

# **MARITIME** Health Research Summit

Moving the Dial on Learning Health Systems



🛗 October 24





## **ABSTRACTS**

Maritime SPOR SUPPORT Unit Unité de soutien SRAP des Maritimes

#### Co-production of hospital inpatient substance use policies for the Medical Teaching Unit at the Halifax Infirmary in Halifax, Nova Scotia *Presented by:* Thomas Brothers, Maya Lowe, & Landon Morton

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**Background:** Hospitals can be dangerous environments for patients who use criminalized drugs. Harm reduction approaches (e.g., distributing sterile injecting equipment) have been inconsistently implemented at the Halifax Infirmary and have not been institutionalized into hospital policies. We aimed to develop and evaluate harm reduction-oriented substance use policies for the Medical Teaching Unit at the Halifax Infirmary.

**Methods:** Co-production and participatory action research methods were used to guide two phases of this policy development and quality improvement project. In phase 1, we formed a multidisciplinary working group comprised of representatives from nursing, social work, pharmacy, medicine, Mainline needle exchange, and lived experience. This group proposed a philosophy of care document and a draft policy to guide clinical care. In phase 2, Mainline hosted a focus group where the proposed harm reduction policies were reviewed and discussed with six people who use drugs who had recently been hospitalized.

**Results:** The working group drafted policies to promote use of evidence-based practices, dignity for patients through a non-judgmental approach, and a safer environment to reduce harms associated with substance use in hospital settings. Proposed approaches were felt to be feasible and focused on seven common clinical scenarios: Antibiotics Administration, PICC Line Maintenance, Administration of Controlled Substances, Sharps Safety, Passes, Patient Environment, and Consultations/Investigations. Focus group participants found the draft policies acceptable. They appreciated transparency about daily schedules, listening to patients to better understand their needs, and ensuring patients feel welcomed when they return to the unit after time away. They noted a need for a safe place to use drugs in the hospital, which was not included in the policies.

**Conclusions:** Outputs of this project to date include drafted harm reduction-oriented substance use policies that are acceptable and feasible for providers and patients. These are informing province-wide policy reform. Hospitals and health systems could follow our co-production approach, adapted to their local context. Next steps involve fully implementing these policies with Nova Scotia Health, planning and conducting an outcome evaluation, and planning for an in-hospital supervised consumption site.

#### Investigating systems responses to violence against women across three Canadian provinces: Findings from The Interprovincial Violence Against Women Project

#### Presented by: Alexa Yakubovich

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**Background:** Violence against women (VAW), including domestic and sexualized violence, increased during the COVID-19 pandemic with detrimental impacts on women's health. With the continued social and economic fallout from the COVID-19 pandemic, collaboration between the health and social care sectors is needed now more than ever to support VAW survivors. However, the capacity for this coordinated systems response is unclear.

**Methods:** We conducted a mixed-methods survey with 465 staff on supportive services for VAW survivors ('VAW staff') across Nova Scotia, New Brunswick, and Ontario and 1,655 people working on health services and policy ('health staff') in Nova Scotia from 2022-2023. This study was conducted in partnership with leaders, advocates, and service providers from VAW and health systems as well as women with lived experience of violence across our three included provinces. We descriptively analyzed and integrated quantitative and qualitative data on VAW staff participants' experiences of service delivery and infection prevention and control during the COVID-19 emergency and health staff's knowledge and preparedness to respond to VAW among patients and considerations of the needs of VAW survivors in COVID-19 programs and policies.

**Results:** VAW staff faced significant strain at the onset of the COVID-19 pandemic, with rising caseloads, staff shortages, and rapidly changing public health mandates they were required to implement (including as congregate care settings), without adequate training and resources. The extent of collaboration between the VAW and health systems varied by province; there was little evidence of policy and funding support for health systems actors to work with VAW leaders to apply trauma-informed approaches to public health protocols -- a critical gap identified for meeting the needs of VAW survivors. Workplace stresses created by the pandemic persist to present day across sectors, with health staff showing substantial variability in their knowledge of and readiness to respond to VAW among patients and communities.

**Conclusion:** There has been tremendous change in the health and social service sectors serving VAW survivors since March 2020. Greater investment is needed in strengthening coordination between the health and VAW systems in the provision of care to VAW survivors and policy development and implementation that will promote public heath without exacerbating the occurrence of VAW.

## Peer support networks for people with chronic pain: A systematic review of the literature

#### Presented by: Virginia McIntyre

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**Background:** An estimated 8 million Canadians live with chronic pain, and many face significant barriers in accessing the care and support they need to improve their quality of life. Peers can play a role in helping patients cope with the physical and emotional toll of living with chronic pain. Peer support is emotional and practical support between two or more people who share a common experience, such as living with an illness. The purpose of this study is to systematically review the existing literature to explore the impact of peer support in the management of chronic pain.

**Methods:** A total of 8 databases (Medline (Ovid), CINAHL, Embase, PsycInfo, SportDiscus, Cochrane Central Register of Controlled Trials, JBI EBP Database, Scopus) were searched for relevant citations. Identified citations will go through a two-stage screening process, by two independent team members using Covidence. Articles will be included if they are a randomized control trial or an observational study exploring a peer-led intervention (individual, group, in-person, telephone or virtual) and conducted in a population experiencing chronic (12-week or longer) non-cancer pain. Studies must report on at least one of the following outcomes: physical or emotional function, pain, quality of life, self-efficacy, self-management knowledge, and health service utilization. Data extraction will include study details (design, population, intervention description, comparator), population characteristics, and outcome estimates. Risk of bias will be measured using the Cochrane RoB2 and ROBINS-I tools.

**Results:** A total of 5,466 citations were identified after deduplication and the first stage of screening is almost complete. Complete data extraction is anticipated by August 2024.

**Anticipated Impacts:** Nationally in Canada, peer support for the management of health conditions is an emerging area, with limited organizations coordinating access. Findings of this project will provide evidence on education-based peer support in the context of chronic pain, thereby providing lobbying power to expand services nationally. Additionally, findings can help to raise awareness among clinicians on the role peer support can plan in their patient care plans.

#### **Concurrent 1B: Practice to Data Abstracts**

#### The socio-economic burden of Cystic Fibrosis in Canada

Presented by: Luis Chavez

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**Background:** Cystic Fibrosis (CF) is a progressive disease that requires arduous interventions and daily treatments. The time and money required for systematic management of CF represents an enormous burden to both healthcare systems and individuals. Most previously published cost-of-illness studies have focused on the direct costs to the healthcare system (or payer), with only a few studies estimating the total burden in terms of the direct and indirect costs of CF to payers, individuals, caregivers, and society. In this study, we aimed to quantify the direct and indirect socio-economic costs of CF in Canada.

**Methods:** People living with CF (PwCF) in Canada and their caregivers were eligible to participate in this study. The Burden of Disease (BoD) survey was available from July to October 2021. Two surveys were available: one for PwCF (or caregivers for children) and a second for caregivers. Participants were asked to provide consent to link their survey responses with the Canadian CF Registry (CCFR). In 2019, 4711 people, nearly all people with CF, were reported on in the CCFR. Triangulating data from the survey (out-of-pocket expenses, absenteeism), healthcare utilization from the CCFR, and publicly available data (e.g., hospitalization costs, equipment costs) we estimated the direct (amount of money spent) and indirect (loss of labor and absenteeism) costs of CF. A prevalence-based bottom-up, human capital approach was used. All costs are reported in Canadian dollars, adjusted for inflation to 2021 values.

**Results:** A total of 369 people with CF (8% of the Canadian CF population), and 241 caregivers completed the survey. The total socioeconomic cost of CF for the Canada population in 2021 (n=4711) was \$414M. Direct costs included costs to the healthcare system (21%), the individual (12%), caregivers (1%) and medications (32%). Indirect costs to society (34%) included the time spent doing daily therapy, travel to and from CF clinics and absenteeism for both people with CF and their caregivers.

**Conclusions:** The total direct and indirect socio-economic cost estimated for the Canadian CF population provides a benchmark to evaluate future impacts of highly effective modulator therapies.

## Implementing Lactation/Infant Feeding Rooms at Cape Breton University: A Community Clinical and Research Project

#### Presented by: Rebecca Jones

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Research has demonstrated numerous physical, social, and cognitive benefits of breastfeeding for both mothers and children. Canadian women are entitled to breastfeed their children, including within workplaces and educational institutions. To ensure the fulfillment of this right, workplaces and educational institutions must address the needs of breastfeeding mothers and provide suitable accommodations. Cape Breton University (CBU), which serves a diverse community of over 12,000 students and employees, previously lacked dedicated lactation and infant feeding facilities. Recognizing this deficiency, a proposal to establish lactation and infant feeding rooms on campus received enthusiastic support from nursing leadership and CBU administration, resulting in the creation of two lactation/infant feeding rooms: "Mae's Room" and "Ksalsuti Space." These rooms enable mothers to return to class or work postpartum while feeling supported in their infant-feeding journey. Additionally, these spaces can serve as educational resource centers for mothers and safe spaces to foster community connections. The next step in this project involves conducting a qualitative descriptive study to explore and understand the lived experiences of students and employees at CBU who utilize these lactation/infant feeding rooms, their needs, and the effectiveness of these facilities. Data will be collected through semi-structured interviews and analyzed using qualitative content analysis. This project is grounded in the principles of patient-oriented research and health promotion planning, guided by pertinent research findings, and attuned to the genuine needs of the mothers who will utilize this essential resource. Moreover, it aligns with CBU's Strategic Research Plan and commitment to Equity, Diversity, and Inclusion. By providing necessary infant feeding facilities, CBU actively supports a diverse and inclusive campus environment that acknowledges and caters to the needs of all members. The establishment of these facilities reflects CBU's dedication to investing in its students and enriching their living and learning experiences by offering essential support to student mothers. Furthermore, by addressing the needs of employees, this initiative empowers faculty and staff, enabling them to flourish in a supportive and accommodating work environment. This oral presentation aims to delineate the initial stage of this initiative and outline the plan for the subsequent phase.

#### Improving the health care experience of children and families through the Community Social Pediatrics Model

#### Presented by: Sarah Gander

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The presentation of children with referrals related to attention deficit hyperactivity disorder (ADHD) is often complex and involves environmental and social components in addition to medical considerations. Many barriers impact children's access to effective, timely, holistic care, which can be further exacerbated by complex social factors and marginalization.

The aim of this study was to determine if a Community Social Pediatrics (CSP) model with an interdisciplinary team and funded support services can improve experiences and outcomes for families of children being assessed for suspected ADHD, who also have complex social considerations.

This pre-post study recruited families with children who had received behaviour-related referrals. Participants received the standard of care and additional resources typical to CSP model, including support from a social worker, home visits, and referral/funding for clinically indicated therapeutic services such as occupational therapy. Measures to analyze results included: Pediatric Integrated Care Survey (PICS), Child Behaviour Checklist (CBCL), and Quality of Relationship Inventory (QRI). Paired t-tests were conducted to detect significant changes in subscale scores across time points.

Thirty-one caregivers completed the intake assessment and 26 of these completed the follow-up assessment for their children at 12 months (ages 5-16 years). The QRI scores indicated a significant decrease in the conflict subscale between timepoints (M1=2.23, M2=1.87, p<0.005). The CBCL scores indicated reductions in aggressive behaviour (M1= 68.65, M2= 64.77, p<0.05) and conduct problems (M1= 68.69, M2= 62.31, p<0.05). The PICS scores indicated families reported fewer access problems (M1= 3.35, M2= 1.19, p<0.005), and better communication with health care providers (M1= 14.53, M2= 16.92, p<0.05).

The findings suggest that some aspects of the family experience and several child outcomes were significantly improved after receiving care through the CSP model. In particular, the reduction of caregiver-child conflict, aggressive behaviour, and conduct problems may indicate that the child's needs are being more effectively met, thus reducing conflict at home and school. Improved access to care, as well as communication between healthcare providers and families, play an important role in whether a child will adhere to or receive appropriate treatment.

# Concurrent 2A: The Cycle of Data, Knowledge, and Practice Abstracts

#### CAPS: Coordinated Aging in Place Services with team-based primary health care: Implementation and sustainability quality initiative

Presented by: Paula Pickard

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**Background:** Several factors impact the older adult's ability to age safely in their home, including effects of living with chronic conditions and/or increasing frailty. Increasing emphasis to use primary health care (PHC) services effectively for health prevention and to reduce avoidable hospital admissions. The goal is to implement and scale-up the Horizon/Healthy Seniors Pilot Project research initiative, "CAPS: Coordinated Aging in Place Services" at the Central Miramichi Community Health Centre. CAPS is a team-based, PHC service that provides equitable, proactive and comprehensive case-management for community older adults with chronic illness &/or at-risk for frailty. The objectives: build capacity and enable the community registered nurse (RN) to work to their full scope of practice, increase the number of community older adults enrolled in CAPS by 10% (40 patients), and to evaluate the experiences of the participants and the impact of the initiative.

**Methods:** Quality improvement (QI) methodology is being used, with the support from Healthcare Excellence Canada (HEC) from November 15, 2023 to September 30, 2024. Planning phase is complete, with development of an Implementation/Evaluation Plan and Long-Term Success Plan. The planning phase involved input from patient experience advisor, community older adults, key community stakeholders, and internal subject matter experts/clinicians.

Currently in the six-month intervention phase, CAPS is led by an RN who provides evidencebased clinical assessments, facilitates patient-centred action plans, provides ongoing case management & self-management support, including patient navigation, referrals, and collaboration with other healthcare providers and community organizations.

**Anticipated Impacts:** The anticipated impacts, based on the initial research, for the older adult population are: improved access to PHC services, improved PHC experiences, more confidence in managing their chronic conditions, more awareness of available community resources, and reduced avoidable hospital admissions. Other anticipated impacts: enhanced PHC team collaboration, increased referrals to other healthcare providers and community partners, and improved PHC access to citizens without a primary provider.

**Results:** The results of the project will provide information on the impact of using an RN-led, PHC team-based approach for improving healthcare experience and outcomes for the older adult population. The results will used to scale up the initiative to other health centres.

## Developing a resident-centred data-informed planning improvement intervention in long-term care

#### Presented by: Caitlin McArthur

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**Background and objectives:** Care plans help individualize and prioritize areas for monitoring or intervention in long-term care (LTC). Poor care planning can limit information exchange between providers and reduce care quality. Data from routinely collected standardized health assessments and geolocation tracking are available to inform care planning but, to date, their use has not been optimized. The purpose of this descriptive qualitative study is to develop a data informed care planning improvement intervention using routinely collected data to guide resident-centred care planning in LTC. The objectives were to: 1) understand how, where, and why routinely collected data are used currently; 2) identify barriers to using data to guide care planning from the perspectives of LTC staff, residents, and family members; and 3) based on objectives 1 and 2, develop a care planning intervention guided by the Behaviour Change Wheel.

**Methods:** This is a descriptive qualitative study. Data were collected through individual interviews and focus groups and observations of care planning processes in fall 2023 and winter 2024, and analyzed by two team members through thematic content analysis to answer objectives 1 and 2.

**Results:** Four LTC homes in Nova Scotia participated in our study (2 large, 1 medium, 1 small; 2 rural, 2 urban). Interviews or focus groups were conducted with 14 residents, 16 family members, and 14 staff across the 4 homes, and 4 observations were completed. Results reveal routinely collected data were used to inform initial care planning at admission, then on a quarterly basis thereafter. Updates to the care plan were also made iteratively through resident, family, and staff input as needed. Barriers to utilizing routinely collected data to inform care planning were limited awareness of the data and its potential uses, and care conferences which focused more on information sharing versus discussion and were driven more by staff and less by residents or family members.

**Conclusions:** The next steps (complete August 2024) are to map results of objectives 1 and 2 onto the central component of the Behaviour Change Wheel, which suggests that Capability, Opportunity, and Motivation are needed for a behaviour (i.e., data informed care planning) to occur. Linkages in the Behaviour Change Wheel will then help us suggest potential interventions to improve data informed care planning in LTC.

## Developing essential coaching for every partner, an mHealth postnatal intervention for non-birthing parents

#### Presented by: Justine Dol

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**Background:** The transition to parenthood is an exciting yet demanding period that requires physical, emotional, and social adjustment to new norms and expectations. While there is significant focus on the transition for the birthing person ('mother'), the non-birthing parent (fathers, LGBTQ+ parents) are less supported in the transition to parenthood. Education via text-messaging has potential to fill a postpartum health service gap for the non-birthing parent. The current study explains the development 'Essential Coaching for Every Partner', a text message program, to improve the non-birthing parents' access to information and support during the immediate 6-week postpartum period.

**Methods:** The content of 'Essential Coaching for Every Partner' was initially modified from a previously designed intervention 'Essential Coaching for Every Mother' which targets mothers and birthing persons. To ensure patients and experts were also engaged in the development process of 'Essential Coaching for Every Partner', a user-centered design development approach was taken. Iterative testing with non-birthing parents (n=10) and postpartum healthcare providers (n=10) through three rounds of iteration. Parents and healthcare providers provide feedback on the text messages using semi-structured interviews with their input guiding revisions of the messages after each round. Primiarous non-birthing parents with infants <6 months living in Nova Scotia were eligible as well as postpartum healthcare providers.

**Results:** Based on feedback, modifications were made to the content of the text messages. In addition to wording and clarification changes in the messages, 6 messages were added to cover new topics. Additionally, an option of information relates to combination feeding was added, as an option to breastfeeding and formula feeding alone. The final outcome is a set of text messages that provide non-birthing parents with information and support during the immediate postpartum period, covering topics such as normal infant development, safe sleep, and parental mental health.

**Discussion:** In combination with the previously designed and evaluated 'Essential Coaching for Every Mother', it is the first comprehensive Nova Scotian text message program providing remote support for all parents during the immediate postpartum period, enhancing the universally available public healthcare. Evaluation will occur to determined effectiveness through a randomized controlled trial.

#### Concurrent 2B: Patients, Caregivers, and Communities Abstracts

#### The re-established Patient Family Advisory Council of the Nova Scotia Health Cancer Care Program: Expanded, equity-focused membership and a new model of onboarding

Presented by: Leslie Hill & Joel Baltzer

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**Background and objectives:** The Nova Scotia Health (NSH) Cancer Care Program (CCP) has a long history of engaging Patient and Family Advisors (PFAs). Engagement opportunities encompass three streams: a virtual PFA network, PFAs as members of quality improvement committees and projects (e.g., lung cancer screening program, annual patient satisfaction survey), and the Patient Family Advisory Council (PFAC). The CCP PFAC acts as an advisory body to ensure that patient and family perspectives are identified and reflected in decisionmaking. Pandemic pressures caused the PFAC to become dormant in 2021. During discussions to align meaningful patient engagement with NSH quality improvement and safety (QIS) guidelines, the CCP lead for Engagement and Diversity identified an opportunity to re-establish the CCP PFAC with an explicit equity-focused approach.

**Results:** CCP PFA engagement shaped the new CCP PFAC design and onboarding methodology. In 2022, CCP PFA feedback from an experience survey identified opportunities for more meaningful engagement strategies. In early 2024, the CCP formed a planning committee to re-invigorate the defunct PFAC. Deliberate inclusion of diverse populations as well as formal onboarding was emphasized to build trust and engagement with the CCP. The committee, comprised of staff and PFAs, worked collaboratively to develop the PFAC terms of reference, expression of interest notices, and communication, orientation, and onboarding materials. From March to May 2024, the committee recruited patient, family, and community members from multiple community organizations and all four health zones.

**Conclusion:** The re-invigorated CCP PFAC supports diverse representation from across Nova Scotia and is comprised of individuals who have lived experience with the Nova Scotia cancer care system as a patient, family member, or friend, as well as members of the public. Designated membership spaces for community representatives support membership diversity and amplify community voices within the CCP. Re-establishment of the PFAC with an expanded membership model will advance the application of person-centered care principles in the delivery of cancer care and ensure that patient-and community-identified needs are met. An evaluation of the recruitment and onboarding process is planned after the first meeting of the PFAC in September 2024.

## Integrating patient partners in peer review: Lessons learned from the Rare Disease Research Initiative

Presented by: Jillian Banfield

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As part of Government of Canada's National Strategy for Drugs for Rare Diseases, the Canadian Institutes of Health Research (CIHR), under the scientific leadership of its Institute of Genetics (IG), launched a suite of funding opportunities called the Rare Disease Research Initiative (RDRI). These four funding opportunities sought to address gaps in research related to diagnosing, tracking, and treating rare diseases. Each opportunity required that applicants detail their plans for patient partnership within their projects. Patient partners also reviewed these applications. Like reviewers with biomedical or other scientific expertise, patient partners reviewed applications, provided comments and scores, and discussed the applications during review meetings.

Including patient partners in the review process as full reviewers is not yet standard practice for most funding agencies. Although they have participated in some review processes across different CIHR's Institutes and strategic funding opportunities, including patient reviewers has been ad hoc and often treated as an add on to the existing process.

IG views as patient partnership as fundamental to research, so we wanted patient partners to be well supported through RDRI reviews, within the limits of the existing processes. IG's Lead for Patient Partnership, who is also a patient partner, debriefed with each patient reviewer after peer review, and with staff who supported the peer review process. We sought to understand patient reviewers' experiences of the peer review process and what could be improved.

Based on these interviews, we found that patients are keen to serve as reviewers and enjoy learning about research. Patients and staff, however, noted barriers that make it challenging to ensure patients' access and information needs are met, like a lack of tailored training opportunities and peer mentorship. Patients also noted gaps in how applicants provide details about their patient partnership plans and how those plans are evaluated during peer review.

Based on these findings, we suggest that organizations should provide more systematic support for patient reviewers and address logistical issues that pose barriers to their full participation. Academic reviewers also need training in how to serve alongside patient reviewers, and in how to evaluate patient partnership plans.

## The role of patients, caregivers, and communities in Learning Health Systems: A narrative review

Presented by: Rachel Giacomantonio

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**Background:** Learning Health Systems (LHSs) seek to rapidly generate and apply evidence in clinical practice. Many Canadian-made LHS models call for active engagement with patients and publics (herein 'contributors'), yet there is little guidance about how to do this and how engagement may differ in these settings. This review examines engagement activities in existing and emerging LHSs for insights into the roles that contributors play in creating patient-oriented and equitable LHSs.

**Methods:** A narrative review was conducted using the PerSPEcTiF framework. Search terms were identified for three domains (contributors, LHSs, engagement); the search strategy was reviewed by two health librarians. Four databases were searched (PubMed-MEDLINE, CINAHL, PsycINFO, Embase). Articles were screened using a domain-based rubric and sampled for richness. Data was extracted including who was engaged, when, where, and how. Engagement activities were coded inductively, then deductively using the IAP2 Spectrum of Public Participation. Boell and Cecez-Kecmanovic's hermeneutic method was used throughout and to synthesize contributor roles. One reviewer performed all steps, with input from an advisory group including a Patient Partner.

**Results:** Thirty-six articles describing engagement in 30 LHSs were included. Findings characterize the literature and report on each PerSPEcTiF domain. In all, 192 engagement activities were coded to create a taxonomy of engagement; 139 activities were also coded to a position on the IAP2 Spectrum. Contributors' influence over decision-making was often unclear or limited, with engagement frequently occurring after LHS implementation. However, LHSs also offered unique opportunities for contributors to be engaged in deliberative system design and effect change through distributed leadership. Ten flexible and overlapping roles were identified for contributors, serving three functions: System Shapers (designing and defining LHSs), Community and Capacity Builders (expanding and supporting LHSs), and Implementers (hands-on efforts). Participatory community engagement was more common amongst LHSs explicitly addressing health inequities.

**Conclusion:** This review provides an overview of engagement practices in LHSs, which build on and are constrained by engagement traditions in research and quality improvement. Findings offer practical examples to support LHS implementation, and a starting point for designing meaningful roles for contributors in LHSs.

#### MSSU Trainee Support Program Recipients: Lightning Blitz Talks Abstracts

## A way forward: A scoping review considering evidence-based interventions to mitigate burnout in critical care nurses

Presented by: Madison Hickey

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**Background:** Nurses represent most healthcare personnel and significantly impact the availability and quality of care received by patients. The World Health Organization predicts a shortfall of 5.7 million Registered Nurses worldwide by 2030, with 117,600 Canadian nurse deficit. As a result, Canada's health care system reports significant effects in quality and patient safety. Seventy-five percent of nurses in Canada report symptoms of burnout representing a key factor influencing nurses leaving.

**Purpose:** The guiding research questions are: 1) What interventions have been implemented to address burnout in critical care nurses since the COVID-19 pandemic? 2) What are barriers and facilitators to the implementation of these interventions? 3) What strategies have been used to implement these interventions?

**Methods:** This project will be conducted according to JBI methodology for scoping reviews. In collaboration with a library scientist, a search strategy has been developed to search MEDLINE, Embase, CINAHL, and PsycINFO. This review will include any study design reporting on Registered Nurses of any gender, age, race, and experience level in critical care, implementing interventions for burnout. Data will be extracted from included papers by two or more independent reviewers using a data extraction tool developed as a team.

**Impact:** This study aligns with Nova Scotia's key priority areas to improve retention of healthcare workers, healthcare delivery excellence and workforce strategy. This work will contribute to delivering safe, high-quality care, reducing safety events through a strengthened culture of quality and psychological safety.

# "They don't judge you, and they treat you like a human": Understanding the experiences of program users in an injectable opioid agonist treatment program *Presented by:* Adrienne Thornton

All Authors: Adrienne Thornton<sup>1</sup>, Caroline Brunelle<sup>1</sup>, Julia Scherf<sup>1</sup>

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Safer supply programs (SSPs) have been implemented across Canada to reduce the harms associated with the opioid toxicity crisis. SSPs provide individuals with access to pharmaceutical grade substances, that can be used as an alternative to the illicit drug supply. Injectable opioid agonist treatment (iOAT) falls under the realm of safer supply and usually provide individuals with opioid use disorder access to regulated opioids, daily supervised dosing, and additional resources. The purpose of the current study was to evaluate New Brunswick's first SSP from the perspective of program users, to better understand program experiences and outcomes. A gualitative design was implemented, with semi-structured initial interviews occurring with participants (N = 22) in November 2022, and follow-up interviews occurring six months later with most participants (N = 18). At the time of initial interviews, all participants were receiving iOAT at the River Stone Recovery Centre, located in Fredericton, New Brunswick. Participants were asked about their iOAT program experiences and outcomes during interviews, which were recorded, transcribed, and analyzed using an Interpretive Phenomenological Analysis. At the initial interviews, participants discussed the low-threshold/low-barrier and harm reductionist approach of the program, positive relationships with clinic staff, carry dose experiences, and program outcomes (e.g., improvements in mental and physical health, financial stability, safety, etc.). Participants mentioned certain barriers (e.g., time constraints, transportation challenges) and interruptions to their safer supply (e.g., from being hospitalized, arrested, etc.) that negatively impact program accessibility and experience. At the follow-up interviews, participants discussed challenges with the iOAT medications (i.e., medication type and composition), alternative programs, and longer-term outcomes. Although most outcomes were consistent with those identified at initial interviews, participants reported decreased clinic attendance at followup interviews. The results from the current study contribute to a better understanding of individual's experiences in New Brunswick's first SSP, which is especially relevant prior to the implementation of additional programs within Atlantic Canada. New programs should emphasize the low-threshold/low-barrier and non-stigmatizing environment aspects, as these were found to contribute to positive experiences and outcomes.

## Sleep for health in hospital and at home: The need to prioritize sleep for children with neurodevelopmental disabilities and their parents

#### Presented by: Momina Raja

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**Background:** Healthy sleep optimizes development and protects against chronic pain and mood dysregulation, conditions commonly experienced by children with neurodevelopmental disabilities (NDDs) such as autism spectrum disorder. However, over 80% of children with NDDs experience disordered sleep. These children often also have co-occurring chronic conditions requiring more frequent and longer hospital stays than average. Despite sleep being critical for healing, hospitalized children often experience disrupted sleep, which negatively influences parental sleep, with immediate and long-term implications for the physical and mental health of both children and parents. Consistent with existing literature, a study on the Pediatric Medical Unit (PMU) at IWK Health Centre showed noise and light were frequent disrupters for sleep of children and parents. Sound levels regularly exceeded World Health Organization (WHO) guidelines, while light showed minimal diurnal variation.

**Aim:** To improve opportunities for healthy sleep for children with NDDs and their parents during stays on the PMU and after returning home.

#### **Objectives:**

1. Collaborate with parents and healthcare providers (HCPs) to prioritize areas for improvement for sleep of children and parents.

2. Agree on strategies to achieve change in these areas.

Participants were recruited via IWK social media, posters, a Facebook group for parents of children with disabilities, and word of mouth. Participants (5 mothers) confirmed eligibility and provided consent. Four mothers of children with NDDs and/or complex medical conditions with hospitalization experiences engaged in a two-hour focus group session facilitated by a parent partner, conducted virtually over Zoom based on participant preference. The session aimed to validate our previous findings, discuss ways to support sleep for families both in hospital and at home, and prioritize potential interventions. Participants completed a demographic questionnaire via REDCap to provide insights into the breadth of experiences represented. Two further focus group sessions are planned: one with parents and one with HCPs with experience working on PMU (e.g., nurses). Audio-recordings from each session will be transcribed and coded through deductive thematic analysis techniques using NVivo software.

**Results:** We will present findings from our focus group sessions, which will guide the development and implementation of interventions. Next steps will be described.

#### Patient perceptions of pharmacist provided primary care

Presented by: Jennifer Isenor & Carla Garrett

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**Background:** Pharmacists play an important role in delivering primary care (e.g., prescribing, immunization), but there is limited understanding of how this care impacts patient experiences and outcomes. Existing literature focuses on patient willingness to seek care from pharmacists and their satisfaction with the care received. The health outcomes (e.g., improved quality of life) that matter most to patients when seeking primary care from pharmacists have not been examined in previous research.

Purpose: This study aims to identify and describe the patient reported experience and outcome measures that matter to patients when receiving pharmacist provided primary care.

**Methods:** A mixed methods study design is being used. Interviews and focus groups are being carried out with diverse populations (e.g. age, gender, ethnicity, rurality) in Atlantic Canada (including those who have and have not accessed pharmacist primary care clinics). This work aims to: develop patient-focused terminology around their experiences with pharmacist provided care; understand the perceived value of this care in meeting their needs; identify other primary care services they would value receiving from pharmacists; and identify outcome measures (e.g., improved quality of life) that are most important to patients. Themes identified through the analysis of interviews, will be refined through the focus groups. These results will inform the development of an online questionnaire to more broadly determine the pharmacist-led primary care outcomes that matter most to those living in Atlantic Canada.

**Results:** Research is in progress and results from interviews with patients will be available at the Summit. The findings will result in the identification and description of patient reported experience and outcome measures related to pharmacist provided primary care.

**Conclusion:** Centering primary care reform around patient experiences and outcomes is critical to ensuring that health system transformation responds to the needs of those accessing care. These results will be shared with key partners including the public, governing and regulatory bodies, and policymakers. In turn, the results will be used to develop frameworks and tools to assess pharmacist provided primary care and improve patient experience.

## Outcomes of a community paramedic service to support emergency department discharge: A case series

#### Presented by: Judah Goldstein

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**Background:** Interdisciplinary health care teams comprised of community paramedics can deliver person-centered care to support discharge from emergency department (ED). The community paramedic scope enables post-ED disease management, in-home clinical assessment, preventative or rehabilitative care, and needs-based interventions. In 2018, a community paramedic program was launched in Cape Breton Nova Scotia to support ED discharge. Our objective was to describe the population served and return to ED outcomes for those who received care.

**Methods:** This was a retrospective case series of ED referrals to a community paramedic supportive discharge service between December 18, 2018 (program launch), and May 1, 2023. A chart review of the paramedic electronic patient care record was conducted. Patients could be referred at the discretion of the ED physician. Referrals from in-patient units and specialist clinics were excluded. The primary outcome was return to ED measured at multiple time points (72 hours & 30 days).

**Results:** This analysis included 244 ED referrals. 53% (n=166) of referrals were female and the mean age was  $73.1\pm15.5$  years (range 15 to 101 years). The mean clinical frailty scale score was  $4.0\pm1.7$  (living with very mild frailty). There were 514 community paramedic encounters for the 244 cases referred (mean 2.1 visits per patient). Infectious disease related diagnoses (e.g. urinary tract infections and cellulitis) made up 17.6% of referrals. Return to ED was observed for 20% (n=50) of patients, accounting for 59 ED readmissions. Of those who returned to ED, 9% (n=22) were within 72 hours post-discharge, and 15% (n=37) were within 30 days.

**Conclusion:** Community paramedics provided post-ED care to a diverse group of patients with a comparable 30-day return to ED to other studies. Whether the service prevents and/or reduces duration of admission to hospital (e.g. via earlier recognition of condition deterioration) requires further exploration. Community paramedics may act as a safety net for some patients who transition from ED to home.

## Changing administrative workload in primary care in Nova Scotia and New Brunswick: Understanding the challenges and exploring solutions

#### Presented by: Ruth Lavergne

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**Background:** There is an urgent need to understand factors contributing to the gap between growing per-capita supply of primary care providers and declining patient primary care visits. Administrative activities, including work related to caring for individual patients and clinic administration, may play a substantial role in understanding changes to primary care workload. Factors internal to primary care clinics and health system context may impact the efficiency and coordination of both direct and indirect patient care activities.

**Methods:** We conducted qualitative interviews with family physicians, nurse practitioners, and administrative staff from primary care clinics in NS and NB. Questions focused on administrative workload relative to patient care and clinic administration, changes in workload over time, factors driving changes, and suggestions for local and system level refinements. A diverse sample was purposively selected. Braun and Clarke's reflexive thematic analysis was employed. Themes and sub-themes were identified. We then examined similarities and differences between family physicians, nurse practitioners and administrative team member interviews and explored variation across payment model, practice model, and practice settings.

**Results:** Information management is central to health care delivery, but often not valued or actively supported. Within primary care most administrative work requires both information management and clinical judgment. Strategies to address administrative workload must be tailored to the type of administrative work. A typology was therefore developed:

1) information management

- 2) information stewardship
- 3) information management and clinical judgement

4) information management and clinical judgement and value/normative judgement Some areas of concern included: lack of control over decisions concerning processes, need for improvements to electronic medical records and connectivity with other parts of the healthcare system, improved training for administrative staff, and the need for office-based guidelines.

**Conclusion:** Administrative workload directly impacts recruitment and retention of healthcare professionals and may influence primary care providers to choose options other than community-based primary care. Identifying practical strategies to make information management more efficient can support innovative healthcare models, improve patient care, and the wellbeing of primary care providers.

#### A critical examination of the social and structural factors impacting people of African descent with uterine fibroids in Nova Scotia

Presented by: Keisha Jefferies

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**Background:** Uterine fibroids are benign growths in the uterus. Correlation studies suggest that Black women are three times more likely to experience uterine fibroids, which are often larger, have an earlier onset, and include more severe symptoms compared to the general population. There is limited literature regarding people of African descent with uterine fibroids in Canada, including trans and gender diverse folks. The lack of disaggregated health data hinders the development of culturally appropriate health services. To address this evidence gap, this project includes three objectives:

1. To describe the social and structural factors that impact people of African descent with uterine fibroids in Nova Scotia.

To develop recommendations to enhance accessible, person-centered, and culturally appropriate healthcare for people of African descent with uterine fibroids in Nova Scotia.
To build research capacity to advance Black health research in Nova Scotia.

**Methods:** This qualitative study is guided by Black feminist theory and uses a combination of interviews, demographic forms, and focus groups to perform an intersectional analysis of the experiences as well as the social and structural factors that impact of people of African descent with uterine fibroids in Nova Scotia. Data analysis involves thematic analysis and descriptive statistics to classify experiences into conceptual themes and present demographic information.

**Anticipated Impacts:** This study will describe how people of African descent in Nova Scotia are impacted by uterine fibroids. Additionally, in collaboration with community partners, the study findings will be used to develop a series of health service and policy recommendations to improve care for people of African descent with uterine fibroids. Finally, this study offers a unique mentorship opportunity that supports capacity building for Black health research in Nova Scotia.

**Conclusion:** This study addresses a long-standing evidence gap in Black health research, including ongoing issues for priority populations who continue to experience health inequities and disparities from decades of systemic and institutional discrimination in Nova Scotia. Through interdisciplinary, international, community, and health system collaboration, this study will provide foundational evidence to inform future research in the area of Black population health.

## Transforming lung cancer screening in NS: A person-centred, equitable, inclusive, and accessible approach

Presented by: Eileen Kilfoil & Kendra Slawter

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**Background:** Lung cancer remains a leading cause of cancer-related deaths. Early detection via organized screening is vital to improve outcomes. Reliance on opportunistic screening (i.e., outside of guidelines or organized screening programs), creates barriers to screening that can delay treatment, may miss individuals at high risk of developing lung cancer and cause undue harm. Lack of public awareness regarding lung cancer risk factors and available smoking cessation supports further increases lung cancer risk. The need for an organized lung cancer screening program in NS was evident to improve equitable access to screening and treatment outcomes. Extensive engagement with patients and equity-seeking communities shaped the development of the Nova Scotia Health Cancer Care Program Lung Screening Program, which launched in Central Zone in January 2024.

**Methods:** Informed by an equity, diversity, inclusion, reconciliation, and accessibility (EDIRA) lens, community engagement took place at the level of 'inform', 'consult', and 'collaborate' to shape the development and implementation of the program. Information sessions took place with leaders of equity-seeking community groups, followed by consultation via focus groups.

**Results:** Patients and community members identified specific barriers to screening awareness and uptake among historically marginalized and high-risk groups such as fear, stigma, historical mistrust of medical systems, and geographic/transportation challenges. This feedback informed the design of a comprehensive education, prevention, and screening program. Community feedback indicates that the need for co-designed/created, culturally specific processes, pathways, and resources remains relevant to improving uptake of screening among equity-seeking groups.

**Conclusion:** Extensive community engagement led to the development of a Lung Cancer Screening Program in NS. The program aims to improve trust in the healthcare system. Resources are strategically allocated to serve groups at highest risk to reduce barriers to screening among equity-seeking populations. From 2024-2026, EDIRA-focused community engagement will drive the planned provincial scale-up of the program. Part program's mission is to break down systemic barriers faced by equity-seeking groups. Next steps include hiring community liaisons, co-designing expansion, co-creating culturally specific resources and evaluation of community engagement and patient satisfaction.

## Voices that count: Providing culturally inclusive mental health and substance use health service delivery to youth of African descent

Presented by: Ifeyinwa Mbakogu, Lotanna Odiyi, & Remi Agu

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The Canadian Institutes of Health Research (CIHR) funded project highlights the structural and systemic issues that moderate the lives and wellbeing of youth of African Descent, their families and caregivers seeking mental health and substance use (MHSU) services in Nova Scotia and investigate the approaches to health care delivery adopted by health providers, in ensuring the delivery of inclusive and equitable care. This will entail exploring the perceptions of barriers to care, sources of strengths and challenges as expressed by youth of African Descent, their families and caregivers as they receive MHSU services in Nova Scotia. To achieve this, our study is situated within Critical Race Theory, Postcoloniality and Afrocentricity to accommodate the multifaceted nature of experiences impacting negotiations for access to health care for participating youth of African Descent, their caregivers and healthcare providers. A mix of data gathering tools that include semi structured interviews, focus group discussions (FGDs), artsbased methods (ABMs); and an online survey targeting healthcare professionals is adopted in recruiting youth of African Descent that are between 18-25 years, their family members and/or care givers resident in Nova Scotia and health service providers working with persons of African Descent accessing MHSU services in Nova Scotia.

The research hopes to understand what health care practitioners perceive as potential barriers in accessing MHSU care; and how they might be able to apply culturally responsive tools to align with the multiple identities of youth, families, and caregivers of African Descent seeking MHSU care in Nova Scotia. Ultimately, by assessing the MHSU care delivered by health providers and the MHSU care received by previously silent youth, families, and caregivers the research hopes to inform the development of comprehensive standards for MHSU assessment and service delivery that is inclusive of the w/holistic needs of marginalized groups.

## **#1.** Implementing and evaluating a framework to support the transition from pediatric to adult care: A mixed methods research protocol

Presented by: Megan Churchill

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**Background:** A Transition of Care (ToC) framework has been developed by a group of youth, caregivers, healthcare providers, and community partners at IWK Health to help support the transition from pediatric to adult health care. The purpose of this study is to develop a strategy to support the implementation and sustainability of the ToC framework and evaluate its impact on patient and healthcare provider outcomes with at IWK Health and NS Health.

**Methods:** This project will employ a research co-production approach, involving youth, caregivers, administrators, and healthcare professionals at each stage. Pre-implementation: Working with youth, caregivers, and healthcare providers we co-designed implementation strategies for the ToC Framework. Next, team members will meet with healthcare providers, patients, and families to determine i) implementation strategies they would like to use in their clinics: and ii) goals for implementing the ToC Framework. Lastly, youth and caregivers will be recruited to complete a questionnaire via REDCap to assess health self-management skills. Implementation: Healthcare providers will be interviewed twice during the implementation period to determine barriers and facilitators related to implementing the ToC Framework. Youth and caregivers will be interviewed once during the implementation period to describe their experiences with the ToC Framework. Lastly, at the end of the implementation phase, youth and caregivers will be recruited to complete the REDCap questionnaire to assess their health selfmanagement skills after using the ToC Framework. Post-implementation: Three chart audits will be completed. The first two will be completed to determine whether there were increases in use for two existing transition support tools, the Readiness Checklist, and the You're in Charge program. The third chart audit will be completed to determine whether patients transitioning from pediatric to adult care during the implementation period accessed care in the adult health system.

**Anticipated Impacts:** We anticipate that by using the ToC Framework, youth and caregivers will feel more supported during their transition from pediatric to adult care.

**Conclusion:** These findings will be used to inform the implementation of ToC Frameworks within other units at IWK Health and NS Health, and ultimately improve the transition in care for children and youth.

## **#2.** How the Data Access Support Hub (DASH) enables external data linkage to support multi-regional research

#### Presented by: Robyn Kydd

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Health Data Research Network Canada (HDRN Canada) supports transformative and worldleading multi-regional health data use and research, with over 13 provincial/territorial and pan-Canadian data centres collectively holding more than 500 data assets. While the network and its data centres actively seek opportunities to add new administrative or clinical data assets, there will always be individual projects that need to link to external data.

Data held by the network's data centres can be linked to external data. External data can come from several sources, including but not limited to a researcher's clinical trial or other research study, registries (e.g., disease or population-based), and other organizations or custodians. To clarify and streamline access to and linkage of data assets external to the network, data centres were widely consulted by the Data Access Support Hub (DASH) team. They identified, modeled and harmonized local linkage processes and other requirements for researchers who request data from multiple custodians. The two most common external data linkage models used personal health information (PHI) to perform linkages at either: 1) a network data centre, or 2) a third-party organization (e.g., Ministry of Health, affiliated data organization, etc.). The data centres reviewed and transferred the final data to a trusted environment in both data linkage models.

DASH has now modelled and documented local linkage processes, agreements and approval steps for cases where linkage using PHI is done both within and outside of the network. This information is provided by DASH as a resource for researchers and data centres, helping to streamline data access and external linkages to data assets across the network.

The network is presently working on nine data access requests (DARs) that involve external data linkages, with two completed to date. Five of the current DARs involve Maritime data centres, with Health Data Nova Scotia involved in all five projects and the New Brunswick Institute for Research, Data and Training involved in one project. Collaborations with data centres, affiliated organizations, and researchers are foundational in the development of linkage models at HDRN Canada. Linkage models help to increase the efficiency and standardization of linkages across data sources within Canada, so that more data sources can be leveraged for health research and supporting learning health systems.

# **#3. Moving from data to knowledge: Engaging Islanders in mapping social and health factors to support equity-informed cross-sectoral responses to climate change in Prince Edward Island**

Presented by: Kate Kelly

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Equity-deserving groups facing health and social challenges are the first affected and hardest hit by climate change. In Prince Edward Island (PEI), recent reports highlight the need for quantitative evidence to better understand these differential impacts and support coordinated cross-sectoral responses. Knowledge of health and social inequities in PEI can enhance decision-making across healthcare, public health, social service, environmental and community sectors to improve community health outcomes.

Community members, decision-makers and researchers will collectively generate knowledge from area-based health and social indicators in census and administrative data. The data will be explored, selected, interpreted, mapped and contextualized to identify PEI populations that are disproportionately impacted by climate change. We will discuss and learn together while creating meaningful research outputs for a variety of knowledge users. Our flexible engagement strategy will prioritize diversity across equity-deserving groups, professions and geographical locations. Research Advisory Councils will guide the project, regularly convening community members and decision-makers to inform study methods, data interpretation and user-friendly outputs. To ensure the voices of equity-deserving groups are heard, individuals preferring less formal or time-intensive roles will be encouraged to contribute their lived experience and expertise in their preferred manner.

Key activities will include: 1) refining health and social indicators, geographic boundaries and maps that maximize accuracy, clarity, accessibility and usability for community and government stakeholders; 2) creating indicator maps that highlight equity-deserving areas with narratives and contextual information; 3) evaluating engagement processes and lessons learned; 4) conducting a workshop to assess study outputs and their usefulness in promoting equity-focused community health decisions.

This study will highlight the value of using existing health and social data for equity-informed decisions. Working with community members, government staff and researchers to translate data into actionable knowledge will foster mutual learning and strengthen relationships that are important in equity-centered learning health and social systems. By prioritizing perspectives of equity-deserving groups, this approach aims to support informed, equitable cross-sectoral decision-making in response to climate change in PEI.

## #4. Charting the literature regarding Black people of African descent with uterine fibroids: A scoping review protocol

#### Presented by: Keisha Jefferies\*

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**Background:** Evidence suggests that Black women are three times more likely to experience uterine fibroids compared to the general population. Black women experience larger uterine fibroids with an earlier onset and more severe or debilitating symptoms. Reported symptoms include pelvic pain, bladder issues, and heavy or abnormal menstrual bleeding. Charting and describing the current state of literature will be used to identify existing evidence gaps and to inform future primary research regarding Black people of African descent with uterine fibroids. The objective of this scoping review is to describe the extent and type of literature available regarding Black people of African descent with uterine fibroids globally.

**Methods:** This scoping review follows JBI scoping review methodology and the PRISMA-ScR Checklist. Inclusion criteria for this review follows the PCC (population, concept, context) mnemonic, which includes sources focused on Black people of African descent [population] with uterine fibroids [concept] globally [context]. A comprehensive search strategy was developed in collaboration with a health science librarian and was used to retrieve peer-reviewed and gray literature. Select databases were searched from inception and no language restrictions were applied. Relevant sources were uploaded to Covidence, where title and abstract screening as well as full-text review was performed by two independent team members. Two independent team members will complete data extraction. Review findings will then be classified into conceptual categories, alongside tables and figures as necessary.

**Anticipated impacts:** Charting the available literature on this issue will illuminate existing evidence gaps as well as opportunities for future research to address intersectional, geographical, and historical considerations. Additionally, the review findings may provide insight for health policy and service delivery to enhance the healthcare received by Black people of African descent with uterine fibroids.

**Conclusion:** Growing attention on the debilitating and disproportionate impacts of uterine fibroids reinforces the timeliness and necessity of a systematic and comprehensive review of the literature regarding Black people of African descent with uterine fibroids globally. To effectively address this emergent health issue, it is necessary to understand the current state of knowledge, identify evidence gaps, and develop recommendations for future research.

\*Was not presented.

## **#5.** Belonging and success for Black nursing students in Nova Scotia: A mixed method study

Presented by: Keisha Jefferies\*

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**Background:** Black nursing students have a complex history in nursing education in Nova Scotia and Canada. This complex history results from the race-based denial of admissions into nursing programs, for prospective Black students. Limited research suggests that there are multiple factors across academics, clinical, and everyday life, which impact belonging and success for Black nursing students. These factors are reinforced by persistent gaps in institutional policies and programs related to the recruitment and retention of Black students in nursing programs. The first aim of this study is to examine the clinical, academic, and life experiences of Black nursing students in Nova Scotia. The second aim is to identify the facilitators and barriers to belonging and success for Black nursing students in Nova Scotia.

**Methods:** This mixed-method study uses Black Feminist Theory to center and examine the experiences, voices, and ideas of Black nursing students in Nova Scotia. Eligibility criteria includes participants who 1) identify as Black and 2) are currently enrolled in a nursing program in Nova Scotia or completed a nursing program within the past two-years. Data collection involves semi-structured interviews and surveys. Data analysis includes thematic analysis and descriptive statistics to classify and visualize the data.

**Anticipated impacts:** The results will inform the development of policies and programs that support belonging and success as well as recruitment and retention strategies for Black nursing students in Nova Scotia. Knowledge gained from this study will be used to refine the Pamoja Nursing Program, which is an evidence-informed initiative designed to enhance the recruitment and retention of Black nursing students. Additionally, the results will inform nursing curricula by elucidating anti-Black racism in nursing education. Addressing the challenges reported by Black nursing students and the issue of anti-Black racism in nursing education has implications for Black health outcomes, culturally competent care, and increasing representation within the nursing workforce.

**Conclusion:** This study addresses an evidence gap regarding the clinical, academic, and life experiences of Black nursing students in Nova Scotia. This study will also have an indirect impact on Black population health outcomes.

\*Was not presented.

## #6. Co-designing ED-PATCH: Working with patient/public partners and clinicians to refine a patient-managed discharge communication tool

#### Presented by: Leah Boulos

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**Background:** The Emergency Department Patient-Activated Transition from Care to Home (ED-PATCH) tool is designed to empower patients and caregivers to use their mobile device to track important information throughout their ED visit. Patient notes are checked by a clinician before they leave, and patients retain a digital summary of their visit for their own records. A prototype of the tool has undergone usability and feasibility testing. This poster will describe the co-design process used to refine the tool prototype in Nova Scotia, where our goals were to make the tool accessible and appropriate for patients and caregivers of varying health literacy levels, to those whose first language is not English, and to busy ED clinicians.

**Methods:** We assembled a working group that included patient/public partners with lived experience as immigrants who work with other newcomers to Canada, ED nurses and doctors from urban and rural areas, and computer science professionals. Meeting biweekly over a three-month period, the group collaborated to identify the essential components and technical specifications of ED-PATCH, and to edit its content. The refinement period will be followed by a second round of usability testing, after which the tool will be subject to a four-year hybrid type 1 effectiveness-implementation trial.

**Results:** The list of core components developed by the working group includes features such as speech-to-text capability, built-in translation functions, and the option for ED clinicians to check patient summaries remotely on their own devices in order to minimize impact on ED workflows. The tool content has been shortened and re-worded to improve clarity for users of all literacy levels. It has also been refined to involve as little free-text data entry as possible, making it more accessible to those with limited ability to type on a mobile device during their ED visit.

**Conclusion:** Our experience working with this diverse group has led to rich discussions about the core components and content of ED-PATCH. By working together, we have co-designed a refined version of the tool that we anticipate will be more accessible to a diverse patient population and more likely to be adopted by ED healthcare providers.

## **#7.** How often and why are residents from assisted living facilities visiting the emergency department

#### Presented by: Pamela Jarrett

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**Background and objectives:** As our population ages, an increasing number of older adults are living in Assisted Living Facilities (ALFs); also referred to as Special Care Homes (SCHs) in New Brunswick. There are 7263 SCH beds across the province compared to 5274 Nursing Home (NH) beds. The level of professional healthcare, social care, and medical care varies between homes and is less than what is available for NH residents. Research has found higher Emergency Department (ED) utilization by ALF residents compared to NHs. Additionally, characteristics of SCHs such as number of beds, distance to the ED, level of care, and the amount/type of health and medical care, also impacts the need for ED visits. The purpose of this study is to evaluate ED utilization by SCH residents in New Brunswick's largest health region, Horizon Health Network (HHN).

**Methods:** All SCH residents who visited an HHN ED between January 1, 2023 and December 31, 2023 will be identified. Charts from those who visited one of the four regional hospital EDs will be reviewed to determine the reason for the visit, need for admission to hospital, and appropriateness of visit.

**Anticipated impacts:** It is anticipated there will be different utilization patterns across the province. Utilization will be related to SCH characteristics and there will be several potentially avoidable ED visits. Descriptive data will include the number of ED visits, reasons for visits, reasons for hospital admission, appropriateness of the visits, and differences in utilization by regional hospital. Correlations between SCH characteristics and ED utilization in each HHN area will also be reported.

**Conclusion:** This work will generate data that will allow a better understanding of the needs of the SCH residents and provide insight into how improvements could be made in the health and medical care models in these facilities to optimize the care these residents receive.

## **#8. Transitions in care for older adults in the community: The need for collaboration and transformational change**

#### Presented by: Pamela Jarrett

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**Background and objectives:** Canadians are enjoying longer lives, however, with more older adults living with chronic diseases, dementia, and frailty the health and social systems struggle to support these adults in the community and support transitions to higher levels of care. This often leads to a "crisis" either due to medical or social reasons and these adults often ends admitted to hospital, where they remain waiting to transition to the appropriate level of care in the community. In 2024, over 30% of New Brunswick's 2,797 hospital beds are occupied by older adults waiting to transition back to the community. In addition, the number of older adults on the waiting lists for nursing homes is at an all-time high.

Collaboration with health and social care providers and administrators in hospitals, home care programs, nursing home, special care homes with policy makers is needed to deal with this crisis and plan for the future.

**Methods:** While there are many factors contributing to the challenge of ensuring appropriate transitions in care for older adults there are three areas that merit special consideration: fragmented care, frailty, and access.

A program of research has been developed to begin this collaborative effort to address the challenges. This is called the TRAnsitions in Care for Older Adults (TRAC) research group. This is being led by a core team. These projects both underway and being planned that involve representation from hospitals, policy makers, administrators, government, community stakeholders, researchers, clinicians, older adults, and their families to better understand the current situation.

**Results/Anticipated Results:** The TRAC Program of Research projects that are under way and being planned will be presented and overviews provided. Each project is aligned with one of three themes: fragmented care for older adults, care of older adults through a frailty lens, and access, availability and navigation through health and social care systems.

**Conclusions:** This work is an example of a Learning Health System with opportunities for further enhancement and growth. Opportunities for further collaborations and partnerships are welcome to continue to grow this work so that it can help make a meaningful difference.

## **#9.** Increasing equity in the service provision of autism interventions for children in Nova Scotia

Presented by: Rebekah Bercovici

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**Background:** Autism spectrum disorder (ASD) is a common neurodevelopmental condition characterized by differences in social interaction, language development, and communication skills, alongside patterns of repetitive behaviour (APA, 2013). Despite an increase in minority language-speaking families in Nova Scotia, parent-mediated interventions for autism are delivered predominantly in English, limiting access to families who are not proficient in this language. A crucial factor influencing the success of parent-mediated interventions is the alignment between the intervention and the family's culture. Therefore, it is essential that services are provided in a culturally competent and linguistically appropriate manner (Albin et al, 2022).

**Objectives:** (1) Determine if the existing service delivery model of parent-mediated interventions used in Nova Scotia is acceptable and compatible with the cultural background of parents of children at risk or diagnosed with ASD from minority language backgrounds and (2) propose adaptations or modifications to specific components of the intervention that require it.

**Methods:** An assessment of the current strategies used in parent-mediated programs in Nova Scotia to support social communication skills of minority language autistic children will be conducted to determine their feasibility and cultural appropriateness. Twenty parents of toddlers and preschoolers at risk of or with a diagnosis of ASD who speak a minority language and 20 interventionists who currently provide services to these children will participate in focus groups.

**Anticipated impact:** This research will contribute to health equity and inclusion in Nova Scotia by strengthening access to the care and services available for underserved populations, increasing the uptake of intervention programs for families of autistic children from minority language backgrounds. It will also contribute to the planning of delivery of services to families who might have limited access as it will inform which minority languages are spoken in the province and will help educate other health care providers across the province, resulting in capacity building and enhanced access to services.

**Conclusion:** This project can contribute to the implementation of culturally sensitive interventions for autistic children from diverse linguistic backgrounds as it will reach underserved populations, reducing wait times and costs, and therefore improving children's social communication skills.

#### **#10.** Development of a framework to facilitate a data assembly plan for multiregional research

#### Presented by: Katelyn Frizzell

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**Background:** Health Data Research Network Canada (HDRN Canada)'s Data Access Support Hub (DASH) provides services to facilitate multi-regional research. Before HDRN Canada, accessing data from multiple data centres in Canada was complex and burdensome to researchers. DASH is streamlining the data access process by developing a framework for specifying a project's data assembly plan (DAP), to accompany a data access request (DAR) form, to support researcher's in requesting data from multiple data centres across Canada.

**Approach:** HDRN Canada's network of 13 provincial/territorial and pan-Canadian data centres worked to understand the variation in processes and local requirements that exist when submitting a request for data and the development of a project DAP. A review of regional forms and processes, as well as consultations with the research community was completed to identify critical requirements for inclusion in the DAP. An iterative approach was used throughout the development of the DAP, with collaboration from DASH data centres and researchers to ensure the plan met local requirements and user needs.

**Results:** In April 2022, the centrally provisioned, standardized DAP form was launched. The DAP allows for specific details about a project's data requirements, cohort definition(s), data extraction(s) and analytical plan to be uniquely documented, and to ensure consistency across the DASH data centres providing data. This framework can also support the linkage of data and safeguard the quality of the results during the analytical stages of the request.

Since the launch, approximately nine new projects have used the DAP (two projects that have included at least one Maritime province), and preliminary feedback from users has been positive. Collection of user feedback and enhancements is ongoing.

**Conclusion:** The DAP is an important step forward in streamlining the process for requesting data from multiple provinces/territories, organizations, and data sources. The DAP and other resources support researchers in undertaking multi-regional research in Canada. Further process improvements are anticipated to address user experience feedback and to promote quality research.

# #11. Bridging the gap from science to uptake: Criteria and processes for adoption/scaling of psychosocial interventions for children with neurodevelopmental disabilities and families: A CHILD-BRIGHT study

Presented by: Kimberly McIvor

**All Authors:** Kimberly McIvor<sup>1</sup>, Karen McEwan<sup>1</sup>, Samuel Ragot<sup>2</sup>, Janet Curran<sup>1,3</sup>, Lucyna Lach<sup>2</sup>, Patrick McGrath<sup>1</sup>

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**Background:** Many of the interventions designed to optimize the development and quality of life of children with neurodevelopmental disabilities (NDD) are psychosocial, yet little is known about how these interventions are moved from the research setting into practice. This study seeks to bridge the gap between research and practice by exploring the criteria and processes used by scientists and decision-makers in the development, testing, and scaling/adoption of psychosocial interventions for children with NDD and their carers.

**Methods:** This is an exploratory mixed-methods study that will use both quantitative and qualitative data sources. Guided by the Consolidated Framework for Implementation Science (CFIR) 2.0, we will use surveys and semi-structured interviews to explore the criteria and processes that each group of participants considers to be most influential in their work. Purposive and snowball sampling will be used to recruit approximately 250 decision-makers (from healthcare, education, and social services) and 30 scientists from across Canada for participation in the surveys. A subsample of survey participants will be selected to take part in a follow-up interview. Interviews will be conducted until data saturation is attained based on recurring codes and themes. An advisory committee of leaders, scientists, and youth/carers with lived experience will be engaged at every phase of the project to ensure relevance and to support integrated knowledge translation.

**Planned Analysis:** Surveys will be analyzed using descriptive and inferential statistics, with results for decision-makers and scientists summarized separately for between-groups analysis to determine alignment and/or differences between the processes and criteria used by scientists and those used by decision-makers. A reflective thematic approach will be used for interview data, using both deductive and inductive coding based on factors from the CFIR and novel themes. Qualitative and quantitative data will be integrated to allow an in-depth understanding of our research questions. Barriers and facilitators to the implementation of psychosocial interventions will be explored.

**Conclusion:** Given challenges around the provision of supports for children with NDDs (Edwards et al, 2022). It is anticipated that this study will provide information that can support the development of increased pathways for the adoption of evidence-based interventions into practice.

### #12. Implementation science for children with developmental brain-based disabilities: Exploring the context using 12 real-world projects from the CHILD-BRIGHT Network

Presented by: Simonne Collins

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**Background:** All children have unique needs when it comes to care compared to adults. Children with developmental brain-based disabilities are a vulnerable group that may have greater caregiving needs than other children, considering the context of additional needs for care at home, at school and multidisciplinary healthcare teams. When implementing healthcare interventions for children with developmental brain-based disabilities it is critical to consider the child's whole context to maximize the uptake of the intervention. It remains unknown which aspects of context implementation teams consider when designing implementation strategies.

**Objectives:** Using 12 real-world implementation projects supported by the CHILD-BRIGHT Network, this project seeks to explore the context of the selection, application and evaluation of implementation science methodologies used for interventions supporting children with developmental brain-based disabilities. Contextual considerations will be evaluated from the perspective of implementation scientists, postdoctoral fellows and patient-partners involved in each of the 12 projects.

**Methods:** Implementation methodologies will be mapped across projects using a content analysis approach, based on project protocols to understand which implementation frameworks are used at each stage of the project. Semi-structured interviews will be conducted to understand the contextual considerations made when selecting implementation frameworks at the project outset, during the project and when evaluating implementation outcomes.

**Anticipated outcomes:** In undertaking this project, we will inform providers and healthcare systems of the perhaps unique contextual considerations when implementing interventions to support this population of children and families, whether the intervention is systems, provider or patient focused. This knowledge will add to growing understanding of how to improve healthcare efficiency, reach and speed of uptake.

**Conclusion:** This project leverages the unique opportunity presented by the CHILD-BRIGHT Network to study the implementation context of 12 varied interventions all designed to support the wellbeing and development of children with developmental brain-based disabilities.

## **#13.** Disparities in outcomes by race and ethnicity in the Canadian Cystic Fibrosis population

Presented by: Miriam Schroeder

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**Background:** Cystic Fibrosis has historically been described as a disease that affects people of European ancestry. Consequently, much of what we know about CF is based on evidence generated from data collected in white individuals. This may lead to systematic bias in how non-white people with CF are diagnosed and treated. In this study we compared clinical outcomes between the white and non-white people with CF in Canada.

**Methods:** Canadian CF Registry data collected between 2000 and 2019 were used in this population-based cohort study. Demographic characteristics and clinical outcomes of people with CF identified as white and those identified as non-white were compared. Analyses were adjusted for cohort effects but not socioeconomic status.

**Results:** Between 2000 and 2019, 5516 people with CF in the Registry were identified as white and 323 were identified as non-white. At diagnosis, the white and non-white groups were similar with respect to sex at birth, age at diagnosis, prevalence of pancreatic insufficiency, and meconium ileus. The non-white group had similar rates of CF-related complications and bacterial infections compared to the white, but worse lung function, worse nutritional status, lower treatment rates, and higher rate of hospitalizations. During the 20-year study period, the non-white group had a 1.85 higher risk of death compared to the white group (HR 95%CI 1.39; 2.47).

**Interpretation:** There is an urgent need understand why outcomes for Canadians with CF differ between white and non-white individuals, including the role of socioeconomic circumstances.

# #14. Improving exercise treatment prescription and program adherence for the management of chronic low back pain: A protocol for a mixed-methods implementation study

Presented by: Samuel Silva

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**Background and objectives:** Chronic low back pain (CLBP) is the leading cause of disability globally and exercise is a first-line treatment for this condition. Exercise treatments are complex and require active participation from patients. There is a need to investigate how to improve exercise delivery and adherence in patients with CLBP.

I will identify 1) barriers and enablers that exercise providers encounter in prescribing exercise for patients with CLBP and how treatments have been individualized; and 2) factors that may influence patients' adherence to exercise.

**Methods:** This will be a mixed-methods study with qualitative (Stage 1) and quantitative (Stage 2) components. I will recruit exercise treatment providers and patients with CLBP seeking/undergoing treatment in primary care settings.

In Stage 1, I will use interviews with pre-specified questions and observations to evaluate three implementation outcomes: acceptability (acceptability of various exercise approaches to treat CLBP), adoption (how exercise treatments have been prescribed), and feasibility (barriers and enablers to exercise adherence from a patient's perspective). The adequate sample size will be determined by saturation. Thematic analysis will be used to analyze the data.

In Stage 2, I will develop a predictive model using regression analysis to predict poor adherence to exercise treatments. The selection of candidate predictor variables to be included in the statistical models will be based primarily on results from Stage 1 and data from previous studies. Adherence will be assessed 12 weeks after enrollment and measured through clinic attendance records, dropouts, and daily logs. The required sample size will be calculated a priori and will depend on the selected predictor variables. I will assess model performance (calibration and discrimination) and internally validate the model (bootstrapping).

**Anticipated impacts:** Understanding the barriers and enablers to exercise implementation and adherence is important for providing more individualized treatment to patients and proposing strategies that maximize patient engagement (e.g., more flexible ways of providing exercise). This could help reduce the burden of CLBP on the healthcare system and improve patient outcomes.

**Conclusion:** Exercise implementation and adherence can be challenging in individuals with CLBP, and this study will inform/guide strategies to overcome some of these challenges.

# **#15. What publicly funded models of home care exist in Canada and beyond and what are their characteristics and quality: A scoping review**

Presented by: Marilyn Macdonald

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**Background and objectives:** The proportion of older adults in Canada is growing, and an increase in individuals with health challenges that require home care will have implications for home care services. There are concerns about inadequate staff resources to meet home care needs including amongst families who often feel dissatisfied with the level of care. The objectives of this scoping review are to identify home care models, associated characteristics, strengths and areas for improvement in Canada and countries with similar healthcare systems, and to analyze evaluations of home care models in relation to quality, patient and family satisfaction, and level of integration in the health and social care systems.

**Methods:** A scoping review using JBI methods will be conducted to review studies about home care and home care models from 2005 onward. A JBI trained library scientist will conduct searches in Medline (Ovid), Scopus (Elsevier), Embase (Elsevier), PsychInfo (EBSCO), and CINAHL (EBSCO). Search results will be uploaded to Covidence and undergo title, abstract, and full text screening followed by data extraction from included studies, and analysis. Both quantitative and qualitative study designs will be considered. Data extracted will include publication year, countries of origin, home care model, characteristics, designs, population, evaluations, key findings, and research gaps.

**Results or anticipated impacts:** Anticipated results include an understanding of successful home care characteristics and models in Canada and countries with similar health care systems, gaps in home care and potential opportunities for improvement. Target knowledge users of this review include policymakers, decision-makers, Health Authorities, Ministries of Health, Centres on Ageing, Canadian Home Care Association, professionals working in the realm of home care, home support, and elderly health, and older adults and/or their family members with questions about home care.

**Conclusion:** This work aims to contribute to bridging the gap between existing models of home care and what clients and their families want from this service. Engaging our citizen partners in the conduct of this review and in the co-production of key messages from the report relevant to citizens is foundational to the successful delivery of home care for all involved.

# **#16.** Gaps and barriers to public health: Emerging themes from community engagements across Canada

#### Presented by: Brianna Legere

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**Background and objectives:** We present emerging themes from consultations with equity deserving communities to develop a public health governance framework for Canada. As part of a CIHR-funded project to develop a Canadian public health governance framework, community representatives were asked to discuss public health strengths and weaknesses during and since the COVID-19 epidemic, who they trusted to make public health decisions, and the values that should inform public health policy, practices, and decision-makers.

**Methods:** Virtual focus groups were conducted across Canada during May and June of 2024. Representatives of equity deserving communities in five provincial jurisdictions (Nova Scotia, Quebec, Ontario, Alberta, and British Columbia) and two specific populations (Indigenous people and frontline public health workers) were engaged in 2-3 hour semi-structured discussions that included a total of 56 participants. Participants were recruited based on their lived experiences and relationships within equity-deserving communities. Transcripts of the data were managed using NVIVO, inductive qualitative techniques were used to code and analyze the data and intercoder reliability was used to assess the coding.

**Anticipated impacts:** The results of these analyses are being used to develop a series of casebased scenarios for national and international deliberative engagements with legal scholars, social scientists and experts in public health policy and epidemiology towards the development of a national Population and Public Health Act: An Act to Care.

**Conclusion:** While comparative analyses continue until September 2024, initial findings demonstrate some consistent themes across provincial jurisdictions, including a sense of precarity related to individual and population health, that public health services across Canada are largely opaque and inaccessible, and emphasizing the importance of local community-led and community-tailored services to the wellbeing of Canadians. Jurisdictions also identified different and varying levels of need and usage of public infrastructure, funding, and resources contributing to their sense of well-being. Community-led initiatives were found to step in to fill gaps left by the hollowing out of the public health system.

#### #17. "... I learned how to see other people's perspectives and compare mine to find differences and similarities": Documenting the process and experiences of youth researchers within Health Promoting Schools research studies in Nova Scotia, Canada

Presented by: Hilary Caldwell

**All Authors:** Hilary Caldwell<sup>1</sup>, Julia Kontak<sup>1</sup>, Rena Kulczycki<sup>1</sup>, Camille Hancock Friesen<sup>1,2</sup>, Sara Kirk<sup>1</sup>

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**Background:** Health Promoting Schools (HPS) is an evidence-based, whole school approach to health promotion that engages partners across the school community in planning, processes, and actions related to factors to improve student health and learning outcomes. An HPS model has been formally adopted in Nova Scotia since 2005; however, understanding of youth perspectives about HPS is limited. Youth Participatory Action Research (YPAR) is an approach to research that engages youth across the entire research process. The peer researcher method is a YPAR technique in which youth are trained in research and ethics to interview their peers.

**Objectives:** The purpose of this study was to: (i) describe the process of engaging youth as peer researchers in two HPS projects and (ii) understand the peer researchers' perspectives of their experience throughout the project.

**Methods:** Youth from across Nova Scotia, Canada in grades 7–10 (ages 12–16) were recruited as peer researchers in Summer 2021 (n=10) and in Summer 2022 (n=11). The project included three stages: (i) peer researcher training, (ii) practicing, recruiting and conducting interviews and (iii) data interpretation workshop (2022 group only). To understand the peer researcher's experience, quantitative data were collected from an evaluation questionnaire in 2021 and 2022. Outputs were produced using descriptive statistics. Qualitative data were collected through a focus group and interviews in 2022 and analyzed using inductive content analysis.

**Results:** Most youth provided positive feedback on the training with satisfaction scores of 8.8/10 (2021) and 8.7/10 (2022). In both 2021 and 2022, most youth agreed or strongly agreed that: the training was engaging and interactive (90%), the training taught them about research ethics (80-90%), and they felt supported during the training (90-100%). Qualitative analysis from 2022 indicated benefits to the peer researchers including opportunities to build interview and social skills and learn about other's perspectives.

**Conclusion:** This study provides a detailed overview of the process and experience of using the peer researcher method in HPS research projects. The research also highlights the benefits and challenges of engaging youth in the entire research process, providing guidance to other researchers using an YPAR approach in their work.

# #18. Development of a new treatment for spatial neglect post-stroke: Protocol to test feasibility and effectiveness

#### Presented by: Catrina MacPhee

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**Background:** Spatial neglect is a common attentional condition post-stroke linked to poor rehabilitation outcomes. In previous research, we have validated a game-like computerized prism adaptation procedure (Peg-the-Mole, PTM) for the treatment of spatial neglect. Our goal now is to extend this treatment to iPad administration and to test the protocol in stroke inpatient and home settings.

**Objectives:** To examine the short- and longer-term effectiveness and feasibility of PTM treatment for neglect post-stroke in inpatient and home settings.

**Methods:** Forty participants with right-hemisphere stroke experiencing mild to severe symptoms of neglect will be quasi-randomized to two groups stratified by neglect severity: Use of PTM with 15-degree prism goggles (intervention) or 5-degree prism goggles (active control). Participants will complete ten treatment sessions within two weeks with the PTM prism adaptation procedure for 15 minutes per day. Blinded assessments will take place immediately before and after treatment and at one month follow-up. The impact of PTM treatment on neglect severity and activities of daily living (ADL) will be evaluated quantitatively using standardized measures of objective and subjective neglect symptoms. Feasibility will be measured by treatment compliance and qualitatively through an exit interview to collect participant feedback regarding usability and enjoyment of the treatment protocol.

**Anticipated Impact:** Our study uses an innovative prism adaptation procedure that can provide access to home treatment for Nova Scotians experiencing spatial neglect. The PTM procedure has the potential to improve patient recovery and quality of life after stroke due to its gamified and portable features that promote treatment accessibility and adherence. The results will help determine if the treatment can be used successfully in inpatient and outpatient settings and who is likely to benefit. Our patient-oriented approach in the development of PTM and current exit interviews will allow us to consult with and empower patients by ensuring we are taking their suggestions and aspirations into account before implementing the treatment clinically.

**Conclusion:** Findings from the present study should aid in achieving improved and more accessible continuing care and ameliorating the well-bring of Nova Scotians by improving rehabilitation outcomes and independence after stroke.

#### #19. Anti-Black racism and children's pain management: A proposal

Presented by: Bianca Matthews

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**Background and objective:** While all children will experience a form of pain (acute or chronic) in a hospital setting, Black populations are negatively impacted disproportionately due to various inequities. The mechanisms of injustice model allows an understanding of how anti-Black systemic racism affects pain management and individual pain outcomes in adults in the United States. There remains a lack of knowledge into how children's pain management is affected by anti-Black systemic racism in Canada, thus prohibiting the ability to create effective child pain management solutions during a period of critical development for Black Canadian families. Therefore, the objective of this study is to gain an understanding of Black caregivers and their children's experiences of the impacts of anti-Black racism on their children's pain management

**Methods and theoretical approach:** A narrative inquiry study, guided by critical race theory, is a methodology that aims to capture the stories of lived experiences for marginalized populations and uncovers how institutional narratives shape an individual's experience. In line with narrative inquiry methodologies, five dyads (pairs of Black caregivers and their children between 12-18 years old) will be recruited through social media and patient-partner help. They must live in Canada and have had a conversation about pain management with a healthcare professional. Interview questions will be created in collaboration with recruited patient-partners to ensure they capture the essence of participant's pain management stories. Participants will answer demographic questions and take part in a semi-structured interview (children and caregivers interviewed separately) where they will be asked a series of open-ended questions to capture their experiences of systemic racism in pain management. Interviews will be transcribed verbatim.

**Anticipated results:** A composite narrative combining the restructured interview of every participant into a single story will be created through using the original quotes from the generated themes.

**Conclusion:** Understanding the stories of lived pain management experiences for Black families will highlight research gaps in incorporating patient perspectives on anti-Black racism in children's pain management. In addition, this will inform the development of accountability frameworks for healthcare professionals involved in supporting children's pain management.

# #20. Optimizing prescribing for individuals with Type 2 diabetes and chronic kidney disease through the development and validation of prescribing algorithms for pharmacists in community pharmacy primary care clinics in Nova Scotia

Presented by: Jo-Anne Wilson

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**Background:** Thirty-four percent of Nova Scotians live with diabetes or prediabetes. It is the leading cause of chronic kidney disease (CKD) and contributes to 38% of kidney failure requiring dialysis. Early detection and management of diabetic kidney disease is important. There is an underuse of guideline-directed medications to slow CKD progression in these individuals. Most are managed in primary care and have much to gain from receiving kidney protective medications. Pharmacists in the community pharmacy primary care clinics (CPPCC) are in an ideal position to support early detection of CKD, and prescribe and monitor guideline-directed therapies. Validated community pharmacist prescribing algorithms in this population are absent in the literature.

**Objectives:** The objectives were 1) to develop evidence and expert-informed collaborative prescribing algorithms for pharmacists in CPPCCs caring for those with type 2 diabetes (T2D) and CKD and 2) to validate the prescribing algorithms with community pharmacists.

**Methods:** Four prescribing algorithms were developed and revised until team consensus using Lynn's three-step method (domain identification, item generation per domain, and instrument formation). Research Ethics approval was obtained for the algorithm validation by community pharmacists. Participants provided informed consent and were provided with a 2-part questionnaire to rate algorithm content and face validity using a five-point Likert-scale per validation round. Pharmacist participant interviews were conducted after each round. Revisions between rounds were undertaken. Content validity index was calculated for each algorithm to quantify content validity. Percentages were calculated for rating of statements used to determine face validity. Interview data was analyzed using qualitative descriptive analysis.

**Results:** Three rounds of validation were undertaken between June 2, 2024, and July 12, 2024. Eighteen pharmacists (6 per round) completed the algorithm validation. Results will be available for the conference.

**Conclusion:** The development and validation of prescribing algorithms for pharmacists caring for individuals with T2D and CKD in CPPCCs may improve primary care access and management of diabetic kidney disease, detect CKD earlier, facilitate referral to other providers, and enhance collaborative team-based care which supports health system accountability and resiliency. Importantly, it may delay kidney disease progression in this population.

#### **#21. Addressing violence against women in Nova Scotian reproductive healthcare** *Presented by:* Jessie Cullum

All Authors: Jessie Cullum<sup>1</sup>, Alexa Yakubovich<sup>1</sup>

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**Background:** Violence against women (VAW) includes intimate partner violence (IPV), sexualized violence, and domestic violence. Pregnancy is not only a period of vulnerability to experiencing VAW but is also a common outcome of VAW. Severe perinatal health outcomes are associated with experiencing VAW during pregnancy. Furthermore, violence present during pregnancy often continues into postpartum. Thus, reproductive healthcare (i.e., perinatal, early years, & abortion services) professionals hold both responsibility and opportunity to address VAW among patients. We aimed to describe the capacity of Nova Scotian reproductive healthcare to identify, respond to, and care for survivors of VAW, with the intent of identifying areas for improvement in reproductive healthcare in Nova Scotia.

**Methods:** In partnership with health system leaders, advocates, services providers, and women with lived experienced of violence, we conducted a questionnaire variant convergent mixed methods survey throughout 2023 and 2024 to investigate health system response to VAW in Nova Scotia. We descriptively analyzed quantitative survey data from 200 reproductive healthcare professionals who answered questions on VAW-related practices employed within their workplace and, using the Physician Readiness to Manage Intimate Partner Violence Survey (PREMIS), knowledge and opinions of VAW.

**Results:** In our sample, 58% of participants reported that addressing VAW is a goal in their workplace. In the last six months, 54% of participants had identified at least one case of abuse, with 11% of participants having identified six or more cases of abuse. Many participants reported screening patients for IPV (66%), although screening practices within the sample were inconsistent. Perceived preparation to care for survivors of VAW was low, with a median score of 3.3 on a 7-point scale. Furthermore, participants felt they had limited support from their workplace to respond to VAW, with a median score of 4 on a 7-point scale. Only 19% of participants reported having adequate referral resources at their worksite to provide to patients experiencing VAW.

**Conclusions:** Despite reproductive care being a high priority healthcare area for addressing VAW, system-level barriers to caring for survivors of VAW are identified through this analysis. Sustained health system action is pertinent to ensuring that Nova Scotian reproductive healthcare is well-equipped to care for survivors of VAW.

# **#22.** Birthing parents who use substances: Nurses' experiences with custody apprehensions of substance-exposed newborns

Presented by: Caitlyn Harper

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The post-partum period is a cherished time for mothers and babies; the interruption of this bonding opportunity, and the trauma and social challenges following child apprehension have been well-articulated. Few studies have captured the perspectives of providers involved in custody loss of newborns whose mothers who use substances (MWUS). The perspectives and experiences of Canadian nurses involved in the care of newborns and MWUS during custody loss has not been illustrated by previous studies.

This study seeks to address this gap in the literature through the exploration of custody apprehensions of newborns born to MWUS from the perspective of the nursing staff that provide direct care to these parents and their newborns. The present study aims to address two primary research questions. First, the study seeks to understand how nurses that provide care to MWUS or to newborns exposed to substances in utero, experience the custody apprehension of newborns. Second, the study examines the nurses' perceptions of barriers to providing trauma-informed care to MWUS when their newborn is apprehended.

The present study utilizes qualitative methods to describe the experiences of nurses during a custody apprehension of a newborn. Nine nurses employed with the labour and delivery or NICU units of the regional hospital participated in semi-structured interviews. Interview data is presently undergoing thematic analysis. Subsequently, a review of relevant policies that impact MWUS will occur. Preliminary results has led to the development of several themes, including 1) Emotional toll of caring for families undergoing a newborn custody apprehension, 2) Nurses' desires for support for themselves and patients, 3) Need for training to care for affected families, 4) Desire for improved interprofessional collaboration 5) Conflict, including both intrapersonal and role conflicts, 6) Provision of trauma-informed care, and 7) Communication as a foundational component of care. Following the completion of the data analysis, the results of this study intend to offer recommendations to policy and decision makers pertaining to the custody apprehension of newborns in hospital. This may include clarity on guidelines of roles, mechanisms to implement harm reduction and trauma-informed policies.

### **#23.** Data communication methods to inform decision-making in acute care hospital settings: A scoping review

Presented by: Alannah Delahunty-Pike

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**Background and objectives:** Strategies for frontline healthcare workers (HCWs) and administrators to leverage data from paper and electronic sources to support point-of-care decision-making are varied. Data dashboards and other real-time or near real-time data communication strategies have become prominent in the past five years, particularly as digital technology is increasingly leveraged in healthcare settings. The objective of this mixed methods scoping review was to explore strategies and tools used by frontline HCWs and administrators to communicate and/or access data in real or near-real time to inform decision-making at the point-of-care in acute care hospital settings.

Methods: This mixed methods scoping review used JBI methodology and included both studies and program descriptions. A health sciences librarian designed and executed the search using MEDLINE (Ovid) with real-time data prompts, alerts, feedback, and dashboards or other visualizations, combined with acute care hospital setting keywords. The search included MEDLINE, Embase, CINAHL, and APA PsycInfo databases. Commentaries and editorials were excluded from the search. Due to the low likelihood of studies being found in the grey literature, a separate grey literature search was not conducted. Titles, abstracts, and full texts of included studies and program descriptions were screened by two reviewers independently. Data extraction was conducted by one reviewer and verified by a second.

**Results and anticipated impacts:** The search strategy for published studies yielded 2,503 sources that underwent title and abstract screening, with 163 undergoing full-text screening. A total of 32 studies and program descriptions underwent data extraction. Anticipated impacts of this scoping review are to increase understanding of tools and strategies used to inform clinical and operational decision-making in acute care hospital settings. An expert advisory knowledge user panel from across the Maritimes will review the final report and use the results to support clinical and informational decision-making in acute care hospital settings. It is anticipated that this will increase understanding of tools and strategies used to inform decision-making in clinical settings, supporting a learning health system.

**Conclusion:** Efficient means of communication in acute care hospital settings can support system improvement for HCWs and administrators and more equitable care for patients, families, and caregivers.

## **#24.** Exploring the pragmatic profile of autistic and non-autistic children with a newly developed task

Presented by: Gabrielle Morin

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**Background:** Pragmatics is a linguistic domain that overarches many key aspects of social communication (Hyter, 2017). Of interest, pragmatics is consistently reported as an area of difficulty for autistic children (Volden & Phillips, 2010). Yet, assessing pragmatic skills is challenging given the heterogenous language profiles of autistic children (Zwaigenbaum et al., 2015). Recently, pragmatics has been distinguished into two categories, linguistic-pragmatics and social-pragmatics, to aid in defining this complex domain. Linguistic-pragmatics refers to communicative situations where structural language skills (i.e., vocabulary and syntax) are required to understand a social situation, while social-pragmatics refers to contexts where, in addition, an individual needs to use Theory of Mind (Andrés-Roqueta & Katsos, 2017). This distinction can help researchers understand the cognitive processes necessary within pragmatics.

**Objective:** This study aims to develop a new pragmatic assessment tool that examines the specific contribution of structural language skills and Theory of Mind to pragmatic skills in neurotypical and neurodiverse children.

**Methods:** Participants will include 30 typically developing children and 5 autistic children (5–8 years of age). The new task has gone through an in-depth development process, and now consists of 10 linguistic-pragmatic and 10 social-pragmatic questions. It will be administered virtually alongside measures of structural language, theory of mind, parent questionnaires, and a pragmatic assessment comparison. These measures will be used to evaluate the validity of the new task.

**Anticipated impact:** This study will provide further knowledge on the relationship between structural language, Theory of Mind, and pragmatics, contributing to our understanding of the social-cognitive underpinnings of pragmatic differences in autistic and non-autistic children. Examining the contribution of these factors to pragmatic skills also has important implications for the development of client-centered interventions that address the specific pragmatic challenges of autistic children (Loukusa et al., 2018).

**Conclusion:** Direct assessment of pragmatic skills is central to gathering more comprehensive information on the specific pragmatic strengths and needs of autistic children. This new assessment tool will help clinicians and researchers understand the contribution of cognitive and linguistic processing within pragmatics.

# #25. Exploring how youth with Juvenile Idiopathic Arthritis (JIA) and their caregivers react to experiences of pain-related stigma

Presented by: Blair Irish

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**Background:** Juvenile Idiopathic Arthritis (JIA) is a chronic inflammatory condition associated with pain in childhood. Pain from JIA often lacks an observable cause. As such, many youth with JIA must explain their pain to others. This increases their risk of experiencing negative judgement from others in response to their symptoms of pain (i.e., pain-related stigma). For instance, youth with JIA have reported experiencing pain-related stigma in the form of pain dismissal and disbelief. Pain-related stigma can negatively impact the health and wellbeing of those affected (e.g., greater perceived pain severity, decreased self-esteem). However, the extent to which pain-related stigma negatively affects individuals' health outcomes is partly determined by how they react to these experiences. This study aims to explore how youth with JIA and their caregivers react to pain-related stigma as well as to assess for similarities and differences between their reactions to these experiences.

**Methods:** 15 youth with JIA (13-18 years) and their caregivers will complete separate semistructured interviews. During the interviews, participants will be asked about their (child's) experiences of pain-related stigma and how these impacted their thoughts, feelings, and actions (i.e., reactions). A reflexive thematic analysis (RTA) approach will be used to generate themes based on participants' answers to interview questions. A matrix analysis will be done to assess for convergence between the final themes generated for each group. Two patient partners (1 youth with JIA and 1 caregiver) will inform this research based on their expertise from their lived experiences with JIA and pain.

**Results:** Final themes will describe the different ways youth with JIA and their caregivers may react to experiences of pain-related stigma. The matrix analysis will reveal similarities and differences between how youth with JIA and their caregivers react to experiences of pain-related stigma.

**Conclusion:** This study is an essential next step for understanding how pain-related stigma impacts the health and wellbeing of youth with JIA and their families. The results will help inform adaptations to healthcare practices that can assist with mitigating the harmful effects of pain-related stigma for youth with arthritis pain and guide future research in this area.

# **#26.** Mobilizing social media for early social-economic health with diverse family voices

Presented by: Nahal Fakhari

**All Authors:** Nahal Fakhari<sup>1</sup>, Jessie-Lee McIsaac<sup>1</sup>, Ellen Shaffner<sup>1</sup>, Tracy Moniz<sup>1</sup>, Misty Rossiter<sup>2</sup>, Janice Osei-Essah<sup>1</sup>

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**Background and Objective:** Positive parenting practices that support social-emotional health during early childhood are essential for healthy child development. Parents increasingly report using social media to search for parenting information but there is a knowledge gap on the quality and relevance of information, especially in the Atlantic Canadian context. Our research aimed to: 1) Understand the current landscape of social media influencers that provide information related to children's social-emotional health; 2) To identify the priority knowledge needs and use of social media of families with young children.

**Methods:** We first conducted an Instagram environmental scan to understand the landscape of Instagram influencers who share information about children's social-emotional well-being by collecting the most recent posts and thematically analyzing content. Second, with support from the MSSU Patient Engagement Coordinator, we recruited eight diverse family members (2 NS, 2 PEI, 3 NB, & 1 NL) across Atlantic Canada to take part in a series of family advisory focus group and interview sessions that focused on their use of social media, the gaps, and what they would like to see to support their parenting journey. All interviews (2) and focus-group style meetings (6) were audio-recorded and transcribed verbatim.

**Results:** The influencer scan found that the majority of influencers on Instagram are white mothers with varied credentials; there was also little incorporation and citation of research evidence. Content from Influencers often emphasizes the behaviour regulation of children rather than the development of social-emotional skills. Atlantic Canadian families identified informational gaps in the areas of newcomer children, developmental delays, and mental health. Families suggested that social media content should use purposefully chosen and consistent visuals, minimal text and demonstrate relatability and authenticity.

**Conclusion:** Our diverse family advisory group representing families in Atlantic Canada acknowledged the importance of evidence-based information on social media to support their children's social-emotional well-being. To mitigate the influence of unreliable Influencers, health organizations in Atlantic Canada need to scale up social media by developing evidence-based content to support parents with their children's social-emotional health.

# #27. Developing a public engagement strategy to guide injury prevention initiatives in Nova Scotia

#### Presented by: Darby Green

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**Background:** Trauma Nova Scotia (TNS) is a provincial program, which leads development and surveillance of the provincial trauma system and facilitates the care provided to major trauma patients through clinical, education, research, and quality improvement activities. Recently, TNS has been expanding the injury prevention (IP) branch of the program. An initial environmental scan of ongoing IP activities in Nova Scotia revealed significant community involvement across various IP organizations. Health equity and social determinants of health are increasingly important in health research, influencing IP initiatives. The environmental scan highlighted how public engagement can provide valuable insights from a health equity lens to inform IP efforts. TNS has expertise in conducting research and therefore will be approaching IP by conducting research projects. Direction from the public will still be required for IP research in order to have meaningful projects conducted.

**Methods:** As a next step, TNS has launched a new initiative to develop a patient engagement structure tailored to inform IP activities and ensure meaningful public involvement. Since IP's audience is the general public, the next step will be to develop a survey to engage the public (Nova Scotians). Initially a public partner will be recruited to consult on the development of the survey. The goal of the survey is to help inform TNS on what IP initiatives to prioritize. Therefore, topics in the survey will include but are not limited to, mechanisms of injury, injury type, and target audience.

**Anticipated impacts:** The anticipated outcomes include the results of the survey being used to identify IP priorities and lead to the development of an ongoing engagement structure. Once the survey has been completed future work will follow methodology similar to the James Lind Alliance (JLA) Priority-Setting Partnership (PSP) method, to bring together public partners, IP stakeholders, and trauma healthcare professionals. Therefore, the environmental scan previously completed (Stakeholder data), survey results (Public input), and trauma registry data (Healthcare perspective) can all help to determine priorities, with the goal of having initiatives identified. This methodology will help ensure IP projects are a part of the learning health system and can be communicated to Nova Scotians, stakeholders, and healthcare.

# **#28. Kamnagogy: Do we need a specialized teaching method for (Cancer)** patients?

Presented by: Don Desserud

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Current practices for communicating devastating diagnoses such as cancer do not adequately take into account the psychological trauma being experienced by the patient. We need a new teaching model that takes into account the present and on-going trauma that results from receiving a devastating cancer diagnosis. "Kamnagogy": teaching the sick.

#### #29. One step together – Expansion of integrated Youth Services in Canada

Presented by: Stacie Smith

All Authors: Stacie Smith<sup>1</sup>, Jillian Stringer<sup>2</sup>

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**Background:** Integrated Youth Services is an approach to organize and deliver health and social services to youth aged 15-24. IYS works like a "one stop shop", so no matter which door you walk through, you will get connected with the resources you need, whether they're for mental health, sexual health, housing, education, or something else. This creates a network that is greater than the sum of its parts by taking advantage of a community's existing strengths and resources to offer services beyond that of any one organization alone. One Step Together is a project to help mobilize community members to expand Integrated Youth Services across Canada. This project was developed based on published research assessing the state of integrated youth services in Canada.

**Methods:** The Frayme Knowledge Mobilization Fellowship supported this project with education, expertise, mentorship, and resources over six months. The campaign design leveraged extensive community consultation with input from several national Integrated Youth Service leaders and hundreds of youth and family members. Our project is currently a website housing information and resources about Integrated Youth Services.

**Results:** We hope to increase knowledge about Integrated Youth Services, encourage community members to advocate for IYS expansion and encourage community members to participate in designing and implementing IYS.

**Conclusion:** Youth-serving organizations and professionals are sharing this evidence to develop IYS across Canada, but there is still a gap in sharing this information within our communities.

# **#30.** Understanding newcomers' experience in accessing healthcare services for their children upon arriving in Canada

Presented by: Sarah Gander & Natalia Fana

All Authors: Faith Igogo<sup>1</sup>, Sarah Gander<sup>2,3</sup>, Natalia Fana<sup>2</sup>, Ziba Vaghri<sup>1</sup>

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Understanding the health of newcomer children is important given the significance of the early childhood years and the complexity of factors that may influence the health status of newcomer populations including past and current adversity and delayed or poor access during the transition to Canada. Access to adequate and efficient healthcare services is one of the core human rights of children under the United Nations Convention on the Rights of the Child (CRC). The CRC obligates all governments to take every measure to fulfill all human rights articulated under the CRC for all children including the refugee and asylum-seeking children who come to Canada in search of a new and better life.

This qualitative study recruited a cohort of newcomer mothers and used semi-structured interviews to explore and better understand their experience as they access healthcare services for their children. The themes that emerged highlighted 1. Access to health care including challenges in seeing a provider, language and communication barriers, cultural sensitivity and Medicare/insurance coverage; 2. Health status and experiences including experiences in hospital, wait times, and improvement in the child's health status; 3. Comparison and Gaps in the Health Care system including comparison to home country, clear gaps and suggestions for pediatric friendly healthcare facilities; 4. Support services and Policy changes including information and support services for newcomer families, policy changes for newcomer families and 5. Miscellaneous mentions including medical screening and immigration requirements.

This study underscores the necessity of adapting healthcare systems to meet the diverse needs of an increasingly multicultural population with unique needs, ensuring that all children can achieve optimal health and development. It is the responsibility of every society that hosts Newcomers to uphold and protect the rights of these new citizens, including the rights of children. As Canada welcomes Newcomer families in increasing numbers, it is important to fully understand their healthcare needs so we can prepare and plan for these services and respond in a timely fashion to those needs and fulfill one of their core human rights.

# #31. Co-creating a daily questionnaire to track food-related digital touchpoint engagement

Presented by: Helen Wong

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**Background and objectives:** Technologies are playing an increasingly important role within our daily lives. In turn, technology use can have great impacts on the types of food that we purchase and consume, which can subsequently have ramifications on our overall health. Digital touchpoints are any moment consumers interact with a brand, business, or product over the internet. Examples of food-related digital touchpoints include grocery shopping websites, food delivery apps, and social media food posts. To date, few studies have examined digital touchpoints as a group within health research, in part due to the lack of tracking tools for them. As part of a mixed methods PhD thesis project, our objective was to develop a brief daily questionnaire to measure the engagement with food-related digital touchpoints and food/drink purchases.

**Methods:** Ten interviews were conducted between August and December 2023. We interviewed healthcare professionals who shopped online for groceries and lived in Nova Scotia to understand technology use within their grocery shopping routines. Healthcare professionals were selected under the presumption that they were interested in health, and they would be motivated to make food/drink purchases accordingly. Interviews were recorded and transcribed verbatim with consent. The analysis of transcripts was guided by a previously reported typology of digital touchpoints by Straker et al. (2015). A drafted daily questionnaire was designed based on preliminary findings from the interviews and feedback provided by the PhD supervisory committee. Three PhD in Health students informally tested the drafted daily questionnaire and provided additional input, which was integrated into the design of the final daily questionnaire.

**Results or anticipated impacts:** A daily questionnaire was developed to measure food-related digital touchpoints and food/drink purchases via an online survey platform. The daily questionnaire takes approximately 5-10 minutes to complete. It measures more than 15 types of digital touchpoints and provides space to enter new ones. Additional questions ask about the influence of digital touchpoint engagement on food/drink purchases and for the upload of food/drink receipts. We are currently pilot-testing the feasibility of administering the daily questionnaire over a 4-week period in a sample of Nova Scotian healthcare professionals.

# **#32. Parental perspectives on structured and unstructured physical activity during cancer treatment and its role within pediatric cancer care**

Presented by: Aidan Nolan\*

All Authors: Aidan Nolan<sup>1</sup>, Melanie Keats<sup>1</sup>

#### Author Affiliations: <sup>1</sup>Dalhousie University

Childhood cancer and its treatments profoundly impact the physical and psychological wellbeing of young survivors, often resulting in a marked decrease in physical activity (PA) following diagnosis. Research indicates that healthy children who receive parental support for PA are 6.3 times more likely to engage in physical activities compared to their less-supported peers. Despite the clear benefits of parental involvement, many parents of children with cancer remain uncertain about the appropriate levels and types of PA, reflecting a significant gap in current guidelines. This uncertainty accentuates the urgent need for novel research to explore optimal PA strategies during cancer care, evaluate how these strategies align with PA guidelines, and clarify parental roles in different types of PA. This may develop evidence-based recommendations that address immediate health challenges but also promote long-term development in childhood cancer survivors.

The purpose of this qualitative study is to explore parental perspectives of structured versus unstructured PA within their child's cancer care. Employing a patient engagement approach, semi-structured interviews co-designed by a patient-partner will delve into these perceptions. Parents of children aged 3-11, currently undergoing or less than six months removed from cancer treatment, will be interviewed. 8-10 interviews will be conducted across Canada, expanding in increments of three if new themes emerge, ensuring thorough exploration until 16 participants maximum. Data analysis will utilize Braun and Clarke's Reflexive Thematic Analysis to inductively develop themes from the interviews. Regular consultations with the patient-partner will ensure a comprehensive and diverse representation of themes.

This study is expected to provide pivotal insights into how physical activity (PA) is integrated within the framework of pediatric cancer care. Anticipated findings include identifying preferred PA types during and after treatment and their perceived benefits and risks. The study will clarify parental involvement in PA throughout the treatment process, examine healthcare professionals' roles in PA promotion, and explore PA's impact on children's sense of belonging and identity recovery. These accumulated findings will be instrumental in informing more guidelines for PA promotion tailored to the needs of children undergoing cancer treatment, aiming to improve both immediate and long-term recovery outcomes.

\*Was not presented.

#### **#33. Impact of eBooks on autistic children's language and reading skills** *Presented by:* Brinn Edgington

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Background and Objectives: The number of children diagnosed with autism has increased in recent years with current estimates being at 1 in 66 in Canada. While there is a large heterogeneity among autistic children, a domain consistently reported to be challenging for these children is reading comprehension. Shared book reading supports literacy and language development in neurotypical and autistic children. However, when compared to their neurotypical peers, autistic children engage less during shared book reading and exhibit more disruptive behaviors. Given that early reading skills are significant predictors of academic success, it is central to identify specific conditions that support language and reading comprehension for autistic children. The objectives of this study are to 1) determine whether book format impacts engagement and reading comprehension for preschool age autistic children and 2) examine the impact of book format on child and parent language skills. Methods: Thirty dyads including a parent and their autistic child will complete a paperback and an ebook 10-minute shared book reading session. Over the course of the shared book reading session, the child's engagement and reading comprehension will be measured in addition to the number of words produced and conversational turns initiated by both the parent and child. Data will be analyzed using a linear mixed-model.

**Anticipated Impacts:** Based on current research, we hypothesize that the use of an ebook will result in autistic children's increased engagement, greater story comprehension, and greater number of conversational turns.

**Conclusion:** Findings from this study will provide key information on the influence of book format on autistic preschoolers' literacy skills. In order to support autistic individuals' academic success and their subsequent ability to participate in the workforce, economy, and self-advocacy, this research will contribute to developing best practices for fostering early literacy skills in autistic children.

# #34. Community-based doulas in Nova Scotia: Defining the meaning of care at the intersection of reproductive justice and biomedicine

Presented by: Anja McLeod

All Authors: Anja McLeod<sup>1</sup>

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**Background:** Community-based doulas provide non-clinical, physical, emotional, and informational support to people through reproductive experiences at low or no cost. Scholarship relating to doulas clearly demonstrates the correspondence between a doula's presence in labor and positive health outcomes. Validating birthing peoples' experiences and advocating against systemic inequities improves health outcomes as well as birthing peoples' experiences. Evidence of improved health outcomes specifically for marginalized groups is used to advocate for the incorporation of community-based doulas into the mainstream health care system. These doulas provide support that is often explicitly politically oriented, however, existing research has not focused on the social and political dimensions of community-based doula care.

**Objectives:** To explore to what extent community-based doulas see their work as a form of political activism, health care, both or something else.

**Methods:** In collaboration with community organizations that run volunteer-doula programs, I conducted semi-structured qualitative interviews with community-based doulas across the province (n=15). Anonymized transcripts were analyzed for key themes.

**Results:** Themes include: 1) Everyday care practices; 2) Encounters with the biomedical model; 3) Living out values; 4) Effective advocacy. Community-based doulas all negotiate their role as part of an unregulated profession that is distinctly non-clinical, yet intimately involved in perinatal health systems.

**Conclusion:** Community-based doulas articulate the meaning of their work as living out their morals and values, including providing a needed support service to underserved populations. Findings support recommendations for sustainable funding of community-based doula programs outside of the mainstream health care system.

## **#35.** Patient leadership in co-creating a how-to guide to patient engagement in research

Presented by: Trudy Flynn & Sabrina Poirier

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#### Author Affiliations: 1CIHR IMHA

**Background:** The Canadian Institutes of Health Research-Institute of Musculoskeletal Health and Arthritis (CIHR-IMHA) has a history of working with patients as partners. In 2020, IMHA convened its Patient Engagement in Research Ambassadors (PERA). This group included 8 patient partners who lived with conditions that fall within the IMHA mandate. PERA was an evolution of IMHA's pre-existing Research Ambassadors—the vision was to increase patients' control of their work as Institute partners.

**Methods:** Over the first few PERA meetings, organic conversations occurred about experiences and resources related to PE in research. PERA identified a gap with respect to practical information related to doing PE in research. IMHA committed resources towards co-creating training on this topic for the research community.

**Results and impacts:** A How-To Guide for Patient Engagement in Research is a series of 4 online modules (<u>https://cihr-irsc.gc.ca/e/27297.html#a2</u>) to help people learn more about PE in research, providing practical information to do this successfully. Covering the same basic material for all audiences, some modules are for patient partners and some modules are for researchers, clinicians, trainees, and others on the research team. From an accessibility perspective, the modules are in English and French, can have narration or closed captions turned on or off, and allow asynchronous learning. Certificates of completion are issued.

The modules have been taken by over 1,500 individuals (>500 researchers, >300 trainees, nearly 300 patient partners, >110 clinicians, and over 200 others). CIHR requires a PI to submit a module certificate for some funding opportunities, and other organizations are using the modules for their funding/training opportunities. IMHA recently hosted PE in research workshops (hybrid and in-person) which take advantage of the modules.

**Conclusion:** We share how CIHR-IMHA's PE Research Ambassadors identified a priority to create practical guidance for the research community to successfully carry out PE in research. The modules are the result of patient leadership, were developed with a co-creation model, and are being used by an increasing number of people and organizations to facilitate patient engagement in research.

#### #36. The endless waiting game: A patient-researcher co-led qualitative study on New Brunswick youths' experiences seeking a Fetal Alcohol Spectrum Disorder (FASD) referral

Presented by: Carly Demont

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**Background:** Early diagnosis of fetal alcohol spectrum disorder (FASD) is of high importance when considering the impact this diagnosis has on the mental and physical well-being of those affected. In 2012, the New Brunswick (NB) FASD Centre of Excellence was inaugurated to address FASD in Eastern Canada. Before being referred to the Centre to be diagnosed, the patients, often youths, are passed through different healthcare professionals and receive many (mis)diagnoses due to the range of physical, mental, behavioral, and learning disabilities they present with. To date, there have been a few studies focusing on this 'pre-referral pathway', and none that explicitly focus on the youths themselves and their lived experiences during this time. This qualitative study explores the NB youths' experiences of the pre-referral pathway to the NB FASD Center of Excellence from their perspective.

**Methods:** We will conduct in-depth, semi structured interviews with NB youths aged 13-20 to gain insight into the experience of the pre-referral pathway from their perspective until thematic saturation is reached. We will conduct thematic analysis and use ATLAS.ti to manage our data.

**Anticipated results:** This study aims to fill an important gap in knowledge in understanding NB youths' experiences during the pre-referral pathway before their referral to the Centre of Excellence. These findings will help healthcare providers understand NB youths' thoughts, feelings and emotions about the pre-referral pathway, their involvement with navigating the healthcare system, and the barriers to care they had to face before being referred to the appropriate facility. With the results of this study, we hope that we can understand the pre-referral process, which will increase the timeliness and accessibility to post-referral care in NB.

**Conclusion:** The path to referral and subsequent diagnosis for FASD is unique for every patient. Identifying NB youths' experiences can help in shortening their time in the healthcare system, achieving a quicker referral, and contribute to better specialized care.

# **#37.** The role of pain sensitization and muscle function in patient-oriented knee osteoarthritis rehabilitation

Presented by: Meaghan Hannigan

#### All Authors: Meaghan Hannigan<sup>1</sup>, Rebecca Moyer<sup>1</sup>

#### Author Affiliations: 1 Dalhousie University

Knee osteoarthritis (KOA) is a prevalent degenerative joint disease, presenting with chronic pain and functional disability.<sup>1–3</sup> The growing aging Maritime population and socioeconomic burdens of KOA highlight the urgent need for effective long-term treatments addressing function and pain.<sup>4–6</sup> This study aims to test the relationship between pain sensitization and quadriceps muscle function in individuals with symptomatic KOA, exploring potential age-related differences during activities of daily living.

Forty individuals with unilateral symptomatic KOA will be recruited from the community, with an equal number of individuals above and below 50 years, with groups matched for sex. A patient engagement plan, involving initial consultations, surveys, and feedback opportunities, will ensure study alignment with patient and clinician priorities, incorporating diverse perspectives, and considering sex and gender differences. Healthcare practitioners and organizations will assist in knowledge translation, sharing findings in accessible formats to inform treatment plans.

Pain sensitization will be quantified using pressure-pain thresholds, as well as the presence/absence of allodynia and temporal summation (pain with innocuous/repetitive stimuli), with questionnaires assessing symptoms, function, and quality of life.<sup>7–11</sup> Maximum voluntary quadriceps strength, quadriceps muscle activation (electromyography), and muscle stiffness (ultrasound elastography) will be recorded. Forces exerted during walking and stair use will be measured with motion capture and force plates, using kinetics to assess sagittal plane peak knee flexion moment (KFM). Functional demand, or KFM normalized to quadriceps strength, will determine the proportion of max strength used during daily activities.<sup>12–14</sup>

Logistic and multiple regressions will be performed on pain sensitization outcomes, with covariates selected from univariate analysis of known pain predictors. Both functional demand and muscle stiffness will be analyzed, with separate models for symptomatic and asymptomatic limbs, repeated for different age categories.

Improved understanding of quantitative measures of patient pain sensitization and quadriceps function during activities of daily living may inform the development of tailored rehabilitation programs to minimize pain and improve functional independence. Further exploration of these interconnected relationships may provide evidence for improving KOA management and treatment.

# #38. Involving parents/carers as partners in research: Reflections from the Sleep for Health in Hospital and at Home 2 (Shhh2) study

#### Presented by: Victoria Foxall

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**Background:** It is widely agreed that engaging persons with lived/living experience in research is best practice. Patient Engagement (PE) in health-related research can contribute to better quality healthcare, including advancing equitable, accessible, and inclusive care. However, positive experiences and outcomes from PE are reliant on having accessible, safe, equitable, inclusive, trauma-informed and efficient systems in place to support PE.

The Sleep for Health in Hospital and at Home 2 (Shhh2) project includes a parent partner as a member of the research team and is guided by a Parent Advisory Committee. We will collectively refer to these individuals as our Parent Partners (PPs). Using examples from our PPs' institutional approval experiences, we aim to contribute to discussions around the facilitators and institutional barriers to meaningful and inclusive PE. We acknowledge that healthcare organizations have widespread responsibilities, but believe it is possible to evolve current processes to support more positive experiences for future parent partners and researchers, and to support more widespread engagement.

#### **Objectives:**

1. Describe facilitators for meaningful and inclusive PE.

2. Highlight structural barriers to PE that often exist in research institutions that disproportionally impede or inhibit equity-deserving groups from engaging as research partners.

#### Anticipated Impacts:

Factors Supporting Patient Engagement:

- Support from the Maritime SPOR Support Unit
- Educational resources provided by SPOR SUPPORT Units and CIHR
- Widespread recognition of the importance of PE, including within research institutions
- Perseverance from PPs despite presence of barriers for engagement

Factors Creating Barriers to Patient Engagement:

- Vaccination requirements that are present even for exclusively virtual involvement
- Seemingly irrelevant training requirements, particularly for virtual involvement
- Criminal record checks
- Lack of infrastructure and clear and consistent processes, including compensation
- Delays in communication about requirements
- Assumptions of strong literacy and computer skills
- Lack of culturally- or community-adapted resources

**Conclusion:** To ensure authentic, respectful, and positive PE, we must shape the existing processes to foster inclusive systems and outcomes. Engaging PPs in developing institutional processes, combined with culturally sensitive and trauma-informed approaches, is essential for equitable PE systems.

# **#39.** Pre-post evaluation of a Shared Decision Making training module for patients facing preference-sensitive decisions regarding major cardiac surgical procedures

Presented by: Ryan Gainer

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**Background:** Shared decision making (SDM) is a formalized process between a patient and their HCP in which patient preferences and values are considered along with treatment options to inform preference-sensitive medical decisions. SDM has been shown to improve patient comprehension and reduce decisional regret, among other measures. There have been challenges in sustaining SDM long-term following training and implementation. We sought to identify barriers and facilitators to SDM implementation and develop a training program which incorporated resources to overcome these challenges.

**Methods:** Guided focus group sessions with former cardiac surgery patients and HCPs were audio recorded and analyzed using thematic analysis. Barriers and facilitators to SDM were discussed as well as HCP learning preferences. An SDM training module was developed which included insights from focus groups. Training sessions were arranged with cardiac HCPs including surgeons, residents, cardiologists, and nurses. Informed consent discussions were audio recorded between surgeons and patients undergoing either coronary artery bypass graft (CABG), valve surgery (AVR, MVR, or TVR), or a combination of both, pericardiectomy, or aortic root replacement. 54 patients were recruited prior to SDM training, and 44 patients were recruited following SDM training. Informed consent discussions were analyzed for SDM content using the OPTION-5 scoring tool.

**Results:** We identified three barriers to SDM implementation in cardiac surgery: assumed authoritative inferiority, deficits in patient comprehension, and lack of time. The SDM training module was developed to address these barriers and incorporate HCP preferences identified. We had high HCP participation in training sessions. Mean OPTION-5 scores of SDM in informed consent discussions increased significantly from 26.6% to 70% after training implementation. Each individual competency category (confirmation/alternatives, support for deliberation, pros and cons of options, preference elicitation, and integration of preferences with choice) was increased in the post-training group.

**Conclusions:** We demonstrated evidence of improved SDM in cardiac surgery informed consent discussions following SDM training. Further follow-up will evaluate the sustainability of these results. The training module has been migrated to an online platform to improve access.

#### #40. Does vaping impair lung function in young adults?

#### Presented by: Irene Yung

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In 2022, according to the Canadian Nicotine and Tobacco survey, 19.7% of Canadian young adults (20-24 years) report using e-cigarettes in the past 30 days. E-cigarettes are perceived to be a safer alternative to combustible tobacco cigarettes but it remains unclear whether vaporization of e-liquids causes damage to the lungs. The most common measure of lung function, spirometry, is insensitive to early manifestation of lung disease in the small airways and may not detect changes in lung function until lung disease is advanced. In this study, we aimed to compare ventilation inhomogeneity, a measure of lung function changes in the small airways, between young adults who vape and age-matched healthy controls.

Individuals between the ages of 18 to 24 years who reported using e-cigarettes and did not have a history of lung disease were eligible to participate in the 'exposed group'. Age and sex matched individuals without a history of physician diagnosed respiratory disease (e.g., asthma) and who did not smoke tobacco or use e-cigarettes were eligible to participate in the non-exposed group. A questionnaire was used to ascertain details about e-cigarette use. Participants in the exposed group were further classified into low (1-2 puffs/hour), moderate (3-4 puffs/hour) and high (5+ puffs/hour) based on frequency of use. Ventilation inhomogeneity was measured using multiple breath washout (MBW); lung clearance index (LCI) was reported as the primary outcome (Ecomedics Exhalyzer D<sup>TM</sup>).

A total of 41 exposed participants and 38 age and sex matched un-exposed participants had valid MBW measurements. Within the exposed group, 16 participants exclusively vaped, whereas 12 also smoked combustible cigarettes and 21 used cannabis. The average LCI in the exposed group was in the normal range (mean LCI 6.22 (SD 0.3)). Overall, the exposed group had worse ventilation inhomogeneity compared to the healthy group (mean LCI difference: 0.16 (95% CI -0.31; 0.004)). Further, a dose response was observed, where the difference in LCI was greatest in the high exposure group (5+ puffs); mean difference (0.22 (95% CI -0.41; -0.03)).

There is a small measurable and statistically significant effect of e-cigarette exposure on ventilation inhomogeneity measured by the LCI in young adults. This may indicate that even in otherwise healthy young adults, e-cigarette exposure begins to cause potentially functional changes in the small airways.

# #41. Analyzing current trends in cardiac rehabilitation programs in New Brunswick: Inclusivity and effectiveness for older adults

Presented by: Dana El-Mughayyar

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**Background and objectives:** As the population of older adults grows, understanding current trends in cardiac rehabilitation (CR) programs is essential for effective cardiovascular disease management. This study analyzes data from Cardiac Rehab New Brunswick (CRNB) to evaluate the state of CR, identify key trends, and assess the inclusivity and effectiveness of programs for older adults.

**Methods:** Data were collected from the CRNB database, which includes patient files and referral data from 12 in-hospital programs and 7 community satellite sites across New Brunswick. The data encompass program utilization, wait times, enrollment, case management statistics, patient demographics, and health outcomes. Descriptive statistics were used to analyze the data, identifying trends and variances across different regions and patient groups.

**Results or anticipated impacts:** Data from CRNB in the fiscal year 2022-2023 show that an average of 205 patients were referred monthly, totaling 3147 referrals for the year. Despite a 90% increase in CR programs since 2005, only 49% of eligible patients were referred, and 25% enrolled. The provincial average wait time from referral to enrollment was 42 days, with significant regional variance ranging from 19 to 118 days. The average age of enrolled patients was 65 for males and 67 for females, with higher urban enrollment (72%) compared to rural (28%). Health outcomes showed blood pressure control achieved for 57% of patients, lipid control for 70%, and a 38% smoking cessation rate among participants.

**Conclusion:** This data underscores the need to enhance future programs tailored for greater inclusivity and support for older adults, acknowledging that not all eligible patients are referred, and potential barriers need addressing. This initial analysis provides a foundational understanding of the current landscape from a data perspective. Moving forward, gathering patient perspectives will further inform program development, technological advancements, and overall efficacy. Addressing these challenges can foster more inclusive and impactful cardiac rehabilitation programs for older adults.

# #42. The health outcomes of women experiencing incarceration in rural and remote places: A scoping review

Presented by: Clare Heggie\*

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**Background and objectives:** Women are the fastest growing population in prison in Canada and yet they remain a small, invisible subset of the overall population of incarcerated people. The increasing numbers of incarcerated women, in a system designed without gendered needs in mind, challenges healthcare provision. Women incarcerated in rural and remote areas may face additional challenges accessing healthcare both while detained and post-release. The objective of this scoping review is to synthesize what is known about the healthcare access experiences and health outcomes of women incarcerated in rural and remote communities.

**Method:** We followed the Joanna Briggs Institute methodology for scoping reviews. A clinical librarian performed an initial search of all relevant databases. Three reviewers independently screened the titles and abstracts for assessment against the inclusion and exclusion criteria. The populations of interest included women who are currently and/or recently incarcerated. The concept of interest was health outcomes and the context was incarceration in rural or remote places.

**Anticipated results:** We are currently under-going full text screening and will have results in Fall 2024. Early results demonstrate a range of qualitative, quantitative, and mixed methods studies, conducted primarily in the United States. The main outcomes of interest are substance use, HIV and HCV status, and mental health.

**Conclusion:** Incarceration results in lack of access to basic health services, including substance use and mental health supports. This lack may be exacerbated in rural areas. There is a lack of evidence on health outcomes beyond substance use and mental health, highlighting a need for future research on the full scope of health needs amongst women incarcerated in rural and remote prisons.

\*Was not presented.

#### #43. From outlier to insight: The power of different perspectives

Presented by: Donna Rubenstein & Judy Porter

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#### Author Affiliations: <sup>1</sup>Patient/Public Partner

PriCARE is a patient-oriented research program studying case management in primary care for adults with complex care needs. It involves active engagement of anglophone, francophone and First Nations patient partners (PPs) from five Canadian provinces. PPs led or contributed to knowledge translation and exchange (KTE) throughout the program. This presentation aims to demonstrate how the involvement of PPs improved research processes, KTE activities and resulting products.

PPs have been involved in PriCARE from the project start in 2018. The role evolved over time and was a learning journey for all team members, researchers and PPs alike. With the investment of time and demonstration of value, team members developed trust, respect and skills for working effectively together. This resulted in PPs becoming valued members of the research team, thereby maximizing the opportunity for an impactful patient-researcher partnership. PPs contributions increased over time and they contributed to and led, or co-led, development of KTE plans and several products. In addition to their lived experience, PPs shared personal skills and network connections to enhance KTE in PriCARE. Support and encouragement from researchers were essential aspects of the successful relationship.

PPs enhanced research content by integrating patients' needs and preferences. For example, the study population was identified as "frequent users of healthcare services" and PPs expressed concern that this description has negative connotations. Team members agreed and language was adjusted.

PPs improved accessibility and relatability of the research. For example, in the case of a validated questionnaire that could not be changed, the team co- created guidelines to administer it in a patient-friendly manner and published a paper on the process. PPs participated in simulated patient interviews to aid research assistant interview training as well as training for case managers, who delivered the intervention.

PPs strengthened knowledge mobilization. PPs developed a clinic toolkit and many KTE materials including a video, infographics, publications, and presentations. PPs regularly present at conferences, webinars and share learnings from the program with healthcare networks critical to program adoption and future scaleup.

Having PPs involved in all aspects of the program has led to the development of KTE products and processes that are more relevant and impactful to stakeholders.

# #44. Challenges in treatment of veterans' chronic pain from the perspective of healthcare professionals

#### Presented by: Julia Keilty

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Members of the Canadian Armed Forces are at increased risk of physical injuries and psychological trauma due to the hazardous nature of their work during training and deployment. Forty-one percent of Canadian veterans report constant pain or discomfort, and 23% report recurring pain (VanDenKerkhof et al., 2015). In Canadian veterans, chronic pain is associated with lower quality of life, suicidal ideation, and comorbid mental health issues (Thompson et al., 2013; Thompson et al., 2014). Chronic pain among veterans is thus a prevalent and complex issue and veterans face many treatment challenges. Veterans with chronic pain are offered rehabilitative services through Veterans Affairs Canada (VAC). These services commonly focus on the treatment of physical ailments (e.g., physiotherapy, massage therapy) and often lack a focus on mental health care. Given the nature of chronic pain, veterans seeking rehabilitative services often see multiple healthcare professionals for an extended period. Healthcare professionals therefore have a unique perspective on the challenges of treating veterans' chronic pain, including barriers to effective rehabilitative care. Understanding the experiences and insights of healthcare providers is crucial for improving patient care and outcomes in this population. Unfortunately, little is known about the perspectives of healthcare professionals providing rehabilitative services for veterans with chronic pain. Therefore, the aim of this pilot study was to utilize interviews to gain a better understanding of the challenges faced by healthcare professionals working with this population. Participants were recruited from multidisciplinary health clinics in New Brunswick and included physiotherapists and massage therapists. Interviews were audio recorded and transcribed verbatim, then analyzed using the six steps of thematic analysis (Braun & Clarke, 2006). Findings suggest healthcare professionals face significant challenges in treating chronic pain among veterans, including navigating complex medical histories, addressing psychological comorbidities such as PTSD, and navigating VAC's procedures and policies. Ultimately, the results from this study aid in informing research questions for a larger, national study investigating barriers to rehabilitative services for veterans' chronic pain from multiple perspectives (i.e., veterans, VAC case managers, and healthcare professionals).

#### **#45. Impacts of extreme flooding events on mental health in New Brunswick** *Presented by:* Sandra Magalhaes

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Floods are the most frequent natural disaster in Canada. Several studies demonstrate negative mental health effects on exposed individuals. Generally, studies have small sizes or are surveybased and those using population-based data sources, with control for confounding, are limited. The objective of this study was to determine the extent to which the need for mental health services is impacted by exposure to extreme flooding, and to gain a better understanding about population subgroups that are most vulnerable. A population-based longitudinal cohort study design was developed using linked, pseudonymized person-level administrative data available for access through the New Brunswick Institute for Research, Data and Training (NB-IRDT). Seven extreme flooding events in NB between 2005–2019 were examined. Cohort members were defined as exposed if they lived in a geographic area identified to have flooding based on a combination of flood-exposure data. Six mental health service outcomes were compared between exposed and unexposed populations, in the year following flooding, while controlling for several confounders. Outcomes include health service use for mental illness, and specifically for mood/anxiety disorders as well as hospitalization for mental illness-related reasons or for post-traumatic stress disorder (PTSD). There were 353,960 exposed individuals, half of which were exposed to more than one flood (51.7%). Health service use for mental illness was most prevalent (14.2%), which was increased by 9% in the 1-year following to flooding (OR: 1.09; 95%CI: 1.08-1.10). Health service use was primarily for mood and/or anxiety disorders (9.8%), and for physician services, as hospitalization for mental illness-related reasons was rare (0.8%: 0.07% for PTSD-related). Population subgroups at highest risk of negative mental health are those who experienced less floods (1 or 2 vs. 3+) or who had a property damage claim in their area, those in the most, but also the least socioeconomically deprived areas, and among children and youth. This study provides a first look into the population-level impacts of major flooding events in New Brunswick and identifies population subgroups at greatest risk of negative mental health outcomes in the 1-year following flooding. This study adds to the limited research on the impacts of flooding on mental health service utilization.



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