Putting Patients First 2024

Abstracts from accepted submissions

This booklet contains abstracts from submissions selected to present a poster at Putting Patients First 2024.

Out of 90 submissions, 68 met eligibility criteria.
A panel reviewed the 68 submissions and
selected 55 submissions to share as posters at the conference.

Submissions that were selected for oral presentations have an asterisk after the title (*).

This content was provided from the authors and has not been edited for style or accuracy.
Any errors are from the original submissions

A Day in the Life of a Longhauler: Amplifying Experiences of Long COVID Patients through Photovoice Methodology

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Long COVID, often termed the "pandemic from the pandemic," is a chronic condition emerging following COVID-19 infection. Characterized by symptoms affecting multiple organ systems, Long COVID can persist for weeks to years, with no standardized treatments available. According to conservative estimates from Statistics Canada, 1 in 9 Canadian adults have experienced Long COVID symptoms, with 40% reporting barriers to accessing healthcare. Experts, including Canada’s Chief Science Advisor, have warned that Long COVID may evolve into a “mass disabling” event. Despite these alarming predictions, "longhaulers" and their caregivers continue to face limited information, public denial, and a lack of awareness about their medical needs.In 2022, our interdisciplinary team at Simon Fraser University (SFU), including patients, advocates, and health researchers, in collaboration with the Post COVID Interdisciplinary Critical Care Network (PC-ICCN), hosted discussions that brought together patients, unpaid caregivers, healthcare professionals, and researchers across British Columbia (BC), with the goal of identifying gaps in Long COVID information and support. The findings from this co-created research highlighted concern across all key informant groups surrounding the public and medical community’s lack of awareness and acknowledgment of Long COVID. These gaps motivated our current project, "A Day in the Life of a Longhauler," which uses photography to reveal the visible realities of this otherwise ‘invisible illness’."A Day in the Life of a Longhauler" is a photography exhibition, set to launch in 2025 at the Museum of Vancouver (MoV). This exhibition, spanning 1,000 square feet and lasting six to nine months, will feature photos taken by longhaulers, documenting their daily experiences. The arts, including photography, have proven to be powerful tools for promoting public health education and policy change. Through this participatory, arts-based approach, we aim to empower longhaulers by reducing stigma, fostering a sense of agency, and promoting critical dialogue and education. By partnering with the MoV, we anticipate engaging a broad audience and expanding the project’s reach. At a rate of 10,000 guests per month, the exhibition is projected to attract over 60,000 visitors, plus those who will participate in accompanying public programs.In March 2024, we launched a pilot of this project, inviting people who identify as having Long COVID in BC to share up to six photographs. Participants were provided with prompts to support them in capturing various aspects of their daily lives and were invited to submit artist profiles with the option to remain anonymous. The pilot received fifty submissions, which were later showcased at a public Long COVID community event, facilitated by Pulitzer Prize-winning author Ed Yong, and viewed by over 2,500 people globally. The formal launch of the project in Fall 2024 will incorporate feedback from community members and partners, including expanding submissions to longhaulers nationwide. This initiative has been designed with knowledge mobilization woven directly into its fabric, using the photo exhibition as a key platform to share the lived experiences of longhaulers with a broad audience. Additionally, partnerships with healthcare professionals aim to bridge the gap between patient experiences and the medical community’s understanding of Long COVID to influence policy and improve patient care. By integrating these aspects, we aim to ensure that longhaulers' experiences are not only acknowledged but also drive tangible change. Future steps include forming a patient advisory group to guide the project, organizing a launch event to celebrate contributing artists, curating accompanying text and public engagement tools, developing a virtual exhibition, and evaluating the project's impact. The collaborative nature of this project emphasizes the critical role learning communities play in driving change within the health ecosystem, particularly in the context of under-recognized conditions like Long COVID.

1 Simon Fraser University, 2 Museum of Vancouver, 3 Post-COVID-19 Interdisciplinary Clinical Care Network

A Patient and Family Cost Calculator called GEOFFE

Kendall Ho 1, Sonya Cressman 1, David Yang 1, Graham Mainer-Pearson 1, Sandra Martin-Harris 2, Kurtis Stewart 1, Lillian Dennis 3, Linda Riches 1, Scott Graham 4, John Pawlovich 5, Emily Bringham 1, Natasha Jones 1, Devon Currie 1, Joan Assali 1, Nimra Akram 1

Introduction and Background Patients and their families pay for healthcare with their time, travel expenses and other out-of-pocket costs. If the cost-sharing ratio between patients and the healthcare system becomes too high, it may prohibit some patients from being able to receive the medical care they need. The Geospatial Economic Outcomes Framework for Equity (GEOFFE) platform is, an interactive platform that enables reporting of regional inequities in cost-sharing between patients and the healthcare system. The GEOFFE platform is supported by a learning community exchanging knowledge between Patients, Community and Cultural planners, the University of British Columbia (UBC), the First Nations Health Authority and the Rural Coordination Centre of BC (RCCbc), with the overarching aim to improve economic evaluations by providing researchers and policymakers with reports on what patients and families pay to receive medical care. The core feature of GEOFFE is the ability to calculate incidences of financial hardship, an indicator that healthcare costs are too high for some patients to be able to access the medical care they need. Learning Community Engagement We used co-design as a method to exchange knowledge with our learning community. To develop GEOFFE in a way that represents patient experiences, we first connected with patient researchers and community cultural consultants in regular monthly dialogue sessions to ensure alignment with patient experiences. Second, we collaborated with patients and healthcare providers in a series of usability development workshops trialing different scenarios where innovations in health services or policy are designed with the goal of reduce patient and family costs, putting patients first by considering the costs they pay in addition to the costs the health systems pay. The team of patients, researchers and knowledge users will demonstrate how GEOFFE works with a series of use-case scenarios including the result of implementing a pediatric virtual care network called CHARLiE (Child Health Advice in Real-Time Electronically) which delivers pediatric care to patients in their home communities. Additional scenarios included the use of drone transport to deliver medications to remote areas, anti-pollution diets to counter the health impacts of wildfire smoke and land-based healing practiced by many Indigenous communities—all aimed at understanding whether GEOFFE's patient and family cost report could represent a wide range of healthcare innovations. The study engaged deeply with community planners and cultural consultants to exchange knowledge about the medicine wheel, and advise on how we could build it into the reports that GEOFFE provides about patient and family costs. Finally, we utilized an advisory committee comprised of healthcare providers, community planners and researchers to guide the platform through its development. Knowledge Mobilization Mobilization of the knowledge exchanged during the development of the GEOFFE platform will strengthen communications between the research partners brought together through GEOFFE's learning community. These include a presentation at RCCbc's research days, a lunch and learn session at the First Nations Health Authority and invited presentations at the Legacy for Airway Health's noon rounds. Convening a diverse learning community to develop GEOFFE demonstrated the importance of flexibility and open-mindedness during the design process; namely the honouring of community and patient wisdom by adapting the design of GEOFFE based on the feedback we received. This resulted in a more accessible user interface and the addition of a medicine wheel to compliment GEOFFE's report on the costs patients and their families pay to access healthcare. The GEOFFE platform is funded by UBC's strategic investment fund as part of the University's commitment to facilitate research excellence through a strategic approach to core platforms. Knowledge sharing via GEOFFE will be further mobilized to support learning communities within and beyond UBC in the next phase of its development. The study team welcomes further collaborations.

1 UBC, 2 UNBC, 3 Witset First Nation, 4 First Nations Health Authority, 5 Rural Coordination Centre of BC

A patient-oriented multi-modal MRI study on myalgic encephalomyelitis / chronic fatigue syndrome

Raminder Kaur 1, Hilary Robertson 2, Xiaowei Song 1

Introduction and BackgroundMyalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) is a neurological disorder characterised by post-exertional fatigue. Despite its clinical relevance, the disease is under studied and its mechanism is poorly understood. Emerging MRI research targeting brain function or metabolite has been inconclusive to understand ME/CFS complexity. Here, we conducted a patient-oriented MRI study that combined single-voxel magnetic resonance spectroscopy (SV-MRS) and functional magnetic resonance imaging (fMRI). We examined the feasibility of the novel research protocol, identify possible differences between ME/CFS and HC, and related MRI findings with clinical symptoms.Learning Community Engagement Three patient partners worked closely with the researchers in the research project and played an active role in each and every of the project development, from study design to experiment execution, from participant recruitment to research trainee supervision, from finding interpretation to knowledge dissemination, and more. The project enrolled 18 female ME/CFS participants (mean age: 39.7±12.0 years) and five matched healthy controls (HC; mean age: 45.6±14.5 years). Each participant had a one-hour MRI scan. The SV-MRS spectra were acquired from three brain locations relevant to the disease pathophysiology, including the anterior cingulate gyrus (ACC), brainstem (BS), and dorsolateral prefrontal cortex (DLPFC). Task-phase fMRI of the whole-brain tested working memory and executive functioning.Knowledge Mobilization Feasibility was assessed as study completion rate and time by the participants. The study showed a 100% completion regardless of patient or control participant group. Differences in brain metabolite levels and functional activation maps between ME/CFS and HC groups were tested and correlated with behavioral and clinical data. ME/CFS group showed a higher N-Acetylaspartate in the left DLPFC compared to HC (OR=8.49), correlating with poorer fatigue, pain, and sleep quality scores (p’s <.015 corrected for multiple tests). An increase of brain activation, involving the frontal lobe, ACC, and BS was also observed in ME/CFS compared to HC (Z>3.4, p’s<.010 corrected for multiple tests). Our project showcased the success of engaging patient patterners in various aspects during the development of patient-oriented research. The research finding demonstrates the feasibility of combining multiple SV-MRS and fMRI to profile brain metabolites and functional activation in ME/CFS. The project suggests the need of further research with larger cohorts to validate the apparent brain functional and metabolite differences between ME/CFS and HC. The feasibility of combining multiple SV-MRS and fMRI to profile brain metabolites and functional activation in ME/CFS enlightened ongoing efforts adopting this multi-modal MRI protocol. Key research findings of the project have been disseminated as a scientific journal article and research conference presentations, co-authored with the patient partners.

1 Fraser Health, 2 Patient Advisor

An analysis of client data by Open Arms Patient Advocacy’s learning community to improve healthcare accessibility and navigation in Alberta

Jotinder Waraich 1, 2, Emma Elder 2, Hali Melnyk 2, Heather Templeton 2, Jen Chao 2

Title: An analysis of client data by Open Arms Patient Advocacy’s learning community to improve healthcare accessibility and navigation in AlbertaBackground:Patients face significant challenges in navigating Alberta’s complex healthcare system, including difficulties in accessing care and understanding healthcare processes. These barriers often result in delayed or inadequate treatment, worsening health outcomes for vulnerable populations. The learning community at Open Arms Patient Advocacy Society identified these issues through their work with patient clients and recognized the need for a structured approach to address these challenges. This study will extend on previous research by analyzing client data from January 2023 to July 2024 to identify recurring themes in patient needs and develop strategies to support healthcare navigation. The relevance of this issue to the health system is profound, highlighting gaps in accessibility and quality of care, particularly for at-risk populations who require tailored support. Learning Community Engagement:The project involves a diverse learning community within Open Arms, including a Client Intake Coordinator, Education Coordinator, volunteer advocates, patients, and their families. Community engagement is central to our work, with regular monthly meetings, educational workshops, and feedback sessions for advocates. In these sessions, advocates discuss patient experiences, identify common challenges among clients, and brainstorm potential solutions to support patient clients. Thematic analysis of patient intake forms will be a key method used to categorize, and prioritize the issues that patients most frequently encounter. Based on identified themes, Open Arms trains advocates on the key topics and related supports in order to best serve our patient clients. Knowledge Mobilization:The insights gained from this study will be used to refine the advocacy strategies used by Open Arms and enhance its support services. The community at Open Arms will play a vital role in disseminating the findings through internal training sessions led by the Education Coordinator, external presentations at community conferences, and the development of patient and advocate education resources. By fostering a culture of continuous learning and adaptation within the Open Arms community, the organization will remain responsive to the evolving needs of its clients. The outcomes of this engagement will include the development of more targeted support strategies, increased awareness of specific patient needs, and a stronger foundation for future advocacy efforts.

1 Researcher, 2 Community Partner

Beyond the Binary in BC: A Continuous, Collaborative, Commitment to Supporting Inclusive Women's Health Research

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IntroductionWomen's health research is a relatively contemporary category of research, established in response to gender-based inequities. To promote gender equitable care, programming, and policy, gender equitable research practices are needed. Beyond the Binary in BC (BTB) is a community-engaged, person centered project initiated by the Women's Health Research Institute in 2018. It aims to support a culture of gender-inclusivity within the women's health research community. Our core output is the BTB Guide: a tool that acknowledges how research is a key determinant in health care priority-setting (e.g. policy, practice), and promotes critical reflection on research decision-making. Trans and gender diverse individuals are increasingly visible in society. In Canada, younger generations are 7 times more likely to identify as trans or non-binary compared to previous generations (2, 3). To address persistent inequities in health outcomes among gender diverse peoples, their experiences need to be accounted for in health research. To respond to and address the discrimination and prejudice experienced in healthcare settings and the poor health outcomes that ensue (1), women's health and the existence of gender diverse peoples must be prioritized. Learning Community Engagement The BTB Guide was developed in relationship with two steering committees, and a core team. The Community Steering Committee (CSC) included people with lived and living experiences of gender-based inequities and those working toward equity (e.g. advocates, educators, care providers). The Research Steering Committee (RSC) included women's health researchers, ethicists, research administrators, and trainees. As agents within our key audience, we convened the RSC first to identify their gender equitable research practice learning goals and preferences for knowledge delivery. Most identified language (additive, neutral, anatomy) as a growth area, and desired guidance to enable change.Mindful of power dynamics and the burden of representation CSC members could feel, committees were met with separately until the following precedents were established: (1) we were prioritizing community experiential knowledge; (2) we were applying anti-oppressive and trauma & resilience-informed principles. Accordingly, RSC and project team members undertook Trans Inclusion training with PRISM, and established reflexivity as critical practice to mitigate the perpetuation of un/conscious biases. In alignment with these goals, we engaged the CSC prior to the RSC in every round. The Guide was developed usingvia justice oriented, participatory, and emergent design. Its contents were elaborated per CSC and RSC engagements, making changes and adding aspects in response to their priorities. The CSC focused on the appropriateness of the Guide, in terms of responding to community experiences. The research steering committee RSC focused on acceptability, as to the application of the guide in real-world settings. It includes sections on why language matters, implications on research practices, and example scenarios of research processes (participant recruitment, data collection, result reporting), in addition to a Glossary of Terms. CSC members emphasized how using the right words is not enough to make research equitable. Researchers need to be able to understand the importance of using the words, and how to use them appropriately. The CSC also called for the use of community-created references, to center the knowledge of those who are most impacted by the phenomena associated with the term/concept. Knowledge Mobilization Our learning community has informed key messages in knowledge mobilization activities and are represented as team members. Our three key messages include: 1) people who embody gender diverse identities have experienced harms; 2) language is continuously evolving; 3) learning (and unlearning) is an active commitment. This relationship-centered work requires time, resources, and care.Our ongoing work, which involves a national consultation with expanded representation of research and community members, is activating these lessons.ReferencesAlencar Albuquerque et al., 2016Easton, R. 2022Stats Canada, 2022

1 WHRI, 2 Independent, 3 Brood Care, 4 L.E.T.S., 5 SFU

Bridging the Gap: Implementing the Transitional Care Approach for New Hemodialysis Patients

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The initiation of dialysis is a high-risk period for patients with end-stage renal disease (ESRD). This period is marked by a significant risk of patient hospitalization, mortality, and decreased quality of life. The fragmented care of patients with this chronic disease is a critical issue that imposes a significant burden on the health care system and affects long term patient outcomes. Recognising the need for a model that integrates and streamlines services across multiple providers, our project aimed to enhance the care of new dialysis patients by leveraging the power of learning communities. We engaged with various stakeholders in the co-design and implementation of a Transitional Care Approach to address learning needs previously identified by new dialysis patients and nurse clinicians in our qualitative study. We collaborated with patient partners, departmental leadership, nurses, and other members of the renal interdisciplinary care team to adapt and design a 4-week Transitional Care Program (TCP) for a 6-month pilot implementation. This approach facilitated interdisciplinary collaboration, continuous learning, and patient-centered care, to help improve patient outcomes and set a new standard for managing this vulnerable population.The transition to dialysis is a complex process that demands coordinated care across multiple disciplines. Traditionally, this period has been managed within silos, with limited communication between healthcare providers, patients, and caregivers. However, the growing emphasis on holistic, patient-centered care calls for a new approach—one that integrates the collective expertise of various stakeholders to address the multifaceted challenges patients face during this transition. To this end, our project established a learning community composed of nephrologists, nurses, social workers, dietitians, patients, and caregivers, all of whom brought unique perspectives and expertise. Initial meetings focused on identifying the key challenges and gaps in care during the dialysis initiation period. A shared goal was established: Improve the care of new patients by implementing a patient-centered education program to bridge the gap for patients transitioning to life on dialysis. By designing a Transitional Care Program (TCP), we aimed to increase patient self-management, improve education and uptake of independent renal replacement modalities, and enhance the overall quality of life for new dialysis patients. The learning community utilized various tools and strategies to achieve these goals. We mapped workflows, identified gaps, and designed strategies to build capacity of existing infrastructure to streamline the care of new patients using five key components: dedicated space, peer support, staff education, online patient-oriented resource hub, and communication tool to coordinate care. We applied the Canadian Institute of Health Research Knowledge-To-Action (KTA) framework to guide the development of the TCP. Regular virtual meetings were held to discuss best practices, share case studies, and review outcomes. The learning community also adopted evidence-based practices and quality improvement methodologies to continuously refine care processes.Results from our mixed-methods evaluation indicate improvements in patient self-management. Patients described feeling more informed and supported, attributing this to the enhanced communication and education provided by the learning community. Staff reported TCP patients are more receptive to information and to being approached by team members. Of the 47 patients who participated in the pilot program, 40% moved on to independent modalities and many of these patients reported feeling satisfied with the quality of care they received during their care transition.Although the implementation of the TCP presented many challenges, our project provided the necessary framework for tracking and addressing the needs of new dialysis patients. By fostering interdisciplinary collaboration, continuous learning, and patient-centered approaches, this project serves as a blueprint for integrating learning communities into other areas of healthcare, highlighting their potential to drive meaningful change in patient care.

1 Providence Health Care, 2 University of British Columbia

Bringing lived experience to peer review: Collaborative development of a learning module

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Introduction and background It is increasingly common for persons with lived experience (PWLE) to take part in the review of research proposals for funding or endorsement purposes. However, as this is a new and evolving process, peer review is not something that is familiar to many PWLE. Traditionally, only researchers were involved meaning that PWLE had no voice in the selection of what research was funded.Non-profit organizations conduct their own recruitment and training as needed to onboard PWLE reviewers; a process that uses a lot of human resources. Given the gap in understanding of the peer review process, administrators from the Kidney Foundation of Canada (KFOC), the Canadian Nephrology Trials Network (CNTN) and the Canadian Donation and Transplantation Research Program (CDTRP) worked collaboratively along with PWLEs to create an online learning module to give PWLE an introductory understanding of the peer review process. The goal of the module is to build capacity and understanding of the peer review process within the PWLE community. Understanding the peer review process will help empower the PWLE community to become involved.To effectively integrate patient engagement into all aspects of research and implementation, the research community must involve PWLE prioritizing funded research and build their capacity to participate in the review and selection of research projects. Learning community engagement It was important to involve two groups in this project: PWLE in kidney disease or transplantation, with previous experience in peer review and patient engagement administrators who currently train PWLE.The involvement of PWLE helped to ensure accessibility of the information being presented to people with little to no knowledge of the peer review process.A call was put out through the communications channels of the three organizations asking for PWLE to join a working group to develop content and design an online learning module for peer review. Training documents from the three organizations were collected and an outline of potential module topics was drafted. This was reviewed by the working group and through an iterative process, the topics were selected. The project manager (PM) filled out each section, which was refined using an iterative process of review and edits by the working group. At each meeting, members came prepared with comments and suggested edits. Following each meeting the PM incorporated edits and suggestions. This process continued until there was consensus. Feedback gathered during the meetings and requested input from all members pre/post meeting was considered and appropriate changes were made to the content, ensuring everyone had an opportunity to share perspectives. Knowledge mobilization The module was launched and communicated through the organizations communication channels and the working group members shared through their personal channels.Collaboration with a learning community provided opportunity to leverage collective expertise, to learn from each other, and to deliver a comprehensive end product that meets needs across various groups and organizations. Collaboration allowed three organizations with a shared goal of improving patient engagement practices and building peer review capacity within the PWLE community to work with PWLE to develop a novel training module that can be widely used and promoted. Collaboration also provided the opportunity to learn from each other and incorporate positive changes into current systems.This collaborative effort resulted in a learning module that is accessible to a broad range of PWLE. It gives the PWLE community an introduction to the peer review process and encourages participation. Increased participation by PWLE helps to ensure that the patient voice is heard in the funding arena.

1 Can-SOLVE CKD, 2 CANTRAIN, 3 Kidney Foundation of Canada, 4 Canadian Donation and Transplantation Research Program

Building a path towards patient-centered program success: Community perspectives on indicators of program success for an Individual Placement and Support (IPS) program for people with persistent and multiple barriers to employment in British Columbia, Canada.

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Introduction and Background People that experience a combination of persistent health and social challenges such as severe mental health conditions, disability, food insecurity, and homelessness are designated as People with Persistent and Multiple Barriers (PPMB) by the Government of British Columbia. Individuals with PPMB status face disproportionate barriers to employment. Supported employment services, such as Individual Placement and Support (IPS), help people with disability secure competitive employment. Though traditional employment services aim to address some employment-related barriers, they are often siloed from healthcare services resulting in unaddressed healthcare needs of PPMB. To address this, Links to Employment, a novel IPS program-embedded within primary healthcare centres in British Columbia (BC) was developed to provide collaborative care while reconnecting adults experiencing barriers to employment.To evaluate the Links to Employment program, a prospective quasi-experimental study was designed to assess the employment and wellbeing outcomes of PPMB over time. Though securing competitive employment is one of the primary outcomes of the program, initial study findings suggest outcomes beyond being gainfully employed are important measures of program success. Improved mental health and quality of life, safe working environments, and supportive employers, were highlighted as equally important indicators of program success. To gain further insights, community sessions were conducted aiming to understand and evaluate what outcomes are important measures of program success to program clients and service providers in the Links to Employment program. Learning Community Engagement Community sessions comprised collaborating with two different groups; individuals with PPMB status accessing IPS program services at a designated primary healthcare centre in BC, and IPS program service providers including vocational counsellors, occupational therapists, and administrative/managerial staff. A Delphi method of consensus development was used, comprising of three survey rounds. In round 1, program clients and service providers (n=23) were asked “What does a successful program outcome mean to you?”. In round 2 and 3, survey respondents were asked to rate each program outcome on a five-point scale ranging from not at all important to very important. Data was descriptively analyzed and categorized into four broad categories of consensus outcomes: pre-employment, during employment, mental health, and quality of life related outcomes. A series of community discussions were then conducted with program clients and service providers. Community discussions involved sharing survey results and engaging them in a focus group discussion with semi-structured questions. To ensure accessibility across the province, the community discussions were organized virtually using a virtual communication meeting platform. The discussions were audio recorded, transcribed verbatim, and will be analyzed using reflexive thematic analysis. Initial findings from these discussions will be shared at the conference. Knowledge Mobilization Collaborating with community members will enable evaluation of the program and research data collection tools to assess whether these tools accurately capture the outcomes that were found to be important measures of program success to community members. These tools will be refined and used for program evaluation in the study's succeeding phases. Community session findings will be shared with the Links to Employment operations team to implement necessary changes to the program based on the community’s recommendations. A report of the findings will also be shared with the funding agency, highlighting the importance of comprehensive measurement of health and employment-related outcomes for an IPS program embedded within primary healthcare. A newsletter will be sent to community members informing them about the implemented changes in the program and research data collection tools. Through initial community sessions, a key lesson learned is the difference in perspectives about successful program outcomes between funding agencies and community members. This highlights the need for co-designing programs and research studies/tools by actively engaging with community members.

1 The University of British Columbia, 2 Canadian Mental Health Association, British Columbia

Characterizing the impacts of engaging with patient advisory councils on long-term recovery for sepsis survivors and their families

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Introduction and Background Sepsis occurs when an infection results in vital organ damage and can lead to death or disability. In Canada, there are nearly 100,000 cases of sepsis per year. Global, regional, and national sepsis organizations have engaged with patients to raise awareness of sepsis and improve advocacy and clinical care through patient involvement. The University of British Columbia (UBC)'s Action on Sepsis Research Excellence Cluster and Sepsis Canada (a national sepsis research network) established patient advisory councils (PACs) to guide strategic decision-making and facilitate patient-oriented research in sepsis. Despite the identified benefits of patient engagement, there is limited research on the experiences of sepsis survivors and their families in PACs, including how these experiences impact their long-term recovery. Understanding the long-term recovery of sepsis survivors and their families is critical as they may experience significant physical, cognitive, economic, psychological, and emotional challenges. Thus, here we aimed to explore the experiences of sepsis survivors and their families engaging in PACs and characterize the impact on this engagement on long-term recovery. By understanding sepsis experiences and establishing patient-centered approaches to sepsis care, we aim to inform health system policies and contribute to alleviating the burden of sepsis.   Learning Community Engagement This mixed-methods study was initiated and led by two members of Sepsis Canada and Action on Sepsis PACs and a UBC Assistant Professor (all co-PIs). The study team also included the Action on Sepsis network coordinator and a PhD candidate involved in Sepsis Canada. We engaged additional patient partners (n=3) to inform development of data collection tools and conduct data analysis. All communication was virtual to accommodate the broad geographic distribution of the study team and participants.   We first conducted a quantitative survey using the Patient Engagement In Research Scale and used the results to inform the development of our interview guide. All current members (n=30) of the Sepsis Canada and Action on Sepsis PACs were invited to participate. The gender (primarily women), age (20-80 years), and geographic distribution (residents of 6 provinces) of participants was representative of the existing PACs, which includes both sepsis survivors and caregivers of individuals who experienced sepsis. A research assistant who had not previously engaged with any members of the PACs conducted 10 independent interviews and 1 focus group to gain an in-depth understanding of patient partners' experiences. Thematic analysis is ongoing, and includes coding by one experienced researcher and a review of coded transcripts by a patient partner. Knowledge Mobilization During interviews and focus groups, we sought input on how to best share project findings. We will prepare and share study summaries and present findings to the Sepsis Canada and Action on Sepsis PACs and Steering Committees. We will also publish findings in an open-access peer-reviewed journal (with patient partner co-PIs as first and/or senior authors) and conduct webinars targeted to healthcare quality improvement networks to facilitate learning health systems that enable improved recovery for sepsis survivors. Our primary outcome will be an improved understanding of the impact of PACs on long-term recovery for sepsis survivors and their families. We will identify characteristics of engagement that can contribute to positive or negative impacts on sepsis survivors and their families that must be considered in patient engaged research. The preliminary results of this study have characterized sepsis experiences and recovery journeys, identified characteristics of PACs and patient/families that serve as facilitators and barriers to engagement, and identified potential impacts of PAC involvement. We anticipate our findings may inform advocacy for sepsis-specific patient support groups.

1 Institute for Global Health, BC Children's Hospital and BC Women's Hospital & Health Centre, Vancouver, Canada, 2 Department for Anesthesiology, Pharmacology & Therapeutics, University of British Columbia, Vancouver, Canada, 3 University of British Columbia Action on Sepsis Research Cluster, 4 Department of Health Research Methods, Evidence, and Impact, McMaster University, 5 Sepsis Canada, University of British Columbia Action on Sepsis Research Cluster, 6 Department of Obstetrics & Gynecology, University of British Columbia, Vancouver, Canada

Co-Creating Care: Enhancing Advance Care Planning in Oncology Through Patient & Healthcare provider partnerships

Lilia Laihem 1, Hilary Horlock 1, Heather Kilgour 1, Charissa Chiu 1, Megan Crosby 1, Taslin Velani 1, Crystele Montpetit 1, Penelope Hedges 1, Leah Lambert 1

Introduction and Background As nursing researchers and leaders, we sought to mobilize recent and local, nurse-led research findings to support oncology nurses in conducting advance care planning (ACP) with patients and their families. Despite the value of ACP in supporting patient-centered care, it has not been integrated into standard nursing practice at BC Cancer. Through our research, oncology nurses indicated several important changes needed to support nursing-led ACP. These include: (1) clarity regarding the nursing role in ACP, (2) educational opportunities, (3) dedicated time and space, and (4) interdisciplinary collaboration when approaching ACP. Equipped with this knowledge, we mobilized these findings to co-create a provincial nursing practice change at BC Cancer. This project aimed to foster leadership and knowledge mobilization (KMb) opportunities for direct-care nurses, while implementing systems-level changes to enhance nursing care and patient outcomes.Learning Community Engagement Informed by knowledge translation and change management methodologies, our project adopts a collaborative approach to actively engage the learning community in every aspect of the work, from planning to project completion. Ongoing collaboration ensures activities and outcomes align with the learning community.To engage groups in the learning community, we established an ACP Nursing Working Group comprised of nursing leaders (Senior Practice Leaders, Clinical Nurse Educators, Clinical Nurse Leaders, Clinical Services Managers, Clinical Nurse Specialists), direct-care nurses, patient and family partners, and members from the BC Centre for Palliative Care. Recognizing the importance of collaboration, our working group is co-led by members from Nursing and Allied Health Research and Knowledge Translation and Professional Practice Nursing. We worked with operational leaders to ensure nurses on the working group had dedicated days to work on the project, mitigating any conflict with their clinical workloads.To support further opportunities for collaboration and feedback, the ACP Nursing Working Group held engagement sessions at each of the six Regional BC Cancer Centres on the proposed ACP nursing practice change. Through the sessions, oncology nurses provided feedback that directly influenced their standard practices related to ACP, ensuring the workflow is acceptable and feasible within nursing practice. Additionally, we held patient and family partner focus groups to elicit feedback on our approach to ACP from the patient perspective and the development of patient-facing ACP educational resources. The learning community will continue to collaborate closely as we implement the ACP nursing practice change provincially, evaluate its impact, and establish plans for sustainability. Knowledge Mobilization The learning community will share and implement the work of the ACP Nursing Working Group which include presenting findings from our local research, sharing the proposed ACP nursing practice change, and gathering feedback on potential barriers and enablers. Additionally, members will co-develop a range of implementation strategies, including the distribution of educational resources, nursing orientation materials, and ACP nursing champions. During the launch, members will pilot the adapted ACP nursing workflow and implementation strategies at one Regional BC Cancer Centre, evaluate impact through chart audits and pre- and post- surveys, and plan for long-term success.The key lesson learned was by establishing strong organizational partnerships and grounding our project in co-creation with direct-care nurses, patient and family partners, and nursing leaders, we ensured the new ACP workflow held relevance and was acceptable into practice. The outcomes of the engagement will (1) enable nurses to exert influence from the outset of the new nursing workflow (2) establish a KMb pathway that spans issue identification to mobilization of findings and (3) foster a learning community that is highly motivated in creating change and improving patient care. By taking the time to engage those most impacted by the work, our team has had success unlocking nurses’ motivation for change.

1 BC Cancer

Co-Creating Patient-Centered Solutions through Human Centered Design

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Introduction and Background Repurposing the Ordering of Routine Laboratory Testing (RePORT) is a project aimed at reducing unnecessary and redundant blood work for hospitalized patients. RePORT engages patients, alongside healthcare professionals, to implement tools aimed at reducing unnecessary testing. Research indicates that patient experience is improved, and better health outcomes result, when patients are involved in their healthcare and in health research.Human Centered Design (HCD) is becoming more common in healthcare research. HCD is deeply rooted in empathy and is an approach focused on problem solving. HCD methodology aims to create functional and seamless solutions that resonate with the user’s needs, preferences, behaviours, and perceptions. HCD is centered on the user’s voice and can be used to increase patient engagement. Here, we discuss how we used HCD methodology, together with patient engagement, to create patient engagement tools. Learning Community Engagement The RePORT project is guided by a Patient Advisory Council (PAC) consisting of patient partners, healthcare professionals, researchers, an HCD specialist, and a quality improvement specialist. The Alberta SPOR SUPPORT Unit (AbSPORU) was also consulted to enhance patient engagement. A minimum of three patient partners attended every HCD meeting to co-develop patient engagement tools. During this time, monthly PAC meetings were held with the full PAC to provide updates and obtain feedback on the HCD process from those not directly involved.Knowledge Mobilization This work produced three co-developed patient engagement tools: an infographic, a website, and a video. To date, the infographic is the primary patient engagement tool and is displayed within hospitals throughout Alberta. This infographic briefly explains the bloodwork process so patients have a better understanding of what is happening, why blood is being taken, and how they can be more involved in the process. The goal of this infographic is to empower patients to be more active in their care.Surveys and interviews are being used to evaluate these resources with recently hospitalized patients as participants. Patient partners from the PAC helped create the survey questions and interview guide. They were also involved in developing methods for deploying the infographic in hospitals and in the recruitment plan for the surveys and interviews Much was learned throughout the process of using HCD and patient engagement principles in the creation of these tools.Evaluation of the HCD Process and Patient EngagementA meeting was held with patient members of the HCD process team to debrief and collect feedback about the experience after it was completed. The biggest lesson learned from this was that any facilitator of HCD also needs to be trained in patient engagement principles. While we had patient engagement specialists involved in the HCD process, the HCD specialist ran all of the meetings and led the engagement tool development. Many of our patient partners felt that, due to the HCD specialist lacking patient engagement training, the process got drawn out, communication decreased over time, and feelings of tokenism arose. However, there were also many positive experiences identified by our patient partners about being involved in the HCD process. The group added diverse experience and knowledge to the project, there was an overall culture of respect amongst team members, a welcoming environment pervaded the team, and there were many learning opportunities provided and opportunities for involvement throughout the process. Overall, the HCD process enhanced patient contributions and resulted in better patient engagement tools.

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Co-developing a Period Pain Awareness Campaign with Youth as Research Partners

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Introduction and Background 45 to 95% of females of reproductive age experience dysmenorrhea (period pain). Symptoms of dysmenorrhea are more pronounced among adolescents who are at a critical developmental stage of their lives, presenting challenges to academic performance, social interactions, activities of daily living and quality of life. Dysmenorrhea can often be treated with self-care strategies and over-the-counter analgesics, however, in some cases, dysmenorrhea is an indicator of underlying pelvic pathologies. Current evidence suggests that youth's knowledge of dysmenorrhea is low, which influences their ability to access appropriate care and select effective self-care strategies. In this context, knowledge mobilization to share information about care options for dysmenorrhea and how to obtain them can improve youth's access to care. As such, we co-designed a social media campaign and a website with youth partners to share information about dysmenorrhea among Canadian youth. Learning Community Engagement Co-designing the Period Pain Awareness Campaign with youth partners will yield a knowledge mobilization plan that is relatable to youth and drives deeper engagement of youth audiences. To foster trust and engagement with youth partners, we planned a series of four virtual workshops where youth partners will participate in brainstorming ideas for the campaign. Following a public invitation to join the workshops, we selected nine youth in Canada aged 15-20 to participate in these workshops. The youth partners involved in the project represent a spectrum of identities and lived experiences critical to developing a campaign relevant to youth of diverse backgrounds. In these four virtual workshops, the youth partners will generate key input for creating content and aesthetics for the social media campaign and website. These findings will inform the generation of the content.Knowledge Mobilization Some youth partners involved in the project are patients living with dysmenorrhea and endometriosis. Integrating agility in the co-design approach when engaging people with lived experience (PWLE) is critical to enabling meaningful engagement. This can be operationalized by providing various mediums to contribute feedback, flexibility with meeting times, and adapting to the learning goals of the project. Specifically, we learned that youth partners have a strong desire to learn about research and gain technical skills from their involvement in the project.We learned from the first two workshops that youth desired the focus of the campaign to be centered on period pain validation, as many youth partners experienced dismissals of period pain. Youth partners generated a 'mood board' (i.e. a collection of images, typography etc.), which will form the basis of our social media campaign. Youth partners also identified Instagram and Pinterest as potential platforms for the campaign to attract our target audience. The social media campaign and the website will be launched in 2025. Youth partners will be involved in co-creating the social media posts based on the ideas generated in Phase 1 of the project.Our collaborations with youth partners may serve as a model for iKT projects involving youth. In addition, our work in progress will highlight the contributions of youth partners as enablers of change in dysmenorrhea care.

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Collaborating to Support Unhoused People with Wounds

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Unsheltered people with wounds face many barriers to accessing care. If wounds go untreated, they often become chronic and complex, negatively impacting quality of life, with a high cost for both the individual and the healthcare system, as they may lead to prolonged hospital stays and even amputations. Research shows some patients avoid medical care because of a history of receiving stigmatizing care and distrust in the healthcare system. The model of set appointment times may not work for this patient population. “Mend & Tend: Drop-in community wound care services” (M&T) was created to provide treatment for simple wounds in a day shelter in Vancouver’s downtown eastside.M&T was launched in October 2023, operating two days per week, using a team model, composed of one RN (registered nurse), one LPN (Licensed Practical Nurse) and a Peer Support Worker (PSW, person with lived experience, trained and oriented to an outreach role). Community consultation was conducted to ensure the services offered by M&T would be complementary to other services offered in downtown Vancouver. Consultation with a Patient Partner (we use his initials, BL) was also conducted.In its first six months M&T has completed 690 client encounters. An interdisciplinary team, including a patient partner, BL, who has living experience of wounds and precarious housing, worked to develop the model for Mend & Tend. The team’s numerous consultations with BL took place partly at a community health centre (organized by a nurse who has worked with BL for many years and built trust with him), and partly through email or phone conversations with BL and the nurse. In those consultations, BL emphasized the importance of establishing the wound service in a setting that was familiar and comfortable to those in the downtown eastside. He also advocated for a care team that would include PSWs, emphasizing that potential clients would need outreach in order to know wound care was available and to offer reassurance to hesitant clients that the M&T nurses would be respectful.M&T follows a model of collaboration with PSWs, and their value to the team has been vitally important. Our recent evaluation of the M&T program included interviews with numerous staff people, including PSWs. Staff people, including PSWs, were overwhelming positive about the services provided and the model of care at M&T, noting, “Some clients are embarrassed to go to Emerg, so I tell them there’s no judgement here [at M&T].” Another staff person commented, “If it wasn’t for Mend & Tend, they [clients] wouldn’t have received any care at all.”The model for M&T was developed after months of preparation, primarily with an interprofessional team of health care providers, and also including individual consultation with BL, our patient partner. The decision to host M&T in a shelter required many hours of work, including creation of a contract with the City of Vancouver, who operates the shelter. Similarly, choosing to include PSWs added additional cost to the M&T budget and required a contract be created with Raincity Housing, who trains and supports PSWs. Without the strong encouragement of our patient partner, we might have been tempted to choose a different location, and host M&T with a team of only nurses. Our evaluation has shown overwhelmingly positive response to both the shelter location for M&T, and the inclusion of PSWs in the M&T team. Knowledge mobilization from M&T learnings has included one conference presentation in 2023, which our patient partner, BL, helped to create. (BL attended the presentation, but did not feel comfortable co-presenting). One of the PSWs from M&T will co-present at Putting Patients First, should this abstract be accepted.

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Collaborating with Patients to Create UBC Health's Position Statement for Patient and Community Engagement in Research

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Background UBC Health is a strategic unit at the University of British Columbia that fosters collaboration across health disciplines to advance collaborative health education, interdisciplinary research, and health systems transformation. A position statement on patient and community engagement was co-created to recognize the need to involve patients and community as equal partners and the benefits of meaningful partnership. This idea emerged from discussions with UBC Health's Patient and Community Advisory Committee (PAC), a diverse group of patients and community members (n=9) who provide valuable advice to guide UBC Health's initiatives. Members emphasized the importance of partnership and meaningful involvement of patients, especially those from equity-denied groups, in shaping research that directly affects them. This statement outlines UBC Health's commitment to embedding principles of mutual respect, equity and inclusion, co-creation, and support in all research activities, initiatives, partnerships and programs supported by UBC Health. Learning Community Engagement The development of this statement was a collaborative effort, bringing together PAC and UBC Health staff involved in interdisciplinary research and patient and community engagement portfolios during several advisory committee meetings. PAC members shared their experiences as participants and partners in research and provided resources that informed the statement's content. We conducted an informal scoping review of existing resources and consulted widely to ensure the statement reflects best practices and the specific context of UBC Health. Engagement methods included meetings with PAC, focused on enabling input and feedback to shape the statement. This collaborative process ensured that the statement is practical, relevant, and tailored to the unique context of UBC Health's research activities. It commits to integrating patient and community voices into decision-making processes, priority-setting, and governance across all UBC Health-supported research initiatives and promoting best practices. It is not intended as guidance for research conduct or a replacement for existing frameworks and resources for patient and community engagement. Knowledge Mobilization PAC was instrumental in initiating the statement and shaping how it will be shared and implemented. Through ongoing dialogue and shared decision-making, the statement was crafted to guide diverse activities and support UBC Health in embedding, demonstrating, and facilitating best practices in patient and community engagement. Delegates will get to meet PAC members who will share their experiences of serving on a patient advisory committee and being involved in the co-development of a position statement for patient engagement in research. Key lessons learned include the importance of trust, respect, and ongoing support to sustain meaningful engagement and the benefit of patient-led initiatives and involving patient partners in governance. The statement will be implemented starting Fall 2024. It will guide program development, UBC Health-supported research initiatives, and evaluation of how UBC Health meets its commitments to patient and community engagement in research. It will also inform the assessment of the impact of these practices on the overall impact of research initiatives.

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Conducting mixed-methods research with individuals with traumatic brain injury: Reflections and considerations

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Introduction and Background:Traumatic brain injury (TBI) has become more prevalent, with an estimated 69 million cases globally. Individuals with TBI have varied health outcomes due to the complexity of the injury and the individual characteristics of a person. As such, researchers need to tailor their approach and ensure their interactions are person-centered. Conducting research alongside individuals with TBI can be challenging, both for researchers and participants. Each individual with TBI is unique and requires a personalized approach when collecting research data. However, researchers may have limited resources and strategies to create study protocols that facilitate inclusion, safety, and relationships with people with TBI. Individuals with TBI may also find it difficult to engage in research as the protocols may not consider accessibility requirements of people with TBI.In our study, we reflected on our research processes and provided considerations when conducting research with individuals with TBI. Approaches to facilitate person-centered interactions that can improve researcher-participant relationships are described.Learning Community Engagement:In this study, researchers from the University of British Columbia partnered with people with TBI to reflect and develop key considerations to improve research practices. The engagement methods of this study included working with patient-partners (i.e., individuals with lived experience of TBI) to develop the research protocol (recruitment methods, interview questions). Additionally, we collaboratively reflected with community organizations and patient-partners to develop the findings.We recruited 16 participants with moderate to severe TBI for this study. Our data collection methods included both an individual interview and a questionnaire session with each participant that explored topics around life after TBI. Transcripts of interactions with the participant during data collection, researcher journal entries, and retrospective researcher notes were also reviewed.Knowledge Mobilization:Sharing of Findings. We are planning multiple knowledge translation activities targeted at various key stakeholders, such as other researchers and the brain injury community. To disseminate knowledge to other researchers, findings will be presented at research conferences and this study will be published in a scientific journal. For the broader brain injury community, we have partnered with the British Columbia Brain Injury Association to create and share knowledge translation documents, which include infographics and video summaries. These documents will be shared online through their social media channel and website (www.brainstreams.ca).Lessons Learned and Findings. Three experiences were identified: (1) ‘creating conversations’ focused on encounters where researchers may have inadvertently minimized participant experiences, (2) ‘asking the right questions’ examined participant reception of interview questions and questionnaires, and therefore, the need for researchers to consider revising terminology and phrases used in TBI research, and (3) ‘wearing academic armor’ explores how researchers can reduce barriers to establishing rapport and properly address participant needs. Additionally, three key strategies were identified to improve research-participant relationship, including: (1) using a multimethod design to create a broader understanding about the research topic, (2) collaborating with patient-partners as well as participants prior to the study to increase the suitability of study design and protocol, and (3) practicing active listening and reflection to discern the verbal and non-verbal cues of the participant.

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Design and Implementation of a Patient Advisory Council (PAC) for the Department of Anesthesia at Providence Health Care

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Introduction & BackgroundIntegrating patient voices in health science research ensures that patient perspectives guide research questions, projects, and the synthesis of new evidence. Patient partner input is crucial to ensure research questions, study designs, and interpretation of results are approached in a patient-centered manner and accurately reflect the needs and priorities of patients. While the Department of Anesthesia at St. Paul’s Hospital has previously involved patient partners on select projects, it has lacked a consistent and structured approach to guide patient engagement. The nature of anesthesia practice further complicates this issue, as anesthesiologists may not follow patients longitudinally throughout their perioperative journey.Learning Community Engagement We aimed to design and implement a tailored, robust, and longitudinal Patient Advisory Council (PAC), composed of patient partners with relevant lived experiences, that will provide ongoing feedback and help shape research projects. Our department holds regular research rounds to discuss new and ongoing projects. These meetings were identified as an ideal setting to incorporate patient perspectives. Successful development of the PAC required collaboration among various stakeholders, including: patient partners, researchers, trainees, and clinicians. Eligible patient partners were identified as BC residents with recent surgical experiences, either personally, as a family member, or as a caregiver, within the past two years. Diversity in surgical procedures, geographic location, age, and other demographic factors was also a critical consideration to ensure a broad spectrum of voices. To engage these groups, a multi-faceted recruitment strategy was employed. Patient partners were recruited through a combination of online and physical platforms to maximize reach. Online applications were posted on platforms such as Patient Voices Network, Reach BC, iVolunteer through United Way, social media, and university hiring sites (UBC, SFU, UVic, CapU, Langara). Physical recruitment involved posting flyers in the hospital. Interested individuals were onboarded through virtual interviews and materials to mitigate potential geographic barriers. Throughout this process, department staff and researchers were consulted for their advice and input.Knowledge Mobilization We formalized the PAC structure and mutual responsibilities, and created resources to facilitate a structured and consistent onboarding process: an onboarding package, glossary document, and patient partner agreement form. We intend to share our experience and these resources with other research groups. We will also engage with our patient partners in the knowledge dissemination process, seeking input to develop, draft, and distribute manuscripts and other materials.We recognized that implementing a PAC may pose challenges, particularly in terms of power imbalances, which can make it difficult to empower patient partner voices during research meetings. To address this, we found it essential to dismantle hierarchical structures. Acknowledging and addressing power imbalances related to position and expertise was key to creating an environment where everyone is on equal footing, fostering open communication, and ensuring meaningful participation for all. Furthermore, we acknowledge that the PAC structure will require ongoing iteration and evolution, and we remain open to future feedback from our stakeholders.Outcomes of the EngagementThe establishment of the PAC has been successful, with 31 patient partners onboarded from 47 applicants. Five applicants were lost to follow-up, and nine were deemed ineligible. Despite ongoing interest, recruitment was halted due to limited resources, as the department could not support additional patient partners.Key outcomes of our project include the development of onboarding documents, recruitment posters/posts, a glossary of terms, and a patient partner agreement form that will be disseminated and shared with other research groups.The formation of the PAC at St. Paul’s Hospital has established a structured and consistent approach to integrating patient perspectives into anesthesia research. This initiative not only enriches the research process but also ensures that findings are more aligned with patient needs and priorities, ultimately enhancing patient care.

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Designing a patient-first virtual service

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Fraser Health (FH) is designing a Virtual Hospital at Home service, an alternative option to traditional in-person hospital-level care that allows hospital patients to receive their medical care without having to physically be in a hospital. Medical services are provided remotely using digital technology and virtual health care. To ensure patient perspectives were incorporated into the design of this service, the virtual health team actively engaged patient partners to gather their thoughts, ideas, and concerns. The goal was to design a service that is truly informed by what matters most to our patients and their essential care partners (ECPs). Virtual Hospital at Home service aims to increase overall system capacity, improve patient flow and efficiency, reduce hospital-acquired harm, enhance patient and ECP experience, and enhance clinician experience. Given that this service model is new to B.C., it was imperative to co-design the service with patient partners to maximize the adoption and sustainment of the service.The key contributors to this initiative included the virtual health team (educators, facilitators, and clinical specialists), the virtual hospital project team, the patient engagement team, and the patient partners. Two primary methods were used to engage patient partners: 1) three 1:1 patient interviews to bring patient voices to the Executive team and the clinical leadership visioning sessions; and 2) a patient partner visioning session with 14 patient partners, which was co-designed with a patient partner, to collect detailed feedback to inform the service design of a virtual hospital. The patient partner visioning session was facilitated in-person with engagement activities and direct questions to allow conversation around previous positive or negative hospital experiences, as well as the concept of a Virtual Hospital at Home. A video synopsis of the three patient interviews was shared with the FH Executive team and during provider and staff visioning sessions to guide the service design. A summary of themes derived from both the interviews and the patient partner visioning session was then presented to patient partners for feedback, which helped refine the content. The summary was also shared with the Virtual Hospital at Home project team to drive further design efforts.Ultimately, a service design framework was finalized featuring: 1) five patient experience aim statements; 2) a driver diagram highlighting tangible ways of incorporating patient experience aims into service design; and 3) two patient journey maps. This framework was shared with both patient partners and the FH Executive team.Engaging patients in the design process revealed invaluable insights, including key themes around trust, connection, fear, knowledge, and empowerment. Unexpected concerns and fears were also brought to light such as respite for ECPs in a virtual hospital service. Additionally, involving a patient partner in the co-designing of the patient partner visioning session allowed for careful attention to language, diversity, and inclusion. Although this initiative represents only the initial planning stages of the Virtual Hospital at Home service, we recommend continual engagement of patient partners throughout all stages of developing and implementing novel service models.The outcomes of the patient partner engagement process have been directly incorporated into the service design framework, which now guides each project task team as they move forward with the design, development, and implementation of the virtual hospital service.

1 Fraser Health

Development of a unique advisory committee for mental health service improvements

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Introduction & Background: clearly specify the problem or issue being exploredThe engagement of People with Lived & Living Experience (PWLLE) of mental health challenges is a vital resource to inform health system improvements. Knowing that PWLLE face disproportionate barriers to engagement, we created a unique advisory committee to work alongside community partners and clinical leadership in our Acute Mental Health and Substance Use department at the Royal Jubilee Hospital in Victoria, B.C. Clearly articulate the relevance of the problem in the health system:Healthcare organizations need to hear from PWLLE, yet the mechanisms to share are not in alignment with PWLLE's preferences and priorities, in the following ways:· the meetings' cadence and timing are often catered to the health authority partners' needs, rather than those of the patients and caregivers.· the content is often dense, ever-changing, and acronym-heavy. Institutional updates are not easily accessible to onboarding PWLLE.· there are few opportunities to discuss and ask questions.· those with experience in sub-optimal care have reported to be hesitant, even discouraged, from sharing because of the emotions that arise from doing this workThese factors can impact PWLLE's voice in key decision-making conversations.Learning Community Engagement: Describe who needed to be involved in this work:PWLLE of acute mental health challenges are essential participants. This includes patients and caregivers, and particularly those with lived experience in Psychiatry Emergency Services and inpatient care. It is crucial that we have community service representatives alongside leadership from the health authority, to ensure that decisions made at this table can be operationalized.Describe the methods used to engage them:We formed a unique advisory body—Promoting Improvements in Psychiatry Emergency Services (PIPES)—to unite PWLLE, community service representatives, and leadership in the Mental Health and Substance Use (MHSU) department. This collaborative forum meets bi-monthly to discuss improvements in acute mental health services, in a safe and supportive environment.Describe the methods used (or to be used) to address the problem:Our aim is to evolve the PIPES meeting structure using feedback from our committee members. At the outset, we determined that meetings should focus exclusively on meaningful decision-making as guided by the International Association for Public Participation (IAP2) Spectrum of Public Participation, rather than simply informing PWLLE about existing operations.We ensure the PWLLE has one health authority contact to create regular check-ins with the committee membership, and to relay noted challenges and feedback.We aim to reduce the volume of acronyms, and simplify operational and clinical jargon, when needed. We respect the emotional dimension of PWLLE work, provide appropriate financial compensation for PWLLE's time, and provide accessible staff supports before, during, and after formal meetings.Knowledge Mobilization Describe how the Learning Community supported (or will support) the sharing or implementation of findings:By continuing to participate in the PIPES meeting structure, our Learning Community members support the identification of ongoing challenges and implementation of priority initiatives in an environment that promotes safe, non-hierarchical communication. Each PIPES meeting begins with a call for new ideas/challenges, followed by a review of previous action items, and closed loop communication, to ensure good accountability for all those involved.Describe the lessons learned about collaboration with a Learning CommunityThe conclusion drawn from the PIPES Learning Community is that the benefits of engagement must outweigh the costs. We continually ask ourselves, "how can we make the most of this time with and for PWLLE?", and we've developed the following strategies:· building relationships within the group· ensuring meetings are as inclusive as possible· demystifying organizational language· checking-in on process updates· supporting our PWLLE before, during, and after meetingsBriefly describe the outcomes of the engagement:Our PIPES meetings are currently made up of:· 6 regular attendees with Lived or Living Experience in MHSU challenges· 2 representatives from community organizations· 6 regular attendees from MHSU leadershipAs a result, there has been important input on key decisions, such as:· improvements in the physical space of the Young Adult Mental Health Unit· the design and implementation plan for Patient and Caregiver Feedback surveys· input on the Collateral Form, used to collect relevant information from families and caregivers of new admissions with mental health challenges· a list of self-care options that will make meaningful impact to patients with mental health challenges

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Empowering the Citizen Patient

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Introduction and BackgroundThe current Canadian healthcare crisis with limited numbers of primary care clinicians and few urgent care options is particularly critical in rural areas like the Kootenay-Boundary (KB) resulting in an estimated 20,000 unattached patients. Lack of providers led to overuse of emergency departments for non-urgent care, poorer patient outcomes and contributed to clinician burnout. Local healthcare administrators, providers and several patient members of the KB Collaborative Services Committee (CSC) began working together to create solutions for improved health and access through team-based care.Learning Community Engagement The KB Patient Advisory Committee and Community (KB PACC) was established in 2018 to provide additional regional patient voices to the CSC on restructuring healthcare within the KB systems. A KB Divisions' member survey indicated a need to establish informed patient relationships. In 2022 PACC began a patient-led education project - Empowering the Citizen Patient - to design, monthly, engaging, accessible, inclusive informational content, actionable tips, and resources, supporting people navigating health with team-based care. Using PDSA (Plan-Do-Study-Act) methodology, this patient-led project was established, incorporating inclusion and outreach through Google documents and in-person meetings with our emerging learning community: A retired physician PACC member creates article content, PACC members edit and add experiences through quotes, the communication lead formats the article and prepares the final version for publication on social media and in local newspapers and websites Before posting, local clinicians and administrators vet content, and final edits and suggestions come from the CSC co-chairs representing Interior Health (IH), Family Practice and First Nations. We added a survey specialist from the Division to create electronic surveys and our readers are encouraged to provide input on the articles impact and content to use in the futureKnowledge Mobilization PACC engages additional groups of patients and providers through in-person and zoom meetings, presenting our findings and soliciting new ideas for articles. This can be seen as new ways to improve patient self-care and navigation skills to enable patients to get the right care from the right person at the right time. Sharing our collective knowledge and insights to strengthen our understanding about patient/family/ community needs in the Kootenays, helped bringing our more appropriate health messages across our remote communities as a positive pathway to be more inclusive and responsive healthcare. Short-term outcomes of this project are:o   Creation of 11 articles and publication of 9, including content on medication, adherence, caregiving, preventive care and first aid that have reached 17,000 individuals who have seen our posts on Facebook and thousands of others through newspapers (e.g., Nelson Star circulation is 8500 households) and our website (3,425+ views with 1,665+ unique users).o   We have conducted community and provider presentations, including to the Ministry of Health resulting in topic ideas and a research plan and additional funding to continue this work for the next year. We have also established a patient education working group as part of the PACC and Division of Family Practice collaboration.o   Survey data from 64 subscribers found that the best distribution source is through social media as an educational tool. Most respondents found the content easy to read and informative, 54/63 found the content relevant, and 25 planned to share the article with someone else. Based on the most recent article, the top three new healthy behaviors respondents were motivated to try were exercise (35%), improved diet (27%), and improved sleep (23%). Nearly half (45%) expressed confidence (8 of 10) in their ability to perform tasks necessary for managing their health, expanding team-based care and potentially reducing reliance on medical visits.

1 Kootenay Boundary Patient Advisory Committee and Community

Empowering Women with Endometriosis and Adenomyosis through a bilingual, anonymous platform and Open Data outcomes

Zouhoura Hadji 1

Introduction and Background Endometriosis and adenomyosis significantly impact women's health in Canada, with 1 in 10 women affected by endometriosis alone. Many experience inadequate care due to healthcare system gaps. The EndoAdeno project addresses these issues by developing endoadeno.com, a bilingual, anonymous platform where women can propose actionable solutions to improve diagnosis, management, and quality of care. This initiative is vital for influencing health policy and practice through patient-driven insights, directly addressing the need for patient-centered care in the Canadian health system.Learning Community Engagement The primary participants are women with endometriosis and adenomyosis. The platform encourages them to suggest actionable improvements based on their experiences without sharing personal stories, ensuring anonymity and privacy. Healthcare professionals, researchers, and patient advocacy groups are also involved to provide expertise and ensure the project's relevance and impact.Methods of engagement include:• A secure, user-friendly, bilingual online platform featuring voting and commenting systems to prioritize and refine ideas.• A 3- to 5-month focused consultation period with weekly themed challenges to stimulate participation on specific aspects of care• Creation of engaging content (e.g., weekly summaries, infographics, educational content) to maintain community interest and participation.• Moderation by trained bilingual volunteers guided by a clear code of conduct to ensure a safe, constructive environment.The project uses quantitative thematic analysis with a collaboratively developed codebook to systematically analyze and categorize community suggestions, ensuring patient experiences are objectively translated into actionable insights for healthcare improvement.Knowledge Mobilization The Learning Community supports sharing and implementation of findings through:• Converting community-generated solutions into open data files to encourage innovation (e.g., new diagnostic tools, training programs for healthcare providers).• Utilizing these open data files in the project's second phase for implementation and adaptation based on priorities and feasibility.• Developing comprehensive reports based on thematic analysis.• Organizing webinars and workshops for healthcare stakeholders to disseminate findings.• Collaborating with patient-oriented organizations to advocate for change.Lessons learned include the importance of maintaining engagement through regular feedback, the value of anonymity in encouraging open participation, and the need for clear, bilingual communication to ensure inclusivity.Expected outcomes• A rich list of patient-proposed solutions converted into open data files to drive innovation.• Detailed reports highlighting key themes and priorities identified by the community.• Concrete recommendations for improving care pathways.• An engaged community empowered to advocate for better care.• Increased awareness among healthcare providers and the public.Long-term impacts may include improved policy formulation, increased funding for endometriosis and adenomyosis research, and a shift towards more patient-centered care models.By focusing on open data outcomes and a bilingual, anonymous platform, EndoAdeno empowers women to shape healthcare solutions, driving meaningful systemic change in women's health care.

1 Patient partner

Engaging with patient and family partners to develop education materials

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Introduction and Background:The Patient Health Education Materials (PHEM) committee reviews and publishes materials used by patients, residents and families at Providence Health Care (PHC). The PHEM committee is a group of health care professionals, and patient and family partners, who work together to support the creation of materials that incorporate plain language principles. Materials submitted to the committee come from a wide range of clinical areas across the organization.When PHC started the journey towards person- and family-centred care in 2011/12, it became apparent that patient health education materials were a perfect opportunity to involve patients and families. The existing PHEM review committee at that time included several PHC staff and evolved to include patient partners who participate in assessing, reviewing, and providing feedback to ensure materials are relevant, clear, and understandable, and support person-centred care.Learning Community Engagement:The PHEM committee meets monthly to review materials submitted by content experts from across the organization. Committee membership has changed over the years, and each patient or family partner who joins the committee has lived experience with the health system. The committee currently includes 3 patient and family partners who provide an important lens and voice to the creation of person-centred education materials together with PHC staff.All materials reviewed and approved by the PHEM Committee include a “Patient Approved” graphic and are made available via the PHEM catalogue. The PHEM catalogue is an online catalogue available to staff, patients, and families, and also provides access to resources developed by Vancouver Coastal Health.Knowledge Mobilization:The PHEM committee recently updated guidelines to support authors at PHC to develop materials which incorporate plain language principles, including considerations for the audience, content, word choice and writing style, organization, and visual aids. These guidelines will be shared with PHC staff in Fall 2024 through a communication strategy which will include sharing of information regarding who the PHEM committee is, what the PHEM committee does, and key considerations from the updated guidelines for creating person-centred and plain language materials. The communication strategy will also include a webinar created and presented with PHEM patient partners during Health Literacy Month in October 2024.The inclusion of patient and family voices in creating patient education materials helps to improve the quality of health materials across PHC and serves to promote sharing of information that enables patients and families to participate in their care. Future directions for the committee include exploring other tools, resources, and education to support awareness of the PHEM committee and skills related to plain language and health literacy.

1 Providence Health Care, 2 Patient Partner

Every Move Matters: Royal Inland Hospital Patient Activation Team Keeps Patients Moving Forward

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Maintaining mobility is key to improving patient outcomes in hospital. The health human resource crisis at Royal Inland Hospital (RIH) has led to staff moral distress when patients were not being sufficiently activated or mobilized for optimal care and system outcomes. All patients in hospital who do not stay active have an increased risk of falling, complications, and overall increase in length of stay. This has emphasized the importance of leveraging other healthcare providers to fill gaps in care. In March 2022, RIH Clinical Operations Leadership and Quality began exploring the opportunity for an activation team to adjust their care team composition and support safer quality of care. The project group team engaged RIH teams and colleagues from other hospitals, including senior leadership, unit managers, clinical educators, allied health leaders, frontline teams, unit PCCs, frontline nursing and other care staff. This brainstorming led to the development of The RIH Patient Activation Team (PAT).The PAT was inspired by, and built off, various other programs employed in IH and beyond. Various disciplines were explored for this role, including, Rehabilitation Assistants, Unit Support Workers, and Kinesiologists. Health Care Aids were found to have the right skill mix, fit within the role description and were deemed appropriate to support this work. The PAT has now been rolled out to 7 inpatient units at RIH, covering medical and surgical, pre-rehab and acute neurological. Coverage is provided from 0900-2000, 7 days a week.The PAT project team has intentionally engaged units and other partners, and sought feedback at all stages of project planning, implementation, and evaluation. Quality improvement methodology has been utilized throughout the pilot project, utilizing PDSA cycles to inform workflows and expansion. Priority has been placed on two-way communication with teams, obtaining feedback from all partners and holding regular troubleshooting meetings with frontline PAT to help guide next steps. Baseline and midway staff surveys were completed, in addition to collaboratively creating unit expansion plans and standard work by meaningfully involving unit educators, leadership and frontline staff. To promote sustainability and spread, the project team has sought opportunities to collaborate, and share information with other IH hospitals. The project team has utilized a variety of larger forums to share learnings beyond IH’s boundaries, attending the BC Quality Forum, Interior Health’s Linking Leaders conference and submitting for the BC Quality Awards. Finally, voluntarily submitted patient feedback has been collected and themed to identify growth areas, reinforce strengths of the program and maintain focus on “the why” of this work.To date, the overall project outcomes have been favorable. The total number of patients on the PAT caseload on trial units has trended positively since the program rollout in October 2022, resulting in more RIH patients being activated on a regular basis. The average number of patients being activated has increased from 23 per day at project start to an average of 56 per day. As of June 2024, 61% of PAT patients are being activated three times a day, compared to 6% in November 2022. RIH has observed a decrease in Hospital Harm (HH) events (i.e., pressure injuries, urinary tract infections, and pneumonia) from Q2 (2022/23) to Q4 (2022/23) [current FY data pending from CIHI]. The PAT has demonstrated that leveraging our full team of health care professions helps to keep patients activated and makes every move matter!

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Evidence in Care: A Learning Community Approach to Rapid Evidence Reviews

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Introduction and Background BC Mental Health and Substance Use Services (BCMHSUS) provides health care to people with complex mental health and substance use (MHSU) needs, as well as conducts research and knowledge translation and exchange (KTE) to promote knowledge sharing and evidence-based practice across the organization. Evidence in Care (EiC) is an integrated KTE program that provides decision-makers and direct care providers with relevant research to inform health system policies and practices in a timely way. The EiC program utilizes the expertise of researchers, health care decision-makers, direct care providers, and persons with lived and living experience to conduct rapid reviews and develop tailored evidence syntheses to facilitate the uptake of best practices. In this way, EiC takes a learning community approach to work towards solving specific health system problems.In particular, BCMHSUS recently led an EiC project to address gaps in knowledge on best practices for preventing toxic drug events among people living with co-occurring mental health and substance use challenges. To address this gap, a committee was established composed of healthcare decision makers, researchers, lived and living experience strategic advisors, and KTE specialists. Learning Community Engagement EiC requests are submitted by healthcare leaders at BCMHSUS. If multiple EiC requests are received, a process is conducted to prioritize requests that align best with the organization's strategic priorities. Once a request has been prioritized, a recruitment process is initiated to ensure diverse voices and expertise are involved throughout the EiC journey. For example, the Research Institute at BCMHSUS was engaged to identify researchers with expertise in systematic literature reviews. Additionally, an engagement opportunity was circulated through BCMHSUS' networks to recruit persons with relevant lived/living experience (LLE) to play a strategic role on the project. Finally, a team of KTE Specialists acted as the sponsor for the project and played a key project management role.Once the learning community was established, regular meetings were held to respond to the request. This included refining the research question, defining the exclusion and inclusion criteria, developing a search term strategy, conducting the literature review, analyzing and interpreting the results. An Evidence Brief was then developed to summarize best practices for preventing toxic drug events among people with co-occurring mental health and substance use challenges, inclusive of academic literature, grey literature, and the voices of people with LLE.Knowledge Mobilization Since the EiC request was completed, the learning community has been broadened to include strategic advisors and system design experts to guide knowledge mobilization and the implementation of key findings. Knowledge mobilization efforts include a) consulting with BCMHSUS' Research Leads to advise on the publication of the EiC results, b) leveraging BCMHSUS' Provincial Mental Health and Substance Use Network to share and validate findings with key target audiences, and c) engaging the organization's Transformational Leadership Office to develop a robust prioritization process to guide the implementation of recommendations. Together, results from the EiC project are being used to inform provincial guidelines for effectively preventing toxic drug events in BC. For those interested in implementing a similar EiC model, we recommend project teams develop terms of reference at the start of the project to ensure clear roles and responsibilities, ensure people with LLE are provided with adequate resources and training to engage meaningfully in the research, have the right software in place (such as collaborative coding programs), consider scope of the research question, and ensure dedicated staffing and project management support throughout the evidence review and implementation stages of the project. With the right resources in place, EiC demonstrates how learning communities can effectively address health system problems and improve health outcomes for those we aim to serve.

1 BC Mental Health and Substance Use Services

Evidence-based Cost Accounting for Long-term Care Beds in Home-based and Institutional Settings (Work in Progress)

Jenny Arntzen 1, Gavin Wong 1, Neale Smith 1, Smita Roy 1, Craig Mitton 1

Issue to be ExploredThere is no evidence-based data available to show a cost accounting of Time and Materials expended by family caregivers who are operating a long-term care bed in their home for family members who can no longer fend for themselves. There is no comparative analysis to demonstrate the cost-effectiveness of home care (home-based long-term care beds) in relation to institutional care. The Strategy for Patient-Oriented Research (SPOR) at the Canadian Institute for Health Research found no reviews on this topic during their scoping literature search. Their conclusion was that there is scope to conduct further research in this area. This scoping review is funded by SPOR Evidence Alliance. The final report is due March, 2025.The relevance of this problem is the increase of programs that transfer health care operations to family home-based beds - Hospital to Home, Early Hospital Discharge, Aging in Place - to be managed and staffed by family caregivers. This transfer of work has not been adequately studied in terms of Time and Material expenditures incurred by family caregivers. The work provided by family caregiver operations has not been quantified to rationalize the distribution of resources to home-based caregiving operations compared to beds in institutional settings. The health system is increasingly dependent on home-based healthcare infrastructure without evidence-based cost accounting to ensure equitable resources to sustain these operations. The households of family caregivers show increased socio-economic vulnerability the longer they operate their home-based caregiving bed.Learning Community Engagement This Scoping Review plans to include inputs from four interest holder groups:Family CaregiversHealth Providers and AdministratorsHealth ResearchersHealth Policymakers and Decision-makers The methods to engage these groups include:Blog posting findings from the Scoping Review and discussing them in relation to the Lived Experience of Family Caregivers to alert Interest Holder Groups of the work that is underway; providing an opportunity to weigh in on the discussion through sharing on social media (LinkedIn);Presenting work in progress to Interest Holder Groups at gatherings such as the Putting Patients First on Nov 14;Hosting a one day event to bring together a cross-section of Interest Holder Groups for presentations of the findings from the Scoping Review, small group discussions of the findings, and an opportunity to share inputs of Lived Experience back to the research group for planning next steps;Exploring the efficacy of using Youtube as a platform for sharing short videos discussing lived experience and research knowledge, linking back to the blog posts.Methods to Address the ProblemOur hope is to use the results of the Scoping Review to backstop two research initiatives: 1. Time / Material Study of Families Operating Home-based Long-Term Care beds; 2. Arts-based Narrative Inquiry for Family Caregivers: Lived Experience in relation to Research Knowledge.Knowledge Mobilization There is much work to do to mobilize research knowledge to family caregivers. We will know more about how this is working as we get further into the Scoping Review and Blog posting. Early indications on LinkedIn show a high increase of impressions and engagement in the professional family caregiving community when lived experience is combined with research knowledge. One metric of outcomes of engagement was monitoring impressions and engagement on LinkedIn during the month of July (blog post impressions peaked at 341 post impressions showing an increase of 8,425% in the past 7k days - 2024 07 31).Our proof of concept for video posts on Youtube combined with Blog posts on Blogger - we posted on August 13, today is August 15 and we have had 56 views on our Youtube channel and 23 views of the associated blog post.

1 University of British Columbia

Exploring perceptions on the concerns, challenges, and opportunities around sedentary behaviour awareness and reduction in long-term care homes

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Sedentary behaviour (SB) refers to any waking behaviour performed in a seated, lying, or reclining posture at a low energy expenditure and has emerged as an important public health issue in the past decade. Research has shown that for each 1-hour increment of sedentary time, the risk of sarcopenia (accelerated loss of muscle mass) increases by 33%, independent of physical activity levels. With long term care (LTC) residents being at a high risk of falls, depression, cardiovascular disease, and cardiometabolic diseases; it is imperative that we find ways to keep them moving throughout the day. A study reviewing primary recommendations and guidelines to counteract physical deconditioning in LTC suggests mobilizing three times per day for two to five minutes at a time. Recent studies reveal that LTC residents have experienced significant declines in both physical and mental health due to the COVID-19 pandemic. This includes increased rates of functional decline, sarcopenia, and depression, which highlights a critical need for updated research. This shift underscores the importance of collaborating with stakeholders to address the evolving needs of this population and develop strategies to reduce sedentary behavior in LTC communities, ultimately enhancing their overall well-being.Currently, Fraser Health (FH) has over 80 LTC homes including over 11,000 residents. Actively engaging people with lived experience as co-producers of research is a cornerstone of health research. LTC residents and families in FH have spoken about their need for connection and engaging in activities that they enjoy. Thus, residents, families, volunteers, and staff were invited to be involved in consultative dialogues with the objectives of exploring 1) people’s perceptions of SB in LTC; 2) the challenges for reducing SB in LTC and 3) possible interventions that can be implemented across all LTC communities to promote a 'sit less, move more' approach for residents in LTC.Our team engaged with 100 people from 24 LTC homes, including 8 residents, 6 family members, 1 volunteer, and 85 staff members. The 1-hour sessions were conducted virtually and in-person using a dialogue guide, starting with a brief 10-minute education presentation on SB (residents did not receive education). Surveys were conducted pre and post education to assess any changes in SB knowledge/awareness. Sessions were thematically analyzed to summarize key learnings. Those that engaged in the dialogue sessions had the opportunity to review and confirm the summary of key learnings.Based on our engagement, it was evident that each LTC home has different needs and wants depending on the unique profile of their residents and environment. The dialogue sessions helped develop partnerships for SB reduction and education in the LTC context and increased our understanding of barriers and facilitators in implementing effective 'sit less, move more' interventions for meaningful future research.The three major themes that emerged from the engagement were 1) education, 2) emerging interventions and 3) infrastructure. The identified key learnings moving forward were having structured educational programs for staff and families to empower them to promote resident movement; addressing challenges such as limited staffing levels; and introducing possible interventions, like interactive technology, music/dance breaks and a community of practice, to help reduce SB for LTC residents. Cross collaboration with learning communities of residents, family members, volunteers, and staff were invaluable to identify patterns and themes. This is because it takes a community to solve problems impacting the health and wellness of a population.

1 Fraser Health, 2 Simon Fraser University

Feasibility of the patient-reported outcome measure for the assessment of symptom burden in pediatric chronic kidney disease “PRO-Kid” in children aged 2-7 years.

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Introduction and background: Children with chronic kidney disease (CKD) and kidney failure face significant symptom burden as a result of their disease. While laboratory tests have typically been used to assess disease progression and determine management, emerging evidence suggests symptom severity is another important factor that must be considered when devising a treatment plan. Until recently, there was no standardized assessment tool for quantifying symptom burden in the pediatric population. To address this gap, we developed and validated a patient reported outcome tool (PRO-Kid) to assess symptoms and their impact for children ages 8-18 years with CKD. An adapted version (using emojis for the Likert scale) is now being evaluated for understandability, ease of completion, and face and content validity for children aged 5 to 7, and parents of children aged 2 to 4.Learning community engagement:PRO-Kid was developed by the Can-SOLVE CKD Patient Oriented Research Network. At its conception, the network hosted multidisciplinary brainstorming sessions amongst patient partners, healthcare providers, and policymakers, which led to priority setting for key themes requiring further research investment. Patients were fundamental participants here, with their voices and perspectives ultimately driving the outcomes. Symptom burden was endorsed as a top priority by both adult and pediatric patient partners, and our research project was funded to address this gap for children. PRO-Kid was developed with the assistance of six pediatric patients and six caregivers, who were involved from design and planning, through to execution and analysis, and have contributed to knowledge translation, attending regional and international conferences. Their contributions have been integral in ensuring that the patient lens was represented through every phase of the project, allowing us to maintain relevance and applicability to the target patient population.To examine the relevance and validity of the modified PRO-Kid questionnaire for younger children (2-7 years), we used qualitative analysis of semi-structured cognitive interviews performed with the children (between ages 5 to 7) and their caregivers (for children aged 2 to 4). In these interviews, we asked open ended questions about general experiences with CKD, their symptom burden, and their experience with the PRO-Kid questionnaire. Thorough notes were taken, and these were later analyzed to extract common themes and patterns.Knowledge mobilization:Thus far, interviews have been completed for 9 patients between ages 5 and 7 and for 9 caregivers of children aged 2 to 4, with a goal of 10 for each age group. Analysis of the preliminary results has shown that the adapted tool is easy to understand and straightforward to complete. the questionnaire addresses the most bothersome CKD symptoms and the language used to elicit those symptoms is appropriate and understandable for children in this age group. Children aged 5-7 years especially appreciated the use of emojis to report symptom burden and frequency and were able to engage actively with the questionnaire with these responses.Findings will be shared broadly in the next phase of work, which will pilot implementation of the PRO-Kid questionnaire into CKD and dialysis clinics across 7 sites in Canada, looking at acceptability from a physician perspective. In terms of learning community support for knowledge mobilization, the patient partners on this project have presented at conferences and scientific meetings about the need for the PRO-Kid questionnaire and its usefulness from their perspectives. Sharing their lived experiences, they are able to attest firsthand to the potential that this work holds for CKD pediatric patients and caregivers, and are able to effectively disseminate knowledge within their own communities in addition to the scientific community. Being able to share this work broadly, beyond just scientific conferences has been one of the unanticipated, but highly meaningful, outcomes of patient partner collaboration.

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Get the Message? Improving Access to Virtual Healthcare for Older Adults Through Patient Partner Collaboration

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Introduction and Background The COVID-19 pandemic has greatly increased the adoption of virtual health services; yet, older adults face significant barriers in receiving virtual healthcare. The Canadian healthcare system has been widely criticized for not meeting the needs and addressing the challenges of the aging population. Furthermore, older adult perspectives are often underrepresented in evaluations of virtual care. With Canada's senior population expected to grow by nearly 70% over the next 20 years, there's a need for comprehensive evaluation of virtual health programs to inform continuing and upcoming practices for more equitable and efficacious care. Get the Message? is a project that consists of five research studies that focus on virtual messaging in healthcare to develop and implement equitable virtual care that are designed for older populations. The objectives are (1) to synthesize existing evidence on strategies to engage and evaluate older adults' participation in patient-provider messaging, (2) examine best practices for patient-provider messaging, and (3) develop policies for patient-provider messaging to improve the quality of care for older adults and contribute to the planning and preparedness of Canada's healthcare system. Learning Community Engagement To ensure that the study addresses the challenges and concerns of those most affected by the issues at hand, our research projects include a dedicated team of patient partners, in addition to researchers and healthcare professionals. The patient partner committee is made up of 5 community members with lived experiences, being older adults themselves or caregivers to older adults, who have gone through the healthcare system. We actively engage with patient partners throughout different research stages, through both written communication and monthly meetings. This enables patient partners to provide ongoing feedback on research progress, discuss emerging issues, and offer their perspectives on various aspects of the study. For example, our patient partners have played a role in refining study protocols, developing interview guides, and selecting survey data collection sites. Additionally, in past projects, we hosted co-design sessions to bring together researchers and patient partners to generate ideas and implementation solutions. Some activities included one-on-one talk aloud sessions, group discussions, self-reflection, and presentations. Some outputs created were clinical workflow mapping, development of learning pathways, and a change management plan. For Get the Message?, we intend to engage our patient partners in a similar fashion when creating knowledge products and to continuously inform our research processes. Knowledge Mobilization As our research projects are entering the knowledge mobilization stage, patient partners will play a crucial role in the development of a knowledge translation plan. They will help determine what results are most relevant and meaningful to the community, while ensuring that findings are presented in a way that aligns with their preferences and needs. One key lesson of collaborating with a learning community is the need for maintaining an open and transparent line of communication throughout the research process. Providing regular updates and feedback helped build trust and allow all partners to feel that their contributions are valued. Another lesson is the importance of having flexibility in the research design. Engaging with a diverse group of partners often introduce new insights, thereby shifting priorities and requiring adjustments to the research approach. By incorporating a wide range of partners into the research and knowledge translation strategy, we can ensure that our research findings are accessible, engaging, and actionable for the community, ultimately enhancing the impact and utility of our research.

1 Fraser Health

Identifying social determinants of health and quality of life information for use in health and social services in Indigenous communities

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Background: In response to the Canadian Truth and Reconciliation Commission Calls to Action, there have been increased efforts to address health inequities through culturally aligned and relevant health and social services in Indigenous communities. To achieve this, healthcare services and programs must be guided by the social determinants of health (SDOH) and quality of life (QOL) of the people and communities they serve. This research aimed to identify Indigenous SDOH and QOL that extend beyond theory towards action, and that reflect Indigenous ways of being, knowing, and doing. The overarching objective of this study was to understand Indigenous knowledge keepers' (KKs) and service providers' (SPs) perspectives regarding the collection, reporting, and use of SDOH and QOL information. The study further aimed to reach consensus regarding key areas of SDOH and QOL for a culturally aligned health and wellness measurement framework to be used by health and social service providers in Indigenous communities.Methods: We took a participatory integrated knowledge translation approach that involved sustained engagement with Indigenous KKs and SPs. The research involved two phases: (a) a preliminary phase consisting of literature reviews and a qualitative study with seven focus groups (4 KK and 3 SP groups) and two individual interviews (both KKs) to identify SDOH and QOL areas, and (b) a Delphi study with two rounds of surveys shared with KKs and SPs to reach a consensus on statements about priority areas for SDOH and QOL information. The literature reviews gathered a broad range of SDOH and QOL areas, while the focus groups and interviews provided contextual information by KKs and SPs in Indigenous communities in Canada. In the Delphi surveys, KKs and SPs provided ratings on SDOH and QOL information that they view as priority areas in their community. Statement rated by ≥80% within both groups as "high priority" or "extreme priority" were considered as consensus reached and included in the final SDOH and QOL list. A final meeting was held with KKs after the Delphi surveys ended to share and receive feedback on the results.Findings: Combining the findings from the preliminary phase resulted in 102 statements across 16 SDOH and QOL categories which were presented to KKs and SPs during the Delphi phase. Ten KKs and 12 SPs completed the first round of the Delphi surveys, of which 8 and 6 completed the second round, respectively. At the end of the second round of survey, 44 statements in 11 categories had reached consensus as priority SDOH and QOL information, of which 35 had reached consensus in the first round. With one exception, all statements that did not reach consensus were based on the rating distributions in the SP group.Learnings: Engagement with KKs and SPs was invaluable for identifying relevant SDOH and QOL information in Indigenous communities. It offered a unique way to describe Indigenous conceptualizations of health and wellbeing, understand how certain concepts are understood as areas of health and wellbeing for Indigenous peoples, and prioritize concerns of various Indigenous communities across Canada. It further allowed dialogue around current or potential practical application of these SDOH and QOL concepts. Through the literature reviews, qualitative studies, and Delphi surveys, we reached a multidimensional and nuanced perspective of the unique aspects of Indigenous SDOH and QOL. Further information on the project is available in the following link (https://healthyqol.com/indigenous).

1 Trinity Western University

Implementing Patient-partnered Workshops in Regional Areas of British Columbia to Enhance Clinician Confidence in SCI Care

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Introduction and BackgroundSpinal Cord Injury (SCI) is a lifelong health condition that results in high healthcare utilization and requires specialized clinical knowledge. Persons with lived experience (PLEX) of SCI living in regional and rural areas of BC have difficulty accessing specialized care locally. This creates a requirement to travel long distances to access appropriate care, causing increased financial, equipment, and personal care burdens to access specialized services in urban centres. Clinicians working in regional areas recognize that developing knowledge and skills specific to SCI will improve patient care outcomes. This presentation explores the development and implementation of SCI workshops, from the perspectives of a clinician and PLEX. Specifically, the objectives are to:· Describe the co-creation and co-implementation of regional SCI workshops including engagement of both clinicians and PLEX.· Demonstrate how SCI Workshops delivered by PLEX alongside clinical experts results in increased knowledge and confidence for clinicians in regional areas and PLEX confidence in access to healthcare.· Engage workshop participants to share learnings from other initiatives aimed at improving knowledge and confidence of clinicians working with PLEX in regional areas.Learning Community Engagement A community survey was conducted with 44 people with lived experience of SCI in a BC region to identify priority SCI health-related topics. Twenty-five topics were ranked from 1 to 14, with bowel and bladder management ranked 1 and 4, sexual health ranked 5, and pressure injuries ranked 7. Clinical education priorities were collected from 102 clinicians in the same BC region, who independently ranked 14 of these SCI topics and considered the former 4 topics to be lower clinical priority (ranked 11-14). The top priorities of PLEX informed a series of SCI clinical education workshops conducted by the Praxis Spinal Cord Institute in the BC Northern and Interior Health Regions to improve clinician knowledge about SCI. Some workshop topics included, but are not limited to pressure injuries, neurogenic bowel and bladder management, sexual health, autonomic dysreflexia, specialized equipment and Indigenous perspectives. An evaluation survey is conducted pre and post workshop, comparing knowledge and confidence of topics discussed throughout the workshops. The change in scores demonstrates an overwhelming increase in the knowledge and confidence of the clinical attendees.Fundamental to these workshops has been the integration of PLEX as both key informants and co-facilitators. Supplementing clinical knowledge with lived experience has provided a greater depth of perspective of clinical needs, while also providing real-world knowledge that can only be brought through PLEX. The underlying methodology of our engagement can provide a template for other health conditions to develop similar clinical education initiatives.Knowledge Mobilization There have been 33 workshops conducted to date in the following locations: Kelowna, Vernon, Kamloops, Penticton, Prince George, Nelson, Trail. Every workshop is facilitated by PLEX and clinicians. Results from the evaluations indicate an overall increase in clinical knowledge and confidence in SCI topics and attendees said they would change their clinical practice to provide improved care for people with SCI. Key learnings from the workshops include increased understanding of the PLEX perspective, management of secondary complications of SCI and prevention of pressure injuries. The engagement has resulted in improved SCI networks and knowledge sharing amongst stakeholders throughout the regional areas of BC.In summary, the positive feedback demonstrated that educational workshops supported by lived experience perspectives effectively enhanced the clinicians' understanding of spinal cord injury and their priorities. Ongoing work includes engaging more administrators as part of this initiative to facilitate system changes and conducting workshops in other regions of BC including Vancouver Island.

1 Praxis Spinal Cord Institute

Indigenous Knowledge Translation at the Indigenous Wellbeing Gathering Conference

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The disruption of Indigenous Knowledge translation due to Eurocentric settler ideologies has significantly impacted the identity, culture, and wellbeing of Indigenous Peoples, creating gaps in systems that fail to address the holistic needs of these communities. This disruption has led to a loss of sense of belonging, community connection, and self-determination, which are critical to wellness. The inaugural Indigenous Wellbeing Gathering Conference (IWGC), hosted by the Urban Indigenous Wellbeing Collective on the traditional territory of the Syilx Okanagan People, sought to address these gaps by developing an inclusive platform for knowledge exchange centered on Indigenous wellbeing. Grounded in reciprocity and relationality, the IWGC aimed to bridge the gap between academic research and Indigenous community-led wellbeing practices. In this context, 'wellbeing' encompassed not only biomedical health but also the social and structural determinants of health, including language, land, and self-determination, aligning with Indigenous worldviews. A central focus of the IWGC was to promote health equity and decolonization by integrating Indigenous Knowledge into various sectors, including health and research, through culturally relevant Knowledge Translation (KT) processes.The IWGC is a multidisciplinary gathering that brought together a diverse group of 120 collaborators, including Indigenous Elders, community members, health practitioners, researchers, trainees, and partners from both Indigenous and non-Indigenous backgrounds. Leading up to the conference, urban Indigenous community members were involved in planning meetings to ensure the conference design and content were relevant and responsive to community-identified priorities. With 41 presenters, the IWGC featured keynotes, interactive roundtables, panel discussions, workshops, and creative presentations, fostering a collaborative environment that prioritized Indigenous community engagement. This approach facilitated the formation of research partnerships, the building of connections, and the sharing of feedback that supported Indigenous wellbeing. By engaging relevant health practitioners alongside community members, the IWGC promoted a holistic understanding of health, encouraging participants to consider how the insights and practices shared at the conference could be applied within various systems, including healthcare.To further the goal of integrating Indigenous Knowledge across different sectors, and in direct response to feedback from the IWGC, we developed the Indigenous Wellbeing Research KT Framework. This framework guides future KT and community engagement processes by acknowledging the equal importance of community, research, and wellbeing practitioner knowledges. Reflecting the principles of Indigenous research methods, the framework values the lived experiences of community members, research participants, and knowledge users as equal to those of academic researchers. Grounded in the 4 Rs—reciprocity, respect, responsibility, and relevance—the framework fosters an iterative and ongoing knowledge exchange process, ensuring that KT efforts remain culturally relevant and responsive to the evolving needs of Indigenous communities. This approach not only supports health equity but also provides a model for aligning research and practice with Indigenous values and wellbeing.The IWGC served as a platform for knowledge exchange and facilitated the sharing of Indigenous perspectives and practices. By centering Indigenous Knowledge, fostering multidisciplinary collaboration, and engaging with a wide range of partners, the conference contributed to building relationships and promoting Indigenous approaches within various systems, including research. The Indigenous KT framework developed as a result of the IWGC provides a model for how research and practice can be more effectively aligned with the values and needs of Indigenous communities.

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Interior Health's Collaboration to Rapid, Reliable STEMI Intervention

Karen Kowal 1

The manual ST Elevation Myocardial Infarction (STEMI) notification process for the Regional Cardiac Catheterization Lab located at Kelowna General Hospital (KGH) has faced ongoing challenges in effectively and promptly activating the on-call team. Delays in communication to this team can significantly impact the timely delivery of critical, life-saving interventions for patients experiencing severe cardiac events. Addressing these challenges was crucial to ensure that patients receive the swift and efficient care necessary to improve outcomes and reduce the risk of complications associated with a STEMI.At the time, the STEMI notification system relied on manual escalation, with advances in technology it was noted that there were new systems that had been developed to replace pagers and phone calls. This quality improvement opportunity would streamline the communication of the patient journey in our vast health region.The established Code STEMI review committee review all regional STEMI cases. Representation from the Emergency and Cardiac Physicians, departmental managers, BC Emergency Health Services, Medical Directors, Educators, Cardiac Clinical Nurse Specialists, Cardiac Informatics/ Quality RN, Cardiac Program Lead noted opportunities to streamline and improve the communication process.A collaboration with representation from all teams was formed to initiate the discovery of the current process and identify opportunities. Key partners directly involved in the STEMI patient journey (Cath Lab Manager, Educator, Patient Coordinator (PCC), RN’s, Emergency PCC, Interventional Cardiologists, General Cardiologists, Patient Registration, Shift Coordinators, Switchboard, Security, Cardiac Intensive Care Unit PCC, Digital Health and the Improvement Consultant) were identified and formed a working group. A series of meetings were organized to discuss current state, review options for available technology within Canada that was compliant with patient privacy, and establish project’s scope and aim statement. Guiding principles, team dynamics and expectations were agreed upon for the project. Comprehensive process mapping of the current state identified each step, the responsible team member and included details of the process. These intricate details were eye opening to many of the team members. Discussions and documentation of existing challenges and opportunities inherently occurred. The team then started to build a potential future state utilizing the identified technology for informing the multidisciplinary team. This was then shared broadly for engagement and feedback amongst all staff that would be involved in the process. The learning committee tested and validated the new process, using the plan, do, study, act (PDSA) cycle. Following this, standard process documents for all roles were created to ensure consistency, clarity and adherence to the newly established process. The inter-departmental teams supported a dual approach testing model. By running concurrent systems it allowed the teams to build trust and confidence in the new system.The lessons learned from this initiative emphasize the importance and value of inclusive engagement. Isolated efforts were avoided by involving all relevant key partners and their teams, a transparent comprehensive process was assembled. This collaborative approach not only led to significant quality improvements but also enhanced overall understanding and coordination among all teams throughout the patient journey.

1 Interior Health

Leading from the Edge: Rural Patients & Communities Advocating, Designing & Influencing Digital Patient Tools

Anthon Meyer 1

Introduction and Background Problem:Our patient and community led initiative, supported by the Rural Coordination Centre of British Columbia (RCCbc), aims to revolutionize how patients are empowered to dynamically define problems, influence decisions and advocate for change to better manage and access their electronic health information. Rural healthcare often faces challenges with disconnected information systems and substantial transitions in care. Patients lack significant power to influence digital solutions to improve access to a complete version of their electronic health records, making it difficult to engage in their care and validate their health information.Relevance: Our rural Personal Health Record (rPHR) initiative leverages patient leadership to address these challenges by influencing the design and integration of digital health solutions that enhance the accessibility and accuracy of health information. PHRs are a comprehensive integrated patient digital tool facilitating seamless data exchange, use, and reuse across various healthcare settings. Learning Community Engagement Engagement: This project leverages a “community up, patient led” approach through design thinking workshops held in rural communities with patients, allied health, community members and providers coming together to define the problem and explore opportunities for improvements. Ongoing project leadership (3+ years) is supported by a team of six highly engaged patients from rural and remote locations in British Columbia.Addressing the Problem: The patient leadership team is active in continual refinement of the problems faced by accessing and managing health information. The patient team has influenced the design of the PHR and created a wealth of key messages on their healthcare needs including two public facing videos resulting in highly valuable materials and visuals for communications to convey the problem and advocate for change. Knowledge Mobilization Share Findings: The community workshops and patient leadership team were able to explore the major pain points and barriers to managing and accessing health information to enable the sharing of these findings with critical stakeholder groups to advocate for change at the health system level including key benefits such as: Improved Communication: PHRs provide patients and providers with access to accurate, up-to-date health information, improving communication and collaboration, leading to better shared decision-making and active patient participation.Reduced Workloads: PHRs streamline workflows and care transitions, reducing the administrative burden on providers and navigational burden on patients, allowing them to focus more on patient care.Enhanced Safety: Accurate, current, and accessible health information enhances patient safety, reducing the risk of missed or inaccurate information.Empowerment Through Access: Patients can interact with their complete health records, empowering them to manage their health actively and achieve better outcomes.Support Longitudinal Primary Care: The rPHR maintains comprehensive health records over time, supporting longitudinal primary care, which delivers higher quality care at lower costs with higher satisfaction for patients and providers.Addressing Rural Challenges: The rural environment magnifies many challenges in the current health system. Focusing on these challenges benefits everyone but has a particularly positive impact on those patients and communities "on the edge."Lessons Learned: These collaborations have resulted in valuable learnings including the identification of critical success factors (such as inclusion, diversity, equity and usability) and importance of meaningful Patient-Provider Partnerships. Building strong relationships between patients, communities and providers to co-create health records together is more effective than merely focusing on technology. Outcomes of the engagement: The RCCbc Personal Health Record project represents a significant step forward in empowering patients to influence and create a more integrated, accessible, and safe healthcare information system. By building strong patient-provider partnerships, leveraging technology and advocating for change, we can transform healthcare delivery and improve outcomes for all. These successes would not have been possible without a highly engaged patient partnership team.

1 RCCbc

Learning from Recovery College Peer Educators: A Participatory Research Project

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Learning from Recovery College Peer Educators: A Participatory Research ProjectRates of mental health and substance use disorders have risen over the past decade. Despite these growing challenges globally and in Canada, there remains an unmet demand for counseling and psychotherapy services due to long wait times, affordability issues, and accessibility barriers. This highlights the urgent need for accessible mental health interventions that promote well-being and prevent disorders. Community-based, recovery-oriented services and peer-led interventions, such as the Recovery College (RC) model, have proven effective and cost-efficient in improving access to mental health services and enhancing well-being. RC attendance has shown high satisfaction, achievement of recovery goals, improved quality of life, increased self-management skills, and reduced service usage and costs. RC is gaining traction in Canada, with one developed for Vancouver Coastal Health (VCH) in collaboration with the Canadian Mental Health Association. This program aligns with VCH's strategic priorities of exceptional care, research and innovation, a strengths-based workplace, and a holistic approach to health. Project Aims and ObjectivesThis project aims to understand the experiences of Peer Educators (PEs) and program organizers (POs) within the Canadian RC model to enhance peer work. Specifically, it seeks to identify factors that facilitate or hinder PEs' involvement in developing and leading courses and the benefits and challenges they face. The goal is to base new VCH peer education training materials on the findings, support POs in establishing new RCs in the Vancouver Coastal Health region and prepare local PEs. Learning Community Engagement Recognizing the importance of including researchers with lived experience to gain deeper insights and make the research more relevant and applicable, we formed an RC Peer Advisory Committee and engaged peers as both advisors and research assistants. The committee, composed of PEs with lived/living experience of mental health, has been a vital component of this project. We followed guidelines and recommendations through recruitment, support, and recognition practices to enable Peer Advisors (PAs) to engage authentically and sustainably in the project. PAs were involved from the project's initiation to ensure objectives and questions met users' needs and information was accessible. Their continuous involvement also ensured that data interpretation was consumer-focused and the implementation and dissemination of results were applicable. We used a mixed methods approach consisting of an online stakeholder survey and semi-structured interviews. First, we co-developed a survey for RC PEs and POs to identify barriers, facilitators, preparation and support models, and examples of successful and less successful experiences. Following the survey, we conducted semi-structured interviews with key informants to further explore the issues identified in the survey. Knowledge Mobilization We have co-created knowledge translation (KT) approaches with PAs. The KT was initiated with two training sessions, followed by co-planning KT activities based on various stakeholders and selecting the best format for each activity. One of the project’s main KT products is a co-created toolkit based on the study results that will be disseminated to RC POs. Other co-created KT activities include website updates, infographics, poster presentations, and technical reports. We will draft a manuscript based on our research findings, revise it based on PAs' feedback, and submit it to a peer-reviewed journal.Engaging with PAs in this project has highlighted the importance of open communication, valuing peer experience, and a strength-based, collaborative approach. While PAs gained a deeper understanding of the research process and developed new skills, their contributions and valuable insights shaped the project. This collaboration has fostered a positive team dynamic, enhanced the effectiveness of KT, and ensured the findings are communicated to key stakeholders and applied to improve mental health services. Key lessons from this collaboration include the importance of "curiosity, communication, compassion, commitment, capability, and constructive information sharing."

1 Community partner, 2 VCH, 3 UBC

Let's talk about pain: A qualitative exploration of ways to introduce the current model of chronic pain to patients.

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Background: Clinical guidelines have recommended treating chronic pain using a biopsychosocial (BPS) model for decades, yet the biomedical model is still overused, and public knowledge of the BPS model is lacking. It is known that pain is complex and influenced by many factors, but patient-centred ways to introduce the BPS model have not been explored. A barrier cited by clinicians is the lack of a “sound bite” to accurately describe the neurophysiology of pain to their patients.Aims: To explore patient-centred ways to introduce the BPS model of pain to clients. Learning about the multifactorial influences of pain may provide clients with a wider range of treatment options.Community engagement: During study planning we engaged two community partners with lived experience of pain. Two of the co-authors also have lived experience with chronic pain. Community partners and researchers worked together as a study team that employed principles of shared decision making throughout the research process. The full study consists of three phases, Phase 1, which we describe here, engaged people living with chronic pain to learn about their views on sensitive ways to discuss the psychosocial factors that influence chronic pain. Phases 2 and 3 (in planning) involve additional community partners, along with several health care professionals and decision makers on the study team with the aims of discussing BPS model introduction and exploring barriers to introduction. Methods for Phase 1: The current study employed qualitative analysis of data from four focus groups with people (n = 21) living with chronic pain (> 6 months). We recorded the 90-minute focus group, transcribed the data verbatim, then used reflexive thematic analysis to identify themes and subthemes. Lessons from the Learning Community (Results from Phase 1): Six themes were identified: (1) participants have some BPS model knowledge, largely self-taught; (2) introducing the BPS: the who, what, when, how, and why? (3) Systemic barriers affect BPS introduction; (4) validate my pain! (5) Factors affecting BPS model understanding and acceptance; and (6) individualized evidence for the brain’s role in the manifestation of chronic pain. Participants identified potential modes of communication that may initiate a dialog between patients and their providers. They emphasized a need for validation, the desire for non-biomedical treatment options, and for earlier presentation of options. Participants reported misunderstandings and skepticism surrounding the applicability of the BPS model, a possible result of a culture that has emphasized tissue damage as causal. Knowledge Mobilization: The data derived from this multi-phase project will be used to create resources to support client-informed language and strategies for disseminating the BPS model of pain in practice. As described here, Phase 1 provided insight into the current state of knowledge of our intended audience along with preferred modes of knowledge delivery. The next phase (2024/2025) will explore practitioners’ responses to client-centred strategies regarding discussions of current pain models, along with barriers and facilitators to its implementation in practice. Intended Outcomes: We plan to synthesize key messages, preferred language, and modes of communication to inform the development of prototypes for BPS model introduction. These prototypes will then be reviewed by people with lived experience from diverse, underrepresented groups (Phase 3). Using a client-centred approach that aims to include diverse views from several groups (with patient partner collaboration throughout) we hope to create tools that are appropriate and relevant to our intended audience.

1 University of the Fraser Valley, 2 Actum Health, 3 Community Partner

NEOCATS: Patient-led Resource Development for Clinical Trials

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Introduction and BackgroundThe Neoadjuvant Olaparib Combination Ovarian Cancer Targeted Study (NEOCATS) is a Phase 2 proof-of-concept clinical trial designed for patients with stage IV high-grade serous ovarian cancer. This trial introduces treatment options to eligible patients at diagnosis or shortly thereafter. Introducing complex treatment options to patients who are also facing the distress of a new cancer diagnosis poses significant challenges for clinicians. Effective tools are needed to assist healthcare providers in these difficult conversations and to equip patients with clear and actionable information necessary to make informed decisions about their care. Learning Community Engagement To address this need, we have engaged six patient and family partners from across Canada to develop a comprehensive communication and dissemination strategy for conveying this health information. The Knowledge to Action (KTA) framework has guided the theoretical design of this project, ensuring that our approach is both evidence-based and patient-centered. The Canadian ovarian cancer research community is known to be a collaborative space including perspectives from patient partners, researchers and clinicians. We plan to leverage both the Ovarian Cancer Canada and Gynecologic Cancer Initiative’s platforms as hubs within the ovarian cancer space. The group meets biweekly to review the development of knowledge products and to provide input on language and accessibility, ensuring that the information is clear and actionable for patients and their families.The group plans to prioritize the delivery of information in a format that prospective patients can take home for further review. The initial knowledge product will be a brochure designed to explain the NEOCATS trial, how it differs from the current standard of care, and its unique benefits to prospective patients. The brochure will include a QR-code/link to a podcast episode from the Gynecologic Cancer Initiative’s Gynecologic Oncology Sharing Hub (GOSH), featuring an in-depth discussion with the principal investigator and patient partners about ovarian cancer, treatment options and clinical trials. Additionally, an animated video explaining the trial will be linked. To further enhance understanding, we will utilize GCI’s communications and social media platforms to launch a campaign showcasing “a day in the life” of both clinical trial participants and ovarian cancer researchers, aiming to demystify these environments and ease patient concerns.Knowledge Mobilization The way information is communicated to patients about clinical trials often unintentionally excludes patients in rural/remote areas and patients of equity-seeking communities. To evaluate the impact of our knowledge products on trial diversity, we will assess the reach and effectiveness of our podcast and social media initiatives, correlating these metrics with study enrollment data. Feedback will be gathered through a forum with a larger group of patient partners, followed by a survey and facilitated discussion. We are exploring methods to reach a wide audience of patients by translating available resources, and participating in intentional community engagement through radio shows and social media. The findings will be detailed in a manuscript co-authored by the patient partners involved in this study.

1 University of British Columbia, 2 Gynecologic Cancer Initiative Patient & Family Council, 3 Ovarian Cancer Canada Patient Partners in Research, 4 BC Cancer, 5 UBC

Optimizing Diabetes Care: A Community-Partnered Qualitative Study on Patients with Pre- or Mild Diabetes

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Introduction and Background Prediabetes is characterized by elevated blood glucose levels that do not meet the diagnostic criteria for type 2 diabetes (T2D) (6.0 ≤ A1C ≤ 6.4), while mild diabetes is defined by A1C levels ranging from 6.5 to 7.0. Although both conditions have A1C levels within evidence-based treatment targets for T2D, they present an early opportunity for prevention. However, there are concerns about the potential harms of applying diagnostic labels, which may contribute to overdiagnosis and overtreatment in healthcare. We aimed to conduct a qualitative study as part of a larger multi-methods study to explore patient experiences, priorities, and approaches regarding the diagnosis and management of pre/mild diabetes, and to identify factors associated with initiating antidiabetic treatment. Our study will help inform future policy, research, and quality improvement initiatives to optimize diabetes care, with the aim of improving patient outcomes and using healthcare resources wisely.Learning Community Engagement The study is underway, involving the interview of individuals diagnosed with pre/mild diabetes within the last five years. Sociodemographic data are being collected via a pre-interview survey. Interview transcripts are being created using Otter AI and are then reviewed, cleaned, and coded in NVivo version 14 by two independent reviewers. Reflexive thematic analysis based on Braun and Clarke's framework is being applied. An analytical narrative will be developed from these themes. So far, twelve interviews have been completed and coded, with three to eight more anticipated.This research is a collaboration between health services researchers, healthcare professionals, epidemiologists, patients and community research partners.The Patient Engagement Framework from the Strategy for Patient Oriented Research (SPOR) was used to engage people with lived experience of pre/mild diabetes as community research partners. The team has been working closely with three community partners from three provinces through regular virtual team meetings. Partners have been actively involved throughout the project. They were co-investigators on the grant application, have co-designed the interview guide, and are currently co-conducting patient interviews, reviewing transcripts, and assisting in developing codes and themes. Partners have been continuously supported by participating in training sessions, which provide guidance on research interview techniques and qualitative data analysis.Knowledge Mobilization We will hold team knowledge translation strategy meetings to identify action steps for each co-investigator and collaborator within their respective spheres of influence. Community partners are both participants and researchers, serving as our knowledge user team members. They will play an active role in identifying and liaising with community health centres and other on-the-ground health groups that are actively involved in patient education efforts around T2D.From our experience, we learned that engaging with a learning community helps gain a deeper and more nuanced understanding of patients' experiences. Additionally, our project highlights the important role of continuous partner engagement and support from the research team. Regular meetings and training sessions can play a critical role in maintaining active involvement and ensuring that contributions remain meaningful.Continuous engagement of community partners has helped ensure that the research question, proposal, and data collection are relevant, comprehensive, and capturing real-world issues and needs. By co-conducting interviews and leveraging their lived experiences, community partners built rapport with participants, and identified important areas in the interviews to probe, ultimately enriching the data. Their input in reviewing transcripts and developing codes and themes led to a thorough and reflective analysis. Their contributions will also enhance the quantitative analyses by providing consultative support on covariates to consider and outcomes to evaluate. Community partners will play a crucial role in translating and disseminating findings, ensuring that the results are effectively communicated and applied to policy and clinical practice.

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Organizational Factors that Foster Engagement-Capable Environments: A Study of Health Research Networks

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Introduction & BackgroundThe rising cost of healthcare as a result of a rapidly aging population and the increasing rates of chronic disease have exacerbated the need for the creation and timely application of evidence into practice. Still, the challenges of doing so have led to gaps and variations in the delivery of healthcare services and poor patient outcomes. While the challenges that underpin evidence-based practice are complex and multifaceted, we know that the creation and uptake of evidence is best when multiple knowledge users, including healthcare providers, decision-makers and patients, are engaged in its design, implementation and translation. In Canada, researchers are increasingly expected to meaningfully engage patients in research design, implementation and mobilization. This cultural shift is reflected in key Canadian research strategies, including the Canadian Institutes of Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR). This has led to a rapid expansion in the literature examining the ‘how to’ of patient engagement, however, little attention has been given to the organizational factors that contribute to engagement capacity. This has led to the emergence of opposing viewpoints about patient engagement and increasing calls for the systematic examination of engagement methods and outcomes. This research aims to systematically examine the organizational factors that contribute to patient engagement and engagement capacity within health research networks.Learning Community Engagement Using an Integrated Knowledge Translation (IKT) approach that requires the engagement of knowledge users, including decision-makers, healthcare providers, policymakers, patients, caregivers and members of the public across the research process, we organized the study into three phases.Phase 1: Knowledge Synthesis. A mixed-methods systematic review to integrate diverse forms of evidence to provide a rigorous, reproducible, and contextualized review of the current state of knowledge. Undertaken in partnership with the SPOR Evidence Alliance, a pan-Canadian alliance of researchers, patients, healthcare providers and decision-makers providing high-quality evidence relevant to health and healthcare. The review will provide a new and comprehensive understanding of organizational supports and practices for patient engagement, identify strengths, gaps and weaknesses in the evidence base, and will be used to inform Phases two and three of this research.Phase 2: Multiple Case Studies. Network leaders, research scientists and patient partners from eight health research networks (6 in Canada, 2 in the UK) were interviewed and participated in focus groups to explore their ‘situational complexity’ as it relates to patient engagement and engagement capacity. We then examined these across cases to identify similarities, differences and shared learning.Phase 3: Indicators of Engagement Capacity. The development of evidence-based indicators for engagement-capacity for patient engagement through an in-person cross-network deliberative dialogue meeting with a purposeful sample of network members including patient partners from each of the networks.Knowledge Mobilization Knowledge users, including healthcare providers, patients and patient engagement experts, were engaged in the conceptualization and development of this proposal and the creation of our KT plan. We engaged participants from our planning grant and pilot work to identify key priorities relating to patient engagement and POR. These formal consultations and priority-setting activities were instrumental in the conceptualization and planning of this research proposal. Our objective for our end-of-grant KT plan is to co-produce appropriate and tailored KT products that address gaps in knowledge. We will work directly with our partners from each network to determine preferences for KT outputs, identify potential barriers and facilitators, and co-create targeted outputs including webinars and presentations for network members, SPOR SUPPORT Units and international groups such as the National Institute of Health Research, as well as briefing summaries and infographics targeted to key knowledge user and patient groups.

1 UNBC, 2 Heartlife, 3 ENAP

Partnering with People Who Use Drugs to Create Safe Inclusive Health Care Spaces

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Introduction and Background: Over 14,000 preventable deaths have been attributed to British Columbia’s (BCs) unregulated drug toxicity and housing crises as of July 2024, equating to nearly seven deaths per day. This project sought to contribute to healthy, safe organizational cultures in the health care system, as one method to address this crisis. The project was informed by the grounded expertise of people who navigate stigma within BC’s health care system, as well as the lived/living experience of health care providers (HCPs) who care for patients with substance use disorders. The partnership between a community researcher, staff at an urban tertiary care hospital in Vancouver, and the Eastside Illicit Drinkers Group for Education (EIDGE) began in December 2023.Learning Community Engagement: The principles of qualitative research through participatory action informed the team's approach of establishing relationships between two groups of people with grounded expertise, HCPs and people who use drugs, to develop a better understanding of the barriers and facilitators to safe, responsive care in health care settings. EIDGE involvement was determined through a democratic voting process. Co-investigators attended meetings at the office of EIDGE to talk about the proposed research and invite collaboration in all aspects of the process. EIDGE members facilitated community-led walking tours with partnered researchers through the downtown Eastside neighbourhood, allowing non-resident researchers to learn more about the unique historical and cultural context of the highly stigmatized neighbourhood. These walking tours assisted in building trust between EIDGE members and partnered researchers. We held four Listening Circles as the central part of the research project, two with HCPs and two with people who use drugs. With the expertise of a graphic illustrator, we captured high level themes that emerged through the questions posed in the circles. Indigenous Elders were present at each circle and a member of EIDGE co-facilitated two of the Listening Circles. Knowledge mobilization: We learned about the challenges facing people who use drugs or illicit substances when accessing healthcare services, including stigmatized approaches resulting in long waits (sometimes not being seen before leaving), difficult interactions with HCPs, lack of support to navigate the system, restricted access for friends and family members. We also learned about practices that support positive outcomes and experiences within the health care system: peer navigators were found to be helpful, as well as experiences of health care providers responding with compassion, connection, and follow-through support. HCPs expressed the challenges they face with colleagues who approached people who use substances through a stigmatized lens, and expressed curiosity about approaches that might improve awareness as well as support HCPs in the workplace. HCPs also noted the importance of relationship building, high levels of emotional labour/investment involved in this work, lack of academic preparation they received to prepare for this reality, and support that could be improved within the healthcare system.The project team continues to meet regularly to explore opportunities for knowledge mobilization, and plan for the next phase in the research process. A poster was created using the Listening Circle graphic illustrations to highlight our findings and will be distributed for display in various hospital departments as well as downtown Eastside community programs. A journal article has been co-authored with researchers and EIDGE members and submitted for publication. Presentations are scheduled at health care settings, with co-presenters from across the project team, including EIDGE members, who would also be present at Putting Patients First should this abstract be accepted.

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Peer support for people with traumatic brain injury within community-partnerships: a mixed-methods investigation of feasibility and impact

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Introduction. Peer support is a patient-oriented approach, integrating the expertise of people with lived experience to provide emotional and practical support with others who share a common experience. In traumatic brain injury (TBI) rehabilitation, little is known about the feasibility of integrating peer support and the process of building connections using a community-engaged approach. Objective. Our primary objective was to evaluate the feasibility and impact of a community-based peer support program for people with moderate to severe TBI. Additionally, we explored the experiences of creating meaningful connections during peer support. Learning Community Engagement.Who was involved. We engaged with three partnered groups: (1) Participants with TBI < 1 year ago aged 19-65 who engaged in weekly 30-minute sessions for 10-weeks of peer support. (2) Peer Support Workers aged 19-65 with TBI > 2 years ago who completed 3-day peer support training and conducted peer support sessions. (3) Community team members who identified potential participants, facilitated peer connection, and provided peer support training.Engagement Methods. We used the Involvement Matrix tools, developed by Smits et al. (2020) to determine the level of participation to be expected from both the research team and the community partner. The research team and community partner were partners and equal decision makers throughout the project. Community team members were engaged as equal partners throughout the project. Peer Support Workers were engaged as advisors throughout the execution and implementation stages of the project.Methods. This mixed-methods study used a pre-post feasibility design and a follow-up qualitative component. Feasibility data from the RE-AIM framework and effectiveness data in the domains of resiliency (Connor Davidson Resilience Scale), self-efficacy (General Self-Efficacy Scale), hope (Hope Hearth Index), and quality of life (EQ5D) were collected from participants who received peer support. Qualitative data were collected from all three types of participants through semi-structured interviews, with interview questions co-developed with patient partners, and analyzed using constructivist grounded theory through a social cognitive lens. Knowledge Mobilization.Sharing of findings. Community team members and patient partners are actively partnered in knowledge translation and dissemination plans. We have planned targeted knowledge translation activities for key stakeholders. For the brain injury community, we partnered with brain injury associations to create a short video on the research and impact of peer support, which will be widely shared at the Annual General Meeting for BC Brain Injury Association and further disseminated through social media. For the research community, we have conducted 3 scientific talks at conferences and research forums. Lessons Learned. We learned to operationalize principles of mutual respect and transparency. We aimed to hear diverse experiences by involving multiple community partners in meetings, and separate meetings with community partners were conducted prior to ensure community perspectives were accounted for early in the decision-making process and to ensure research-related project updates and terminology were understood. Outcomes. There were 9 participants (three participants with new experience of TBI, three peer support workers, and three community team members) included in our study. All feasibility indicators were achieved, including recruitment rate (60%; 3/5), retention rate (100%), participant adherence to intervention (100%), fidelity of intervention (100% of sessions aligning to >90% of session content). Measures of effectiveness indicated minimal change from baseline to post-intervention on any measure. Three themes were identified from the qualitative data, expressing experiences of meaningful connections including (1) Sharing experiences of brain injury, describing the importance of having their experiences understood and validated. (2) Being in similar places in life, indicating the valued insight on navigating specific milestones and life events. (3) Finding meaning in conversation, showing participants' desire to bond and relate on a personal level. Conclusion. Findings show the feasibility of the study design and intervention of community-engaged peer support programs for people with TBI. While there were no changes found in the quantitative measures, qualitative results suggest that meaningful connections are made through shared experience and current life context. Future research may examine the implementation metrics and measures best aligned with peer support programs.

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Peer-to-Peer as a Patient Partner Recruitment Strategy in a National Kidney Health Research Network

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Introduction and Background The merits of patient partnership in kidney health research are increasingly accepted and promoted; however, the methods and strategies for recruitment are not widely understood or reported on, leading to a paucity of practical patient partner recruitment strategies and tools.The Canadian Institutes of Health Research's Strategy for Patient-Oriented Research (CIHR-SPOR) was created to transform the role of patients from passive recipients of care to active partners in health research to improve care. Since 2016, the national Can-SOLVE CKD Network, one of five chronic disease networks supported through SPOR, has focused on transforming the landscape of kidney research and care with meaningful patient engagement as its guiding principle. The network has supported 27 research projects to date, each designed around patient perspectives and priorities.Leveraging the work of the Can-SOLVE CKD Network to effectively and meaningfully engage patients as co-researchers, we identified the key strategies used to recruit and retain patient partners in research as well as consolidated the commonly used techniques to develop a patient partner recruitment toolkit.MethodsTwo patient partner members of the Can-SOLVE CKD Patient Governance Council (C.C. and K.L.) were involved in this research from the outset and at every stage of the process, from research design to conducting the research, data analysis, and co-designing the toolkit. We conducted an environmental scan of existing literature, consolidated results from our 27 network projects' reports and review committee project check-in calls, examined the effectiveness of the network-developed website linking researchers and patient partners (www.kidneylink.ca) and consulted with the network's two patient advisory councils, the Patient Governance Council and Indigenous Peoples' Engagement and Research Council. In addition, we conducted a survey with nine Can-SOLVE CKD patient partners in March 2024 to identify how they became engaged in research. We consolidated the data and conducted a thematic analysis to identify successes and challenges to inform the development of a patient partner recruitment toolkit. ResultsAnalysis of network recruitment activities indicates 40.8% (n=39) of patient partners were directly recruited by other Can-SOLVE CKD members; 20.1% were recruited at a health clinic and 16% were recruited through collaboration with a charitable organization. In addition, a review of network recruitment strategies, as reported in research project reports, indicates a correlation between effective recruitment of ethnically diverse patient partners and direct peer-to-peer recruitment. Results of a recent survey (n=9) align with these results indicating that direct recruitment through peers was the most common response (40%). Most participants were recruited, with only two respondents independently seeking to become involved in research.KidneyLink, a website connecting patients with research opportunities, since May 2023, reports that 389 individuals have opted to receive notifications of new research opportunities; 31 studies have been posted and 43 patient partners have been referred to participate in research studies.Discussion and ConclusionRecruiting patients to become involved in research as co-researchers requires a multi-faceted approach that reaches individuals through direct recruitment by a peer, medially (e.g. posting at a clinic) and also distally (e.g. advertising in newsletters and through social media). It is important to consider motivation, retention and timing/illness stabilization. Patient partners want to feel that their participation is valued, meaningful, that they can build connections, relationships and trust with the research team, that they see the impact of their contributions, that they are recognized, and fairly compensated. There exists a strong correlation between direct peer-to-peer recruitment and effectiveness and retention. In order to promote peer engagement in patient partner recruitment, the next steps of this patient partner recruitment strategy will be to enhance peer engagement through the development of a patient research ambassador program. This program will include peer outreach, a buddy system and mentorship through the process to build capacity and further promote meaningful patient partnership.

1 Can-SOLVE CKD Network, 2 University of British Columbia, 3 Patient Governance Council, Can-SOLVE CKD Network

Power and Perspectives: Using Equity Walk Throughs to Inform Equity-Oriented Approaches at BC Cancer Vancouver

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Introduction and Background Barriers to access exist across the cancer continuum and disproportionately affect people with lived/living experiences of health and social inequities (PWLE-HSI). PWLE-HSI are individuals or groups who experience situated vulnerabilities (i.e., vulnerabilities that are socially constructed and sustained by the conditions of people’s lives). As part of British Columbia (BC)’s 10-Year Cancer Action Plan, team-based care (TBC) is being implemented across the province’s six Regional Cancer Centres to build multi-disciplinary, high-functioning, and integrated care teams. To expand upon the foundation of TBC, we have been supported by the Canadian Partnership Against Cancer’s Model of Care Funding Initiative to develop, pilot, and later expand a new explicitly equity-oriented, interdisciplinary, and intersectoral approach to TBC though what is called the Equity Model of Cancer Care (E-MOC) Project. Learning Community Engagement A three-phased project, Phase 1 (2023-2024) activities included, among other things, (1) establishing a Steering Committee (i.e., Learning Community) that includes Lived Experience Advisors (LEAs) with lived/living experiences of health and/or social inequities, BC Cancer leaders, interdisciplinary staff, and subject matter experts; and (2) conducting baseline assessments of the E-MOC Project pilot site (i.e., BC Cancer - Vancouver). As part of our baseline assessment of the pilot site, we sought to (1) better understand the current landscape of health and healthcare equity within the cancer care system, and (2) identify opportunities to support more equity-oriented cancer care spaces at BC Cancer - Vancouver. To this end, we adapted EQUIP Health Care’s Equity Walk Through (EWT) exercise to the cancer care context. Hosting EWTs created an opportunity for participants (i.e., LEA and BC Cancer team member dyads) to consider how health care environments can feel welcoming, culturally, and emotionally safe, and reduce harm for everyone by spending time observing physical and social spaces at the pilot site. Recognizing the existing power imbalances in the healthcare system that often exclude the insight of people with living and lived experience, the EWT tool was adapted in partnership with the E-MOC Project’s LEAs as we intentionally centered perspectives of PWLE-HSI as part of the activity. Each BC Cancer/ LEA dyad (n=5) walked through one of two pre-determined routes with select areas around the pilot site with guiding questions to identify current promising practices, areas for improvement, and areas for opportunity. EWTs participants were able to (1) identify components of the pilot site that may create feelings of discomfort, stigma, or unsafety; (2) consider how these spaces may be perceived by members of equity-denied communities that BC Cancer serves (e.g., 2SLGBTQIA+, Indigenous and racialized communities, people who use substances, people living with disabilities, etc.). Knowledge Mobilization Upon completion of the EWTs, we facilitated dialogue with our LEAs to iteratively organize the observations into findings and co-create recommendations (i.e., for the physical and social environments, including promising practices and suggested actions) for the pilot site to consider. EWT findings will be shared with operational and clinical leaders at BC Cancer by members of our Learning Community, including LEAs. Lessons learned pertain to the meaningful engagement with the LEAs of our Learning Community. Our prioritization to form authentic relationships and meet our LEAs where they are at (e.g., orientation sessions to introduce dyads and flexible scheduling) was necessary to ensure safety and support. Our explicit approach to addressing power imbalances between the project team and LEAs through offering choice to change and/or adapt assigned EWT routes and individualizing support plans in partnership with LEAs was critical to successfully building trust and mutual respect. Continual intentional planning for purposeful engagements with LEAs will remain critical to embedding the voices and input of PWLE-HSI into quality improvement work of the E-MOC Project.

1 BC Cancer, 2 Community Partner, 3 University of British Columbia

Prenatal Opioid Exposure and Neonatal Abstinence Syndrome: A Collaborative Research Project with First Nations Communities

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Prenatal opioid exposure has risen substantially over the past two decades and can have lasting health impacts on infants and children, including potential long-term neurodevelopmental impairments. Neonatal abstinence syndrome is a withdrawal syndrome observed in the babies of mothers who are either using opioids or being treated for opioid dependence. The opioid epidemic has a disproportionate impact on those who are most vulnerable and marginalized, including Indigenous peoples and pregnant women. Opioid use during pregnancy has risen dramatically over the past two decades.Our project team was formed in 2017 in response to First Nations concerns about the impact of prenatal opioid exposure on the health of children in their communities. Our team includes Indigenous and non-Indigenous health care providers, leaders, and researchers. For the past seven years, we have conducted collaboration-based work with 13 First Nation communities to utilize health administrative data on prenatal opioid exposure, fill in the gaps where the existing data does not provide critical information, and mobilize these data to address prenatal opioid exposure in First Nation communities.For Phase 1 of this project, we partnered with 13 Ontario First Nation communities to analyze community-specific data on prenatal opioid exposure, neonatal abstinence syndrome, and other important related indicators from health records data. Qualitative data from persons with lived experience, other community members and services providers explored the impacts of prenatal opioid exposure, the strengths in communities presently addressing the issue, and community-based strategies to further address and prevent prenatal opioid exposure. As Phase 1 came to an end, conversation with our First Nation partners centred on knowledge mobilization; with many people keen to get the information we gathered to different groups inside and outside of First Nation communities. From these conversations stemmed Phase 2 of our project. Phase 2 of the project focuses on supporting the participating First Nations in developing, implementing, and evaluating customized knowledge mobilization plans to address prenatal opioid exposure, based on the data from Phase 1. This research is guided by a community-engaged participatory action research approach. Knowledge mobilization research has historically been Eurocentric in its approach. We are supporting the decolonization of knowledge mobilization practices through a community-engaged model where First Nation partners are leading this work. Each community’s knowledge mobilization and evaluation plan is being developed in alignment with the priorities and ways of knowing in each community.This presentation will provide an overview of the two phases of our research with a specific focus on our process of collaboration, engagement strategies, how we value and integrate Indigenous and Western knowledge, how the principles of OCAP® (First Nations ownership, control, access, and possession of data) are embedded in our project. We will discuss the roles of advisory groups, focus groups, communications material, and our relationship-centred approach to the hundreds of many meetings with First Nations leaders that have facilitated this project’s successes.

1 Vancouver Island University, 2 Sick Kids, 3 ICES, 4 Southwest Ontario Aboriginal Health Access Centre

Project IMPACT (Include Messaging for Patients and Care Teams): Patient Centered Care in Paediatric Type 1 Diabetes Using Texting-Spreading in Interior Health

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INTRODUCTION & BACKGROUND Type 1 diabetes (T1D) frequently develops in childhood, with 75% of diagnoses occurring during this period and a rising incidence of about 3% annually. In British Columbia (BC), the highest rates are observed in the Interior Health Authority (IHA). Poorly controlled diabetes is linked to severe long-term complications, burdening the healthcare system and families. Advances like insulin pumps and continuous glucose monitoring devices require expert management for optimal outcomes and patient safety, but the workforce providing this support is limited.Effective diabetes management in children must consider their developmental stages and the needs of their caregivers. A patient and family-centered approach is essential, ensuring care is accessible, timely, effective, and equitable despite the current shortage of expert healthcare providers. Diabetes Canada recommends quarterly clinic visits for families with diabetes teams to optimize glycemic control, accommodating changes such as illnesses, athletic activities, and puberty. Despite this, consistent outreach for support is lacking in the population.The primary objective is to enhance engagement between clinical teams and patients/families to improve glycemic control and integrate their feedback into service delivery.LEARNING COMMUNITY ENGAGEMENT This Quality Improvement (QI) initiative began in 2019 with a process mapping exercise at Vernon Jubilee Hospital (VJH)'s outpatient pediatric diabetes clinic. The event involved patients, operational leads, physicians, nurses, dieticians, and administrative staff.The COVID-19 pandemic in 2020 necessitated a shift to virtual care. Quarterly clinic visits transitioned to the Zoom platform, and texting was explored as a viable mode of care between visits. Initial structured interviews targeted teens to test the concept.Phase 1 (2021-2022) enrolled adolescents from the Pediatric Diabetes Clinic at VJH into the texting platform. Engagement included weekly check-in messages, regular teen patient consultations, and surveys. The positive response led to Phase 2 (2022-2023), expanding the texting program to include the entire pediatric clinic (parents, caregivers, and age-appropriate patients). Patient partners, including two parents and a teen, contributed to the project, participating in meetings and providing timely input through emails and texts. Feedback was collected through surveys at the project's start and completion. The texting modality received overwhelming support, facilitating "soft touch care" between visits, supporting medically stable new diabetic children in an outpatient setting, and allowing clinicians to manage the growing patient population effectively.In Phase 3, the project extended to three additional sites within the HA, covering approximately 75% of the pediatric diabetes population. A Patient and Family Advisory Committee (PFAC) was established to incorporate patient voices into care delivery design, aiming for representation from each site. Virtual meetings and an Engagement Forum in June 2024, which included presentations from patient partners, have proven productive.KNOWLEDGE MOBILIZATION Knowledge mobilization efforts involved sharing learnings and project outcomes with funding partners through comprehensive reports, as well as communicating key findings, successes, and next steps with clinical teams, patients/families, senior HA leadership, and the wider HA community via newsletters and presentations.Patient involvement has been crucial in shaping survey questions, broadcast message content, and check-in frequency. At the Vernon clinic, engagement with families increased by over 2300% and families have established an active community diabetes support group that allows peer to peer connections with youth and their families (T1D Hub), which organizes safe, supported gatherings (e.g., day camps, Halloween bowling) that include clinical team support.This multiphase QI project has fostered increased engagement, a sense of community and agency, with the aim of reducing distress associated with diabetes, and ultimately, improving glycemic control.

1 Interior Health, 2 Fraser Health, 3 Patient Partner

Putting Indigenous patients first: Lessons learned from improving the quality of nutrition care in a tertiary hospital in BC

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Introduction and Background Indigenous people in Canada experience profound disparities in health outcomes across a wide range of conditions. A recent Human Rights Commission report on the widespread Indigenous-specific racism within BC's healthcare system called for the provision of 'culturally safe' care as an imperative to improve health outcomes of Indigenous patients. A principal way to provide culturally safe care to improve health outcomes is through offering culturally safe and appropriate foods to Indigenous hospital patients. However, hospital nutrition services rarely include Indigenous-specific menu options which is an important component of providing "culturally safe" nutrition care to Indigenous patients. There is a need to improve hospital nutrition care by ensuring cultural safety food options on hospital menus as doing so aligns with Local Health Authority signed Declarations of Commitment to Cultural Safety and Humility in addition to broader commitments to patient-centred care.Learning Community Engagement This quality improvement work was a partnership of clinical dietitians, an academic research mentor, and the hospital's Indigenous-led department with relationships to broader community-based organisations and Elders. The department used community-based methods to undertake a hospital-wide quality improvement project and worked with the Quality Assurance and Improvement (QA/QI) department to develop the Indigenous Relations and Community Engagement Survey as well as a Patient Journey Mapping event. Questions about hospital food were incorporated into both the Survey and interviews. The Survey specifically included an 'Indigenous Food Ways' component with three survey questions that were co-developed. This food-centred component aimed to understand whether providing Indigenous traditional or cultural foods was important to respondents, and to explore what cultural/traditional foods Indigenous respondents wanted to see as options on hospital menus (n=370) or what they did not want to see as hospital menu options (n=253). Self-identified Indigenous participants were recruited through a variety of community engagement events and health fairs from 2021 to 2022. The survey was distributed via paper and online through Simple Survey using a QR code. The interviews were coded by the clinical dietitian team and the survey was analysed by the researcher in consultation with the dietitians. In parallel, the clinical dietitians engaged in their own self-learning through the Nourish 'Food is our Medicine' Learning Journey designed to introduce healthcare professionals to Indigenous Food Ways and colonial history of healthcare and food services. Finally, the team engaged with the General Manager of Food Service at the hospital to learn about barriers and facilitators to developing, sourcing, scaling, and implementing Indigenous-specific menu items.Knowledge Mobilization Our Learning Community supported the sharing of findings in multiple ways: (1) a final summary report of the KT project; (2) a presentation at the hospital open to the public and care providers, with a blessing from an Elder; (3) a department-led report and presentation on the Patient Journey Mapping results, including qualitative data on hospital food; and (4) a scientific article on the Survey results for the journal Nutrition in Clinical Practice (revision resubmitted). A major lesson learned by the clinical dietitians who are responsible for hospital nutrition care to patients was the critical process of relationship-building with a focus on personal stories; relationships are an essential enabler of change in the healthcare ecosystem. Another lesson about collaboration was the extended timeline and patience involved in building new relationships and engaging relevant stakeholders. Other lessons of collaboration related to integrating practice needs with evaluation research and data analysis, and to the challenges of implementing new knowledge that respects the goal of cultural safety to improve nutrition and health among Indigenous patients. A key outcome is the ongoing discussions on opportunities for Indigenous-specific options on the hospital menu.

1 Clinical

Qualitatively Exploring Opportunities to Support Older Women’s Sexual Health and Wellbeing in Fraser Health Authority’s Assisted Living Sector

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Introduction and Background Fraser Health Authority serves over 1.9 million British Columbians and hosts 12,000 beds in its long-term care and assisted living sector. In late 2000, Fraser Health embedded a research team within its long-term care and assisted living structure to integrate research evidence into practice. In 2022, discussions within this research unit and Fraser Health's assisted living leadership highlighted a lack of focus on residents’ sexual health needs, particularly missed opportunities for sexually transmitted and blood-borne infections prevention. Informal dialogues revealed that assisted living managers lacked strategies to promote sexual health and older women residents experienced stigma around their sexual health and intimacy. Funded by the Women’s Health Research Institute, our study addresses these concerns within a learning community by focusing on two priorities: centering research on older women, who comprise almost 70% of assisted living residents, and expanding the focus to overall sexual wellbeing, going beyond sexual health and sexually transmitted and blood-borne infections.Aims and Rationale1. Understand Sexual Wellbeing: Explore how older women conceptualize sexual wellbeing to identify gaps potentially contributing to sexually transmitted and blood-borne infections.2. Develop Strategies: Create strategies to meet these women's sexual health and wellbeing needs through multi-method and women-centered approaches.3. Knowledge Mobilization: Reduce sexually transmitted and blood-borne infection burden and improve sexual wellbeing by translating findings to assist care providers in enhancing screening, treatment, support, and policy recommendations.Learning Community Engagement and Methods Our project engages a learning community united by their interest in the sexual wellbeing of older women and creating safe assisted living environments for intimacy. This community includes assisted living leaders (physicians, administration, care staff), older women residents, and Fraser Health’s Long-Term Care and Assisted Living Research Partners Group (caregivers, residents, family members). We operate on the belief that residents are experts in their own care, family members have important lived experience, and decision-makers value our research. We use an iterative approach, maintaining ongoing communication with the learning community, involving them in multiple studies, and refining our research vision with their input. Our integrated approach encourages assisted living residents, staff, leaders, and family members to reflect on opportunities and concerns through virtual and in-person meetings and informal discussions. For the current study, the learning community will support recruitment, troubleshooting, interpreting findings, and guiding future research directions. Their involvement stems from both their personal interest as well as their enjoyment in being part of a learning community process, which we facilitate as researchers.Study Research Methods1. Focus Groups: Conduct semi-structured virtual focus groups with 8-10 assisted living leaders to discuss policies and practices around women’s sexual wellbeing.2. Walking Interviews: Conduct semi-structured walking interviews with 10 care aides or frontline staff to identify barriers and facilitators to sexual wellbeing in assisted living, including observational insights.3. Unstructured Interviews: Conduct unstructured interviews with 20 older women residents to develop a conceptual framework for understanding sexual wellbeing.Knowledge Mobilization with Learning Community The learning community will play a crucial role in sharing and implementing findings. For example, the community will help to present findings to key stakeholders within Fraser Health, including clinical leaders. Inspired by the learning community’s call for accessible knowledge translation, we will work with a graphic artist to create a visual synthesis of our findings.Lessons To Date While we are in the recruitment stage, past research collaborations with this learning community have taught us valuable lessons. Hosting informal, flexible opportunities to connect builds trust and open communication. Using inclusive, accessible language avoids confusion and respects cultural contexts and diverse lived experiences. Transparency is crucial, providing regular updates and clear research goals and timelines. Sustaining connection with the learning community is vital, as they are likely to value continued involvement post-study. We will also prioritize capacity building, offering training and resources to help the community engage in future research, circulating opportunities hosted by Fraser Health and other local organizations.Conclusion The findings of this study will address critical gaps in understanding and supporting sexual health and wellbeing for older women in assisted living settings. Through collaboration and engagement with the learning community, we aim to develop meaningful strategies and recommendations to improve the health outcomes and quality of life for this resident group, while building a learning community that has capacity and influence.

1 Simon Fraser University, 2 Fraser Health Authority

Raise Your Voice: How to Increase the Effectiveness of Resident and Family Councils in Long-Term Care Homes in British Columbia, Canada.

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Introduction and Background: The devastating impacts of the COVID-19 pandemic highlighted the missing voices of families and residents in long-term care (LTC) decision making and policy processes. Resident and/or family councils constitute one method of raising these voices. A resident and/or family council is a group of persons who either live in a LTC home, their families, and/or the residents' representative, who meet regularly to maintain and enhance the quality of life of residents in LTC. Resident and/or family councils exist to engage the resident community and to improve the experiences of all residents, by providing their insights and advice and represent the collective interests of residents. In November 2022, British Columbia implemented new LTC regulations to strengthen the position of resident and family councils in LTC homes. The regulations require LTC operators to support the operation of resident and family councils and promote their independence. There is currently a gap in evidence of factors that promote or hinder the effectiveness of these councils. This project aimed to identify factors contributing to the effective functioning of resident and/or family councils.Learning Community Engagement: This project was informed by a participatory approach that integrated knowledge users throughout the research process. One family council representative and one LTC advocate were included in the research team and informed all study methods including data interpretation and knowledge dissemination. Five focus groups and two interviews were conducted with 17 LTC home leaders, residents, family members, and advocates in British Columbia. Data were analyzed using a phenomenologically-informed framework analysis approach.Knowledge Mobilization: A series of modifiable and non-modifiable factors were found to affect council effectiveness. While modifiable factors encompassed communication, structure, recruitment/engagement, council leadership, culture/attitudes, and resources/supports, non-modifiable factors included medical complexity of residents and short lengths of stay. The research findings were used to co-develop three key outputs: (a) a research paper currently under review for publication; (b) a 35-item instrument that operationalizes and identifies areas that can increase council effectiveness in practice to ensure their voices are heard in LTC decision-making; and (c) a short film that raises public awareness about the existence and the value of LTC resident and/or family councils. Knowledge users co-authored the research paper, reviewed and provided feedback on the instrument and participated in the short film. Knowledge users also informed the dissemination plan. The successful collaboration resulted in the uptake of the project outputs by a variety of key stakeholder organizations including the Senior's Advocate Office and the Independent Long-Term Care Councils Association of British Columbia.

1 University of British Columbia, 2 Independent Long-Term Care Councils Association of British Columbia

Rising Up: Collaborating with Chinese Families and Communities for Parenting Resources

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Introduction and BackgroundCanada is ethnically and culturally diverse, with almost 37.5% of Canadian children having at least one parent of foreign birth. Of the children with an immigrant background, almost half were from an Asian country of ancestry. Asian Canadians not only have a lower average self-reported mental health but also significantly underuse mental health services. This discrepancy can be attributed to many factors, including stigma, low mental health literacy, and lack of linguistically and culturally appropriate services. In BC, the Chinese population is the largest (>32%) visible minority group, thus making Chinese families an important group to which to promote mental health literacy.In BC, a range of mental health promotion programs are available for families, but most are available only in English. Moreover, resources available in other languages are often simply linguistic translations of existing resources originally developed in English and designed by clinical experts using a mainstream cultural lens and top-down approach. Although such resources are informative and can increase mental health factual knowledge, there is limited impact on reducing stigma and improving help-seeking. Meanwhile, psychoeducation interventions designed from the start in other languages that incorporate cultural beliefs and culturally familiar icons may improve mental health literacy. Working with ethnocultural groups to co-design mental health promotion programs is crucial to ensure that culturally relevant content and approaches are used to benefit children and families. Thus, our project collaborated with Chinese caregivers of children in BC to promote mental health literacy that is culturally tailored. Learning Community Engagement We used a community-based participatory action model, engaging with community partners, researchers, trainees, and families. We used recommended practical strategies for optimizing co-design with ethnic minority populations, including (i) liaising with representative groups (e.g., Canadian Mental Health Association - Chinese Promotion Program, S.U.C.C.E.S.S.); (ii) employing peer-led engagement and co-design (e.g., family advisors who contributed to planning, recruitment, facilitation, and data analyses); and (iii) meeting practical needs for participation (e.g., choice of virtual or local meetings, evening and weekend times).Primary caregivers of children aged 3-13y (N = 91) who are of Chinese heritage (e.g., a family of origin from Mainland China, Hong Kong, or Taiwan) were recruited to participate in a 90-minute focus group. Participants shared about what types of parenting challenges they have experienced, how they would like to access resources. A total of six (four online, two in-person) workshops were held, including 11 Mandarin, 5 Cantonese, and 3 English focus groups. Participants received a $20 honorarium, while family advisors received a $50 honorarium per meeting. Knowledge Mobilization By working directly with community partners and BC's Chinese caregivers, we learned how enthusiastic they were about the importance of this project in meeting the needs of Chinese families. We gained insights about the nuanced regional differences in translations between Mandarin and Cantonese. We also found that family advisors and participants alike preferred attending meetings virtually rather than in-person at local venues.After initial data extraction, the top three parenting challenges identified were: 1) child emotion dysregulation; 2) child anxiety and introversion; and 3) child inattention and poor motivation. Participants also indicated their top three preferred methods of accessing resources as: 1) in-person, professionally facilitated workshops, 2) online webinars and parent groups, and 3) social media. Thematic content analyses will be conducted by the data working group (trainees, researchers, family advisors) this fall, and we'll co-create and co-share our findings via infographics and presentations in collaboration with community partners to the participants, general public, clinicians, and researchers. Next steps include co-developing and co-evaluating the parenting resources based on the above identified priorities and preferences, with expanded partnerships (e.g., Our Kids Health and Hong Fook Mental Health Association in Ontario).

1 Principal Investigator, 2 Worklearn Research Assistant

Screening for trauma in a youth integrated care clinic (Foundry Vancouver); youth and staff experience

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Introduction and Background Routine screening for trauma is supported by numerous evidence-based guidelines, particularly as trauma is associated with a higher risk of mental health and substance use disorders. This study aimed to survey a cohort of youth in an integrated care clinic (Foundry Vancouver - Granville, BC) to determine the prevalence, profile, and severity of trauma, as well as to assess both the youth's and staff's experiences with the implementation of a trauma screen. The broader goal, in piloting this screening tool, is to implement a trauma screen across the network of Foundry sites as the first step in a continuum of trauma care.Learning Community Engagement Prior to implementing a trauma screen, a scan was conducted to identify a measure suitable for a transitional-aged population. Input on the screen's use was then reviewed by a trauma working group, which included representatives from social work, clinical counselling, psychology, psychiatry, and primary care. Concurrently, peer support staff led feedback with a youth advisory committee.Youth (ages 15-24) completed the UCLA PTSD Reaction Index for DSM-5-Brief Form. Both youth and clinic staff also completed feedback surveys (user satisfaction scales and qualitative feedback) on the trauma screen’s use.Knowledge Mobilization Most youth indicated they had experienced trauma in their lives. No demographic characteristics were statistically associated with PTSD scores. Most trauma experiences shared were interpersonal in nature. Youth with recent trauma (within the last month) were connected to additional services. Overall, youth supported the screen, with most expressing comfort in completing it. The majority of staff showed consistent support for the screen and felt capable of addressing trauma, though they requested increased supervision and more options for referring youth for trauma care.This project underscores the value of on-the-ground expertise and input, which was instrumental in ensuring the successful piloting of the screen. A Trauma Care Project team has been established at Foundry Central Office, featuring both clinical and operational expertise in project implementation. The results of this project will be shared with the Trauma Care Project team, to support the roll out of the trauma screen across the growing network of Foundry sites. The project team will work closely with Foundry centres to create a trauma care pathway, support practitioner trainings, and staff trauma education sessions. We envision the trauma screen as a crucial initial step of a future comprehensive trauma care pathway, broadly benefiting youth across the Foundry network.

1 Providence Health/Foundry, 2 UBC/Foundry

The Arthritis Community Learning Circle: A Learning Community Advancing Equitable Arthritis Care for Indigenous Peoples

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Introduction and Background Arthritis disproportionately affects Indigenous Peoples in Canada, yet the healthcare system continues to fall short in providing equitable and culturally appropriate care. These systemic inequities not only limit access to necessary treatments but also perpetuate a cycle of poor health outcomes, further deepening the health divide. To address these challenges, the Arthritis Community Learning Circle (ACLC) was established as a community-driven initiative under the leadership of an Indigenous scholar. The ACLC aims to advance Truth and Reconciliation efforts in arthritis care across Canada by responding to Health Calls to Action 18 to 24. The initiative began in 2021 and continues to create safe and trusted spaces for knowledge exchange, self-reflection, and the co-design of healthcare solutions that align with the specific needs and values of Indigenous Peoples.Learning Community Engagement The ACLC employs a community-based approach, engaging diverse individuals including rheumatology researchers, healthcare professionals, advocacy organizations, decision-makers, healthcare users and Indigenous communities. Engagement approaches include:Educational Webinars: Quarterly webinars are organized to provide educational opportunities for a broad audience. These webinars focus on increasing awareness of arthritis in Indigenous communities and offer insights into specific topics such as Indigenous ethics, Indigenous healing practices, and the medicine wheel.Editorials: Quarterly editorials are co-written with an Indigenous scholar and distributed through targeted email lists and social media platforms. These editorials provide thought-provoking commentary on emerging issues and offer reflections on Truth and Reconciliation efforts across healthcare and health research.Planning Meetings: Regular planning meetings are held with healthcare decision-makers, advocacy organizations and Indigenous leaders, to discuss the integration of Indigenous priorities and methodologies into arthritis care.Mentorship Sessions: Mentorship sessions are offered upon request by an experienced Indigenous mentor to organizations seeking guidance in adopting Indigenous-centered approaches in their work. Truth and Reconciliation Retreat: A three-day Truth and Reconciliation retreat took place in July 2023, focusing on Indigenous health. The retreat incorporated teachings from Indigenous Elders, cultural ceremonies, and workshops that addressed the historical trauma faced by Indigenous Peoples and its ongoing effects on health and well-being. Feedback from participants is collected during and after activities to ensure the initiative evolves in alignment with its goals toward Truth and Reconciliation.Knowledge Mobilization The ACLC has successfully built a collaborative network that fosters trust and mutual learning among its thousands of webinar participants, readership, advocacy partners, mentees, and retreat attendees. This work has illuminated critical lessons including the importance of trust building, respect for Indigenous ways of knowing and being, and the need for ongoing efforts rather than temporary fixes. Feedback surveys suggest that participants have demonstrated increased awareness of the historical and cultural contexts affecting Indigenous health and continue to actively engage in allyship activities. The ACLC has also led to the development of a website dedicated to helping the arthritis community move forward on the path to Truth and Reconciliation.

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The effects of caregiving: setting up our research framework

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Introduction and BackgroundAbout a quarter of all Canadians aged 15 and older are caregivers who provide help or care to their family members, friends or neighbours with chronic illness, a physical or mental disability, or problems related to aging. Caregivers are critical to our health systems and society as they reduce the use of formal home care and other publicly funded health services. While caregiving can be rewarding, it is also time-intensive, challenging, and affects the work productivity and health of caregivers. Our research objectives are to measure how caregiving impacts these outcomes and identify workplace and government support that can improve caregiver wellbeing. In this presentation, we will explore how we refined our research framework during the initial stages of our study.Learning Community Engagement Our research is a patient-oriented study in which caregiver partners, researchers, health economists, knowledge users, community stakeholders and policymakers are contributing. More explicitly, we have engaged our partners at the BC SUPPORT Unit and the SickKids Centre for Innovation and Excellence in Child and Family Centered Care and Health along with 3 caregiver partners on our team, who are informing the entire research process from study design, proposal preparation, questionnaire pretesting and finalization to result interpretation, policy recommendations and identification of additional end-of-grant knowledge translation strategies. The methods to engage these groups vary from prompted feedback, reviews, and periodic committee and team meetings. The interactive loop with our learning community is critical to ensure the delivery of our research objectives in a way that is robust, appropriate and disseminated effectively.Our research framework uses mixed methods with a sequential design in which our quantitative strand follows our qualitative strand. During our qualitative strand, we tested and edited our survey questionnaire through cognitive interviews with 19 caregivers. All research team members were engaged in this testing and finalizing process regarding our questionnaire. At a later stage, our quantitative strand will analyze the results of the survey which will compare the experiences and outcomes of caregivers to that of non-caregivers.Knowledge Mobilization As we are concluding the first phase of our research, the results of our interviews have helped us reflect, and reshape our research framework. The partners, knowledge users and caregivers we interviewed pointed to limitations in our survey (e.g., forcing a postal code entry), cognitive difficulties (e.g., recalling abilities), language clarity and appropriateness (e.g., what constitutes “help or care”, “care recipient” versus “care receiver”). This input helped enhance our methodological robustness (we refined the eligibility criteria to our study), be contextually appropriate and reflective of real-world experiences (e.g., introducing care recipients as persons first) and shape our research concepts (i.e., how should a caregiver be defined?). These inputs have been pivotal in elevating our research framework. We integrated feedback into our research cycle, promoting not only scientific rigor but also our research’s relevance, significance, and practical applications for all stakeholders within our learning community.As we progress to later stages of our research, our findings will be disseminated through expected scientific publications with open-access options, conferences (e.g., the Canada’s Drug Agency symposium), and social media. Targeted knowledge products for caregivers and employers (e.g., infographics and short stories) will also be created in partnership with our learning community. Lay research summaries (blog posts, press releases) will be shared on our partners’ websites, newsletters and social media. Building on the outcomes of the engagement with our learning community, we aim to expand the scope and scale of our current study by exploring international applicability of our research findings.

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The Head and Neck Cancer Application for Patients and their Partners (HANC APP) Study: Co-designing through patient partner workshops

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Background: People with head and neck cancer (HNC) can experience severe symptoms and side effects that impact basic functions such as chewing, swallowing, and talking. Treatment, like chemotherapy and radiation therapy, impacts social activities and relationships as people with HNC report reduced sexuality and have the highest rates of depression compared to other types of cancer. Patients are often provided the option of selection one or more treatment types. The scientific literature reports that people with HNC suffer unjust anxiety because treatment options can be overwhelming and hard to understand. This is partly due to being given too little or too much information that is explained in a way that is difficult to grasp (e.g., too many medical terms). Patients who feel they received the right amount and type of information at the right time, before and during treatment, are more likely to have positive outcomes. Interviews with local survivors of HNC confirmed the need to support patients in making treatment decisions by using pictures and videos to better explain treatment options and their associated benefits and risks. If they had this information, survivors thought they would have felt more confident in their treatment decision and had less stress. As a response to this need, the research team is creating an app to be used on computers, phones, or ipads that will provide information on HNC in an easy-to-understand way. This app, called the “HANC APP” (Head and Cancer Application for Patient and their Partners), is being created alongside a group of 8 patient partners who are advising on every step of the process. This poster aims to report on our experiences and progress so far in dreaming up and creating the HANC APP. Learning community engagement: The HANC APP Study began by interviewing 12 survivors with HNC who were treated within the past 5 years at BC Cancer on the usefulness of an app that provides information and is designed to help patients make decisions. The study team, including radiation oncologists, a dietitian, and health informatics specialists (including two members with lived experience with HNC) from the University of Victoria are committed to following survivors’ recommendations and developing then testing the HANC APP. A dedicated group of 8 survivors of HNC were recruited before starting the development of the HANC APP to make sure every part of the app involved (i.e., co-designed by) community members with lived experience with HNC. To date we have completed two workshops with our group of patient partner survivors. Both workshops focused on patient information needs to guide the HANC APP content. At the end of the second workshop, a creative prototyping exercise was completed as a way to brainstorm potential HANC APP designs.Knowledge mobilization: The informational content (e.g., type of information, level of detail, etc.) and key design features (e.g., colours, use of buttons, etc.) of the HANC APP have all been decided by our patient partner group with medical oversight by the study team oncologists. A challenge has been the web designing specialization needed to execute this study, as it means that neither the medical study team nor patient partner group are able to implement the vision but rather need to relay it to the technology design team instead. This has affected the study timeline, being a slower process than initially planned; however, the technology team is doing an excellent job of consulting the study team for guidance. The final outcome of our co-design engagement will be a new app designed by and for patients with HNC and their partners.

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Transforming Access to Pediatric Rheumatology Care for Remote and Rural Communities: Findings from the Northern BC Project

Brittany Barnes 1, Georgina Clarkson 2

Introduction and Background Cassie and Friends Society (C+F) is a Vancouver-based, national reaching nonprofit dedicated to transforming the lives of the 24,000 kids and families in Canada affected by childhood rheumatic diseases such as Juvenile Arthritis, Lupus, and Fever Syndromes. Research indicates that Canadians living in rural and remote communities face complex barriers to accessing healthcare, including low physician-to-population ratios, long travel distances, significant financial and time costs, and limited awareness of lesser-known health challenges (Booker, 2023; Johnston & McLean, 2023; Mandal & Phillips, 2022). In 2021, to understand how these challenges may impact childhood rheumatic disease patient-families in remote and rural communities in Northern British Columbia, C+F, supported by the BC Children's Hospital Pediatric Rheumatology team, launched the Northern BC Project (NBCP). Over one year, C+F engaged with patient-families at four in-person clinics in Prince George and Terrace to learn about their experience reaching a diagnosis and accessing ongoing pediatric care. From September 2023 to March 2024, a Royal Roads University Master of Arts in Leadership graduate student, supported by C+F, conducted an action-oriented research study to further investigate and identify support needs from the patient-family perspective. Our research was guided by the principal inquiry question: How might C+F effectively support families impacted by childhood rheumatic disease in Northern BC? Our ultimate goal: to advance inclusive and equitable access to healthcare.Learning Community Engagement Our learning community included internal and external members including the guidance of the C+F NBCP Advisory Committee composed of representatives from C+F, BC Children's Hospital, a Prince George parent, and a research student with oversight from an Academic Research Advisor. External engagement and research involved patient-families (parents, caregivers, and youth with rheumatic diseases) and relevant support organizations within the Northern Health Authority's jurisdiction. Multi-modal, culturally safe engagement methods were employed to connect with families and learn about their experiences including informal in-person dialogues at clinic appointments, a family connection event, email, social media, online surveys, and semistructured interviews. Collaboration with BC Children's Hospital's Pediatric Rheumatology team and the Northern Health Authority was essential for establishing effective communication with patient-families. Beyond gathering insights into patient experiences, engagement aimed to co-design recommendations for advancing inclusive and equitable healthcare access. Methods to implement these recommendations will include continued collaboration with our learning community, awareness and educational initiatives, and resource development. Knowledge Mobilization We learned that the use of culturally safe, accessible and adaptable engagement methods was key to ensuring broad participation and legitimizing outcomes; insights from those with lived experience were crucial to identifying the root causes of challenges and potential solutions. Engagement and research with our learning community revealed prevalent feelings of isolation, gaps in awareness of childhood rheumatic disease both generally and within Northern BC's healthcare sector, and highlighted significant financial, emotional, travel and time burdens faced by families when seeking diagnosis and care. It also identified existing useful supports. The NBCP led to a deeper understanding of challenges within our community and resulted in four key recommendations for advancing inclusive and equitable healthcare support in the region. Moving forward, our learning community will continue to grow to include new and evolving perspectives and be centrally engaged in providing feedback on and supporting the implementation of the following recommendations: 1. Investing in/facilitating connections among Northern BC families affected by rheumatic disease.2. Developing an accessible knowledge hub on the C+F website tailored to Northern BC patient-family needs, including existing local community resources.3. Exploring the recruitment of volunteer family navigators in Northern BC to support community building and resource connection.4. Elevating patient-family voices through Continuing Medical Education sessions to raise awareness of childhood rheumatic diseases among local healthcare providers.

1 Project Director, 2 Research Student

Transforming Research with Patients First: Building Capacity through POR eLearning

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Introduction and Background The Patient-Oriented Research (POR) eLearning Modules Series addresses the gap in familiarity and knowledge of adopting a POR approach. Though its benefits have been promoted in recent years, a systematic review of the prevalence of POR from 2018 found that less than 1% of 371,159 clinical trials involved patient engagement. Common barriers include uncertainty about conducting POR and meaningfully engaging patient & family partners (PFPs). This series educates clinicians, researchers, and people with lived/living experience (PWLLE) on this topic, particularly for mental health, substance use, forensic, and correctional health research.Without equipping researchers and PWLLE with the tools to conduct or be engaged as a partner in POR, research may fail to yield relevant, accessible findings for the target population. Including patient perspectives in research can improve health outcomes for the target population and are less likely to perpetuate stigma.Learning Community Engagement To ensure the eLearning series met the diverse needs of researchers and PWLLE, a learning community approach was utilized. Course development involved engaging an advisory committee comprising researchers with and without POR experience, PFPs, and staff from BCMHSUS and the Research Institute. The IAP2 spectrum of engagement informed how input from the advisory committee would be integrated into the final product and to ensure transparency on how decisions would be made. The committee was engaged at the 'Collaborate' level, contributing to curriculum development, eModule design, and providing feedback throughout the project. PFPs in the committee also co-created the Co-Presentation infosheet for the course. To inform the development of the infosheets, interviews were held with operational leadership, Indigenous Care Coordinators, and researchers with POR experience. Interviewees also provided ongoing feedback from interview to infosheet completion. The learning community approach involved structured interactions where people with diverse experiences and expertise collaborated to address gaps in course content. Engaging different voices in a group helped shape the content to meet the expectations of the learning community as a whole.Knowledge Mobilization The development of the eLearning course resulted in 4 modules covering an introduction to POR, implementing POR, reporting on POR, and evaluating POR. 6 infosheets are also included, covering tips for facilitating engagement sessions, co-presenting with PFPs, and considerations on how to engage patients in active care at mental health & substance use treatment centres, forensic psychiatric services, and correctional health services, as well as engagement with Indigenous patient partners in a culturally safe way.The course is accessible through Learning Hub, allowing users to learn at their own pace and apply the content to their research. To support course dissemination, Advisory Committee members from the Research Institute and PFPs collaborated with the project team to pilot the course in BCMHSUS' Research Challenge. Participants included researchers, clinicians, and PFPs who needed to learn about the POR approach to conduct their research projects. Additionally, Advisory Committee PFPs and Research Institute staff collaborated to plan and organize a PFP-hosted POR panel to discuss how to apply course learnings to research projects in the Research Challenge.Collaborating with a diverse learning community revealed the importance of role clarity to ensure that everyone understands their responsibilities and can be recognized for their efforts accordingly. Creating communication systems with routinely documented feedback also helps ensure that each voice is accurately represented and integrated.Though the short-term outcome of this project is anticipated to be greater POR uptake by learners across BCMHSUS and PHSA, the long-term goal is for this project to support more trauma-informed and culturally-responsive patient engagement in POR projects. By encouraging a POR approach, we hope that the research community can recognize the importance of research that centers on the needs of those they serve. ReferencesFergusson, D., Zarah Monfaredi, Kusala Pussegoda, Garritty, C., Lyddiatt, A., Shea, B., Duffett, L., Ghannad, M., Montroy, J., M. Hassan Murad, Pratt, M., Rader, T., Shorr, R., & Yazdi, F. (2018). The prevalence of patient engagement in published trials: a systematic review. Research Involvement and Engagement, 4(1). https://doi.org/10.1186/s40900-018-0099-x

1 BC Mental Health and Substance Use Services

Understanding the lived experience of participating in exercise in youth with cerebral palsy and their caregivers

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Word count = 597 (not including headings)AbstractProblem: Children with chronic non-progressive neuromotor conditions, such as cerebral palsy (CP), experience gross motor limitations affecting participation in physical activity (PA) and exercise. While previous work has demonstrated the positive effects of PA and exercise among children with CP, these studies often determine the effectiveness of the trial by setting outcome measures without addressing the specific needs of the clinical population, especially for children with severe motor limitations. Following the completion of a recent scoping review by our team investigating how physical, cognitive, and patient outcomes are evaluated in adaptive exercise technology research, we identified a gap in the literature regarding the patient experience of engaging with PA and exercise. Therefore, this study aims to work with patients and their families to understand what motivates them to exercise, what outcomes matter, and how adaptive exercise technology can be developed to better meet their needs. Methods & Analysis: Co-creation workshops and individual interviews are offered to children aged seven to thirteen, accompanied by their parent or guardian, or adolescents aged fourteen to eighteen, with parent or guardian participation as optional. Workshops and interviews focus on themes including 1) experience with informal and formal PA and exercise, 2) opinions on the ideal exercise intervention, and 3) insights related to adaptive exercise hardware and software development in healthcare spaces. Audio recordings and text responses from all discussions are transcribed verbatim and analyzed using conceptual content analysis. Findings: The anticipated findings of this study will provide patient-centred data that will inform the development of an adaptive patient-centred application to promote exercise in children living with CP, independent of motor limitation. Preliminary data suggests that themes related to caregiver well-being, risk of injury, and access to affordable adaptive options are key considerations that will need to be addressed. Implementation strategies: This study is the first of three complementary projects that will ultimately deliver an adaptive patient-centred application to promote exercise in children living with CP. The qualitative feedback from patients and their parents or guardians in this initial co-development phase will serve to guide the creation of expert interviews for the second phase of this project, focusing on the healthcare providers administering care to this clinical population. Together, data from both phases will contribute to the co-development of an adaptive application to promote exercise in children with CP, independent of motor limitation. Learning community engagement This project is carried out in close collaboration with the staff of BC Children's Orthopaedic Cerebral Palsy Clinic, other healthcare provider partners, and the patients and their families who volunteer their time to share their experiences. To engage this clinical population, our research team partnered with healthcare providers and CP organizations across Canada, as well as through social media and word of mouth. In the current study, participants can choose between a co-creation workshop with other patients and families or an individual interview to share their lived experiences. Co-creation workshops allow participants to share their experiences with others, while interviews allow participants to engage privately in the research. Knowledge mobilization The partnered Learning Communities will support the patient-oriented knowledge translation through fliers, social media and blog posts, as well as key insights shared on relevant websites across BC Children's Hospital's platform and other healthcare facilities nationwide. The primary lesson learned while collaborating with Learning Communities has been to appreciate the importance of forming relationships and integrating into the research ecosystem of the groups we have had the privilege to work with so far. A notable outcome from our engagement so far includes a much broader recruiting network for future work aimed at children and healthcare providers associated with our research partners.

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Using the Delphi Method to Build Consensus with a Patient-Partner Team

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Introduction and BackgroundAcquired brain injury (ABI), including conditions such as stroke and traumatic brain injury, can significantly impact an individual's cognitive, emotional, and behavioral function, as well as everyday functioning, and independent living. Post-traumatic stress disorder (PTSD) following ABI is highly prevalent and can further complicate the course of recovery. Yet many healthcare professionals either do not know about trauma, or feel insufficiently equipped to support people with PTSD. Trauma-informed practice (TIP) is a way of supporting people with traumatic stress without having to discuss the trauma directly, yet it does not seem to be widely adopted in ABI contexts. The goal of our project was to convene an expert panel to create consensus guidelines on how to adapt TIP for the ABI rehabilitation context.Learning Community Engagement:Our learning community consisted of a fifteen-person team of relevant stakeholders - persons with lived experience, experienced clinicians, researcher-educators and trainees. Our team of rehabilitation clinicians were recruited from Victoria General Hospital via a presentation by the research team regarding the goals of the project. For our patient-partner team, we worked with the BC SUPPORT Unit to advertise a public talk on the project and recruit potential patient-partners to attend. Interested parties were invited to contact the BC SUPPORT Unit and fill out a demographic questionnaire. The research team compiled all questionnaires and then selected a team that was meant to represent as diverse demographics as possible. Our final 15-member panel consisted of a four-person research team (including two registered psychologists who were also clinical psychology professors), five experienced rehabilitation professionals, and six persons with lived experience (four of whom had direct experience of ABI, and three who were caregivers of either an adult or child with ABI).In order to create consensus guidelines, we used the Delphi method:First, we held a Zoom call where the team was able to get acquainted, and the researchers discussed the aims of the project and outlined our timeline for the project.Second, all panel members were provided with a workbook which consisted of reading material about the subject matter, as well as reflection questions and prompts for journaling. This was to insure that all participants had a shared knowledge base for the project. Participants were also taught self-regulation tools in case they had any emotional reactions to the material. People could reach out to the two registered psychologists for further support if needed.Third, every panel member (including the researchers) participated in a 90-minute qualitative interview reflecting on how TIP should be applied in a neurorehabilitation context. These interviews were then transcribed and coded by the two researchers/psychologists, and turned into a questionnaire.Fourth, every panel member completed the questionnaire twice, rank-ordering the most important items to be retained.Knowledge Mobilization The two researchers/psychologists used the top-ranked items to create draft guidelines. These were transformed into a Canva brochure that will be distributed to other rehabilitation professionals. A scientific manuscript on our work will also be submitted for publication. It is novel for a Delphi study to include people with lived experience, and it is likewise novel to include patient-partners as co-authors on a paper, particularly as this requires disclosure of names. As such, we sought consent from every panel member to include their name on a final paper for publication. All patient-partners indicated their enthusiasm to have their names included on a scientific paper. This collaborative project was deemed to be highly successful for everyone involved. Patient-partners in particular reported it to be highly meaningful and they were excited at the possibility of enhancing care for other survivors/families of persons with ABI.

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