged in the governance of the Network such as the executive, steering and/or program committees. Two committees that are really critical to the Network are: the Citizen Engagement Council, which involves predominantly parents of children with developmental disabilities; and, the National Youth Advisory Panel, which are youth with disabilities. These two groups really guide and support POR in the network and continually develop strategies to address new issues along the way.

⁴ CHILD-BRIGHT: Child Health Initiatives Limiting Disability – Brain Research Improving Growth and Health Trajectories



In terms of processes, the Network has a Parent Liaison (Carrie Costello) who acts as a mentor to support parents on a one-to-one basis as they learn about patient engagement and their particular role. The Network also has transparent compensation guidelines and a tool to help match patient partners with researchers. The Network also provides consultation services across the country through the National Youth Advisory Panel and Parents with lived experience. The Network also offers multimodal approaches to POR training.

In terms of outcome measurement, the Network uses both quantitative measures (eg: the Community-based Participatory Research and the Public and Patient Engagement Evaluation Tool) and qualitative measures using interviews with patient partners and researchers to dig a little deeper about barriers and facilitators and perceived impacts.

In terms of raising awareness, the Network has taken the responsibility to take this expertise and to share it across the country and globally. In addition to the traditional ways of disseminating and sharing information, CHILD-BRIGHT presentations include researchers and patient partners together. The Network is using social media to really push the message of patient engagement. CHILD-BRIGHT is now building a Child Health Patient Oriented Research toolkit for clinician scientists in pediatric hospitals and rehab centers in partnership with Passerelle.

Ms. Costello presented additional tips and tricks on engagement with children and youth. First, get the right equipment. Most of your communication will be by text messaging. Second, if possible, try to compensate youth within two weeks of an event. Third, sow the right seeds from the beginning (eg: separate youth from adults; start simple; don't have judgement built in; no right or wrong answers; have examples ready; and, don't seek agreement). Fourth, start off well (eg: leave more sensitive questions for later in the meeting; ask permission to call on people to speak; and, start with a question everyone can answer). The session ended with a video with more important tips and tricks.

Dr. Majnemer commented that CHILD-BRIGHT is very fortunate to have two very distinct patient partner groups, the youth, and the parents, caregivers and other family members. Parents and caregivers are different in terms of the perspectives and the lived experiences they share with researchers. Parents think beyond the moment and really look to the future since their children are developing rapidly, and they're constantly changing with new roles and new challenges.

A Whirlwind Tour of Implementation Science and Practice

Dr. Noah Ivers (OSS, Women's College Research Institute, Toronto), Panel Moderator

[Session 5, 00:00:44] Dr. Ivers, a family physician and scientist at Women's College Hospital, began the session with a description of implementation science - the science of figuring out how to put what ought to be done into practice. Decades of research has shown that evidence-based guidelines don't self implement. The field of implementation science emerged to try to shrink the gap between what should happen, and what actually happens in the real world. Implementation science leans on a whole host of social and behavioral sciences because, ultimately, if you want to make what ought to happen, happen reliably, you need people's behavior to change.

When defining implementation science, some very non-scientific language can be helpful:

- The intervention/practice/innovation is THE THING.
- Effectiveness research looks at whether THE THING works - what's the right thing to do in a given clinical situation.
- Implementation research looks at how best to help people/places DO THE THING - how we make the right thing happen more often.

- Implementation strategies are the stuff we do to try to help people/places DO THE THING - what are the queues and processes we can put into that clinical interaction, or before it or after it, to make sure THE THING happens properly and reliably.
- Implementation outcomes are HOW MUCH and HOW WELL they DO THE THING - whether the queues, the processes or strategies were effective in making the thing happen the way we would have wanted.

For implementation science we have to ask some key questions.

- Who needs to do what differently? Who are the actors?
- Why aren't they already doing those things reliably?
- What feasible options might help address these issues?
- What are the underlying factors (motivation, or opportunity or capability) that will help us understand how to map and change behavior.
- How will we know efforts to support implementation are working using an equity informed lens?

The COACH Trial – Comparison of Outcomes and Access to Care for Heart Failure

Dr. Douglas Lee (University Health Network, Toronto)

[Session 5, 00:10:22] Dr. Lee introduced himself as a cardiologist at the University Health Network and lead of the cardiac program at ICES. He received funding through an OSSU IMPACT award to improve outcomes for acute heart failure patients presenting at emergency departments – the COACH Trial. The project considered two intervention strategies: (1) a risk stratification method, called the EHMRG 7-day risk algorithm, that identifies low risk patients who could potentially go home who might not need to be admitted to hospital, and high-risk patients who have a high probability of an event happening and who should be admitted to hospital. (2) RAPID HF follow-up clinic visit where patients would receive transitional care, all of the care that they would have gotten in the hospital, but in an outpatient setting. Overall, the study found a 12% reduction in the risk of death or cardiovascular hospitalization out to about 20 months and 16% reduction in cardiovascular hospitalizations out to about 20 months.

The intervention was implemented at two hospitals as an Ontario Health Team Quality-based Procedure (QBP) demonstration project involving primary care, ambulatory care, and cardiology, general internal medicine and emergency departments at Sinai Health, University Health Network, and Women's College Hospital. For those patients presenting with a low EHMRG score, an integrated care lead helps to coordinate and navigate their care through outpatient specialty visits in general internal medicine or rapid clinics, technology enabled care such as remote patient monitoring or virtual follow up, Home and Community Care, and Primary Care. Some key implementation supports for this project include:

- Dialogue and a collaborative approach to pathway design (eg: Rounds and training on pathway and EHMRG score).
- Emergency Department Champions and the Integrated Care Lead.
- Interpretive guidelines for the score and an up loadable primer for electronic health record system, EPIC.
- Dedicated Emergency Department Integrated Care Lead calculating EHMRG score and bringing it to inform clinical decision making.

The team are currently testing an automated 7-day and 30-day EHMRG score generation system for the electronic health record system, EPIC, which will automatically calculate and present a score to the Emergency Physician.

With support from OSSU, the team have developed an EHMRG Score Knowledge Translation (KT) Plan that seeks to increase the uptake of EHMRG score in Ontario Emergency Departments and hospitals. The plan has three stages: (1)



Identify champions and analyze gaps and opportunities for implementation; (2) KT strategy refinement and product development; and, (3) KT implementation and ongoing evaluation.

A Pragmatic Strategy Empowering Paramedics to Assess Low-Risk Trauma Patients with the Canadian C-Spine Rule and Selectively Transport them Without Immobilization

Dr. Christian Vaillancourt (University of Ottawa, Ottawa)

[Session 5, 00:24:29] Dr. Vaillancourt presented the results of this OSSU IMPACT award. It is estimated that there are 1.3 million transports for patients with a suspected spinal injury in Canada each year. Less than 1% actually have a cervical spine bony fracture, and only half of these actually have a spinal cord injury. Yet all patients are transported with complicated immobilization devices which is not evidence based.

The Canadian C-spine rule is a decision aid that was first derived, validated, and implemented for use by emergency physicians to help in deciding when to remove these immobilization devices without the need for X-ray and more importantly, without missing any single important injuries. Several validation studies have been completed focused on paramedic use of the Canadian C-Spine rule. Recently, the OSSU IMPACT award allowed the team to work with a few agencies, such as Clinical Trials Ontario who they would not normally work with, and to engage patients in the project. Bringing the patient experience really helped broaden the focus of the project, not just from safety, but also patient preferences which helped facilitate reviews and approvals for the project. Engaging with Paramedic partners also contributed to the success of the project.

Paramedics function and work under the medical license of a Medical Director in a Pre-Hospital Region. All paramedics perform their work in the same way under a series of medical directives that are updated every 5 years. The project obtained a special medical directive for research from the Medical Advisory Committee of the Ministry of Health and Long-Term Care – Land Ambulance service which allowed all paramedics to adopt this new protocol. The study was successful in decreasing immobilization rates, however, at three months before the end of the trial, The Ministry of Health and Long-Term Care implemented a rule called the Spinal Motion Restriction where most patients could be transported with or without a cervical collar according to the Canadian C-spine rule, but without a backboard which causes most of the pain and discomfort. What this meant was that the paramedics were trained to deal with two protocols together.

Overall, the study showed decreased immobilization rates, improved patient comfort, reduced rate of diagnostic imaging and as well the risk of diagnostic radiation exposure. Working with OSSU partners at SickKids and CHEO, the Canadian C-spine rule was implemented in a pediatric population. That is something that would not have been possible without the collaboration with SPOR and OSSU. Also, for the very first time, a formal cost analysis on the implementation of the Canadian C-spine rule, for the nine months of the study, showed that roughly a million dollars worth of healthcare resources were saved. The paramedic service and fire service are the ones most impacted by the results of this project. Certainly, engagement with patient partners and paramedic partners was essential to implement the study and implement the findings. The final study results have been presented to the Medical Advisory Committee of the Ministry of Health and Long-Term Care - Land Ambulance service and final approval is anticipated in the coming months.

Patients as a Virtue

Introduction

Dr. Stuart Nichols (Ottawa Hospital Research Institute, Ottawa), Panel Moderator

[Session 6, 00:00:54] Dr. Nichols highlighted two aspects of patient engagement that are linked to some of the drivers behind POR and engagement. The first aspect illustrates the importance of engaging patients on moral or intrinsic grounds as they are directly impacted by the work researchers do and the evidence they produce. They are the end users of the knowledge and evidence produced by research that informs their care. The second aspect illustrates instrumental, or more practical reasons to engage patients. Patient engagement can improve the quality and relevance of research on a very practical level. Their lived experience and perspectives can help shape the focus, direction, and conduct of health research, thereby increasing its value. This idea of patients as a virtue, taps into both drivers and has pushed POR forward into the mainstream. As discussed in some earlier presentations, researchers also gain a greater understanding of the impact of their work through the shared experiences and perspectives of patient partners. All this has contributed a lot to the changing landscape of health and health services research.

Patient Engagement in Clinical Research: Key Learnings and Reflections

Mr. Terry Hawrysh

[Session 6, 00:05:23] Mr. Hawrysh, a semi-retired professional engineer and survivor of a rare form of cancer, share some key experiences and insights on patient engagement. Whether one is called a patient partner or a patient advisor, we are talking about individuals with personal experience of a health issue which also includes informal caregivers, like family and friends. Patient Engagement represents a meaningful collaboration between partners and researchers actively engaged in priority setting, developing the research question and even performing certain parts of the research itself. This type of participation really helps to ensure that the research being conducted is relevant and valuable to the patients that it impacts.

Effective patient partnership can occur throughout the clinical research process including Trial Design, Trial Participation, Trial Conduct, Analysis and Dissemination of results. Patient partners should seek the good balance between healthy family personal time and work commitments when engaging as a research partner.

Here are some key actions and approaches that researchers and patients can utilize to ensure successful patient engagement in research.

- Engage patient partners early and encourage input into things like the research question, design of the clinical research studies so patient outcomes, and patient experiences are considered.
- Adapt EDI principles to ensure the demographic relevance of the research - getting the geographic and cultural mix just right is difficult and time consuming, but very, very important.
- Onboard patient partners early to ensure they understand the research project, process, timing and roles.
- Treat patient partners as part of the team with mutual respect and professionalism.
- Regular clear communication, collaboration and support all lead to a positive team dynamic.
- Clarify expectations regarding compensation and recognition for the valuable input and time spent on the project.

Good patient engagement can bring benefits to clinical research stakeholders such as:

- Stronger, more relevant, funding applications.
- Gaining new perspectives about the disease.
- Other knowledge and skills (eg: communications, finance, social networking, etc).
- Developing plain language study materials to support trial participants, participant accrual and retention, help enable knowledge translation.
- Effective and meaningful clinical translation of research where everybody learns and grows together.



Although great progress has been made, key challenges and chronic issues continue to plague patient engagement in clinical research including:

- Engaging patient partners that are demographically dissimilar to the study population;
- Engaging inadequate numbers of patient partners which can lead to issues of tokenism and improper power dynamics.
- Inadequate policy training tools.
- Changes in the research program priorities and/or protocols that leave patient partners feeling unprepared or a poor fit for the research activities.
- Poor onboarding, budget and resources not adequately identified to patient partners.
- Long research cycles and challenges to sustained participation.

In summary, patient engagement in clinical research has become accepted practice and has progressed. Engaging early in the research cycle, is very, very important and a Patient Engagement Plan should be jointly developed with patient partners. Ultimately, patient engagement is really about people working together in a respectful, supportive, and collaborative manner.

Strengthening Patient Engagement in Clinical Research: The CanVECTOR Network Experience

Ms. Carol West and Dr. Lisa Duffett (Ottawa Hospital Research Institute, Ottawa)

[Session 6, 00:20:30] Carol West is a patient partner with the CanVECTOR Network and co-lead of the Patient Partner Council. Dr. Lisa Duffett, is a clinician and a researcher co-lead of the Patient Partner Platform with CanVECTOR at Ottawa Hospital. The objectives of the session are to: describe the elements of CanVECTOR's Patient Partner Platform; highlight the value of Patient Partners in research; and, describe some strategies for successful patient partnership.

CanVECTOR is an international network, launched in Canada in 2015, focused on venous thromboembolic (VTE) research and is now in self sustained phase two. The network was co-built with patient partners right from its inception and they are fully integrated, not as a side counsel or an advisory group, but as full partners, in all meetings and decisions of the network. Patient partners are really persons with lived experience and include caregivers and family members who have shared the journey through venous thromboembolic diseases. They can be recruited through referrals from clinicians, research staff and/or by other patient partners through their own networks, or they can volunteer by themselves. We look for the people that are inquisitive, who challenge dogmas but also value two-way communication and listening, and who are ready to see beyond themselves and can generalize to the many. Although some patient partners bring an evangelical spirit to the conversation, CanVECTOR is also very respectful of those who do not, and balance individual needs between privacy and exposure.

Regarding CanVECTOR's structure and governance, the Patient Partner Council has 8-10 members and meets monthly. There is an open transparent onboarding process that provides training and mentorship to new patient partners. CanVECTOR tries to have two patient partners allocated to every project and practices shared decision-making (eg: extensive discussion, collaboration and shared decision making with respect to compensation). Patient Partners participate at all stages of the research cycle from the development of research questions and proposals to knowledge translation and quality assurance.

Two examples of patient partnership in research were presented. The first project, funded as one of OSSU EMPOWER knowledge mobilization projects, involved dissemination of the top 10 list of priorities for VTE research. The "Clot Top 10 Priorities" were developed using the James Lind Alliance methodology involving joint consensus building and listening to healthcare professionals, researchers and patients. Patient partners were fully engaged in the process and shared, "I felt

that it was very respectful of others opinion” and a healthcare professional shared “my printed opinions on the priorities were influenced by hearing the patient's point of view”.

The second project involved the establishment of an International Core Outcome Set for clinical trials on interventions for VTE in adults (VTE-COS). Patient partners and people with lived experience were integrally involved and made valuable contributions to defining international standards on what and how to measure patient reported outcomes.

The following strategies can lead to successful patient engagement:

- Provide resources to patient partners such as glossaries with defined acronyms and links to lay language resources.
- Be clear about the project timelines and expectations.
- Provide regular updates on the project.
- Listen to all opinions, be respectful, and seek consensus from the group.
- Provide sufficient time for patients to review and comment on research documents.
- Clearly defined (in a Terms of Reference or similar document) at the outset, the roles and expectations of both the researcher and the patient partner regarding communication, timelines, time commitments, acknowledgement, compensation and processes.
- Include time for patient partner input on meeting agendas.

The session ended with a quote from Mother Teresa describing the ideal of patient partnership: *“I can do things you cannot, you can do things I cannot, added together, we can do great things”.*

Tools, Strategies and Approaches to Anti-racism in Patient/Public Partnership in Research

Mses. Annette McKinnon and Samira Chandani

[Session 6, 00:44:16] Mses. McKinnon and Chandani spoke about their experiences and reflections on co-leadership in research based on their work with a patient-initiated SPOR Evidence Alliance synthesis project on Anti-Racism in Patient/Public Partnership in Research. The presenters co-led the project with Drs. Linda Li (UBC), Ellen Wang (UBC), and Hilary Edelstein (OSSU) to look at tools, strategies and approaches to anti-racism in patient and public partnership in research. The idea for this project was conceived at an OSSU Patient Partner Working Group meeting during a discussion of the lack of diversity among patient partners on research teams.

When patients are engaged as co-leads, they bring a patient lens which can help refine the project scope and perhaps make it more relevant to more people. Early engagement can have a greater impact on the output and the usability of the research evidence. As initiators of the query, Mses. McKinnon and Chandani selected the primary researcher who then gathered the rest of the team. The whole team comprised five co-leads (two patient partners, the primary investigator, research assistant, and a content expert from OSSU), six trainees, a librarian and research administration support person.

Negotiation was a key approach used throughout the research project. This includes negotiation of the work plan including the roles of the patient partner co-leads throughout the project, key words, the abstracts, the article reviews, and on to writing the report and knowledge translation approaches. For example, 25 hours of compensation was originally allocated to the patient partner co-leads. However, since the patient partner co-leads wanted to be engaged in all aspects of the project, this was increased to 100 hours, which still was not enough. In total, 24,000 papers were reviewed with patients and researchers having access to the same data. The patient partner co-leads also suggested additional keywords to make sure that the papers encompassed all of the racialized communities under study. This demonstrates how, by adding the patient lens on top of the researcher lens, patient partners can make a difference.

In summary, the whole team had the shared goal of success which contributed to an enabling environment and supportive team culture. Everyone on the team made an effort to build capacity and support each other. Power sharing and shared decision making requires additional effort. It was really an advantage to have two patient partner co-leads on the team to provide peer support and manage power balance on the team.

Graduate Student Presentations

Moderated by: Dr. Kerry Kuluski (Trillium Health Partners, Mississauga)

[Session 6, 1:01:47] This session features presentations from two students who attended a graduate school course on patient engagement in research led and co-developed by Dr. Kuluski along with many community members and OSSU. As part of the course, students are asked to pick one core challenge that they're learning about in their research related to POR or something that seems a bit understudied. The students then present on the core issue or challenge they are working on and propose some solutions to address that challenge.

Strategies to Address Trauma in Engagement Research

Ms. Krystle Amog (University of Toronto, Toronto)

[Session 6, 1:04:48] Ms. Amog presented on a problem that was identified by a patient partner, which was the idea of trauma, and how we should strive for trauma informed partnerships. Trauma is described as a lasting emotional response to one or more distressing events or circumstances. Trauma can stem from a range of experiences, such as abuse, grief, loss, violence, cultural and historical trauma, as well as the healthcare system and health care experiences. It is important to note that lived experience can be intertwined with experiences of trauma. In the context of engagement research, this means that certain discussions can trigger or cause patient and caregiver partners to re-experience difficult parts of their lives when sharing their stories for the sake of a project. By nature, traumatic events also create power differentials. Therefore, it is important that we don't reproduce these feelings throughout the engagement process.

Trauma informed approaches to patient engagement should be applied at the beginning of a project. A framework such as Valuing All Voices developed by Roche and colleagues⁵ uses a trauma informed, intersectional and critical reflexive approach, which can be used to guide the engagement process. To complement this, research teams can utilize Trauma-Informed Care (TIC) principles suggested by Gum and colleagues⁶. The TIC principles are: Safety, Trustworthiness & Transparency; Peer support; Collaboration; Empowerment; and, Humility & Responsiveness. Some of these principles may look familiar, as the authors argue that these are consistent with patient and caregiver engagement research strategies.

Another key aspect of trauma informed engagement is being transparent and reflexive from the outset. Patient and caregiver partners should be informed about the possibility of experiencing trauma or other emotions throughout the engagement process. This will give them the opportunity to decide if this is the right engagement opportunity for them at this time. And it should be made very clear that they have agency over their stories and lived experience so they can decide what to share or not or what not to share.

What happens in the moment when someone is triggered? First, look for signs of distress. For example, panic, flush face, shaking hands or voice. Help the person manage their feelings by using grounding techniques such as encouraging them

⁵ Roche et al., 2020. Research Involvement and Engagement: 6(1), 1-13.

⁶ Gum et al., 2023. Health Expectations: 26(1), 388-398.



to take deep breaths, sipping water slowly, or looking at an object in the room to bring them back into the present moment. You can also offer to pause, take a break, or move on to a different topic.

Finally, if a person is triggered while sharing their story, take the time to acknowledge the impact of what they shared, and how it has influenced the activities and priorities on the project. It is important to check in after the experience occurred and link the individual to appropriate resources as needed.

Making diabetes management more culturally appropriate

Ms. Divya Mathura (University of Toronto, Toronto).

[Session 6, 1:10:11] Ms. Mathura presented on the impact of colonization on indigenous peoples in Canada and the challenges it poses to community partnership in health research. With the generational trauma of dealing with those in power, who use and destroy indigenous identity, how does one begin to trust again. How are indigenous communities expected to participate full heartedly with the same kinds of people like those in power, who dismiss their culture, feelings and way of life. These are the feelings that engaging with researchers can spark and can include a sense of being used, tokenistic and dismissed.

The challenges with engaging with the indigenous community and patient partners is rooted in their historical context which hits on power dynamics, trust, communication, and team building. First and foremost, to address these challenges, when engaging indigenous communities and research, it's crucial to recognize their inherent rights, cultural diversity and unique worldviews. To develop strong relationships, researchers must prioritize active listening and open dialogue, maintain consistent communication and be open to new ways of learning. Researchers must be prepared to adapt to indigenous ways of doing and learning. It is important to maintain an open mindset and to learn new ways of doing research. It's also important to maintain a vision of sharing knowledge rather than telling indigenous communities how to do research. Together we can bridge the gap between academia and indigenous knowledge systems, leading to transformative research outcomes. Research should not be seen as a one-time transaction, but rather, as an ongoing collaboration.

Closing Remarks

Drs Dean Fergusson and Vasanthi Srinivasan closed Research Day 2024.