BC SUPPORT Unit
Advancing Patient-Oriented Research

British Columbia Academic Health Science Network

Putting Patients First:
Connecting Face to Face in Virtual Space

October 8, 2020

Conference Booklet

The BC SUPPORT Unit would like to thank:

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BC SUPPORT Unit
Advancing Patient-Oriented Research
British Columbia Academic Health Science Network

Putting Patients First: Connecting Face to Face in Virtual Space, October 8, 2020
Conference Booklet

Putting Patients First: Connecting Face to Face in Virtual Space (#PPF20)

Conference Program

October 7&8, 2020

Delivered virtually via Zoom with OpenWater

Host: BC SUPPORT Unit Interior Centre

We acknowledge that our event takes place on traditional, ancestral,

and unceded Indigenous territories. As guests to this beautiful land,

we are thankful and consider it a privilege to do our learning here.

Time	Event
Wednesday October 7	
6:30-8:00pm (at the latest)	Meet and Greet: **Stirling Bryan, Danielle Lavallee** Moderator: **Kent Cadogan-Loftsgard** Join the BC Academic Health Science Network's President and Scientific Director to learn more about what the AHSN and BC SUPPORT Unit have been up to and what's coming up in the future. This will be an opportunity to have an informal "chat" via Zoom's Chat feature, hosted by Patient-Partner Kent Cadogan Loftsgard. Q&A support: **Larry Mroz**
Thursday October 8	
8:15-8:30	Plenary Room #01

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	Moderator's Remarks: **Anni Rychtera** & **Wendy Petillion**
8:30-9:00	*Plenary Room #01* *Moderator:* **Leslie Bryant** *Opening prayer* **Elder Roberta Price**
9:00-9:05	*Plenary Room #01* *Welcoming Remarks from the BC Academic Health Science Network and BC SUPPORT Unit* **Stirling Bryan, Danielle Lavallee, Minnie Downey**
9:05-9:45	*Plenary Room #01* *Moderator:* **Dee Taylor** *Keynote presentation* *Title:* **Person-oriented research from an Indigenous perspective** **Christopher Horsethief**
9:45-10:00	*Q&A lead:* **Danielle Lavallee**
10:00-10:05 (Break) *10:05-10:30 (Networking)*	*Break and Networking Sessions: Regional Centres* *Come have an informal chat with staff from the Unit's Regional Centres, and learn what's going on in the region.* *Room #02: Fraser Regional Centre; Moderator:* **Richard Sobel** *Room #03: Interior Regional Centre; Moderator:* **Wendy Petillion** *Room #04: Island Regional Centre; Moderator:* **Taylor Hainstock**

	Room #05: Northern Regional Centre; Moderator: **Tina Strudsholm, Rachael Wells, Julia Bickford** *Room #06: Vancouver Regional Centre; Moderator:* **Larry Mroz, Lynne Feehan**
10:30-11:30	*Room #02* *Breakout session #1a:* **Panel Presentation** **BC SUPPORT Unit Methods Clusters: What progress? What successes?** *Host:* **Amber Hui** *Recorded presentation* *Danielle Lavallee, Nick Bansback, Kim McGrail, Linda Li, Erin Michalak, Rick Sawatzky, Hubert Wong, Amber Hui*
	CANCELLED *Breakout session #1b:* **Panel Presentation** *Host:* **Andrea Burrows** **A Pandemic Pivot – Patient-Oriented Research in Mental Health during COVID-19**
	Room #03 *Breakout session #1c:* **Oral Presentations: Coordination of Care** *Host:* **Michelle Smith** **Presentations are 15 minutes including time for questions** • *10:30-10:45 1c1:* **Can a patient/family-oriented discharge process improve the patient and provider experience of discharge from hospital?** • *10:45-11:00 1c2:* **Coming of Age as a Pathway towards Wellness for Urban Indigenous Youth in Care**

- *11:00-11:15 1c3: **ED2Foundry: Building a partnership between the emergency department and community health services for youth and young adults with mental health and substance use care needs***

Room #04

*Breakout session #1d: **Oral Presentations: Digital Engagement***

*Host: **Jason Curran***

Presentations are 15 minutes including time for questions

- *10:30-10:45 1d1: **Personal Health Records: Contrasting Views of Rural Patients and Providers***

- *10:45-11:00 1d2: **Bridging the Digital Divide: A scoping review to understand the barriers and facilitators youth face in accessing digital mental health technology***

- *11:00-11:15 1d3: **Integrating Patient-Centered Measurement into Team-based Care Workflow***

Room #05
*Breakout session #1e: **Panel Presentation***
*Host: **Kim Peake** and/or **Sage Runner***
xaȼqanaǂ ʔitkiniǂ (Many Ways of Working Together): Sharing Lessons Learned through Community-Driven, Culturally-Informed Co-Learning and Co-Creation of Knowledge

Room #06
*Breakout session #1f: **Panel Presentation***
*Host: **Larry Mroz***
Learning, unlearning and relearning in patient-oriented research: A panel discussion

Room #07
*Breakout session #1g: **Skill-building workshop***
*Host: **Colleen McGavin***

	Amplifying and Engaging with Patient Voice Using Recorded Audio as a Knowledge Translation Tool - Podcasts and Beyond
11:30-1:00	*Sessions with Poster Presenters (see details below; Rooms 02,03,04)*
1:00-2:00	*Plenary Room #01* *Plenary Session:* **What considerations should be reflected on in LGBTQ2S+ POR?** *Host:* **Marilyn Parker** *Moderator:* **Beverley Pomeroy** *Panelists:* **Jessy Dame, Nathan Lachowsky, Rowdy Reeves, Leo Rutherford, Travis Salway** *Q&A support:* **Larry Mroz** & **Alia Januwalla**
2:00-2:05 (Break) *2:05-2:30 (Networking)*	*Break and* **Networking Sessions: Hallway Chats** *Come and have an informal virtual hallway chat with moderators on POR topics they've identified. All are welcome to all chats.* *Room #02:* **Patient Partners Meet and Greet**; *Moderator: Anni Rychtera* *Room #03:* **Patient Partners in Clinical Trials**; *Moderator: Alison Orth* *Room #04:* **After initial recruitment – what strategies have you used to support sustainable engagements?**; *Moderator: Tina Strudsholm* *Room #05:* **What do you want to know about doing patient engagement in Vancouver?**; *Moderator: Larry Mroz* *Room #06:* **Seeking Input on the New Patient-Oriented Research Database**; *Moderator: Brittney Schichter*
2:30-3:30	*Breakout Room #02* *Breakout session #2a:* **Oral Presentations: Patient Engagement**

Host: **Marilyn Parker**

Presentations are 15 minutes including time for questions

- *2:30-2:45   2a1:* **The Tapestry Project: Methods for Supporting Diverse Patient Engagement in Research in a Diverse World**

- *2:45-3:00   2a2:* **Patient Experience and Outcomes Surveys for Kootenay Boundary Primary Care Network Implementation**

- *3:00-3:15   2a3:* **Stronger muscles start with stronger partnerships: Evaluating the patient engagement process using the Patient Engagement In Research Framework**

- *3:15-3:30   2a4:* **Measurement properties of the short-form Patient Engagement In Research Scale (PEIRS)**

Breakout Room #03

Breakout session #2b: **Oral Presentations: Exemplar Projects of Patient-Oriented Research**

Host: **Andrea Burrows**

Presentations are 15 minutes including time for questions

- *2:30-2:45   2b1:* **EmPOwER: Engaging persons with cerebral venous thrombosis for meaningful outcomes and peer support**

- *2:45-3:00   2b2:* **Working with research patient partners in conducting MRI study on Myalgic Encephalomyelitis: selection and set up of the functional MRI task**

- *3:00-3:15   2b3:* **What Happened to Me: Theatre-based Knowledge Translation for Changing Childbirth in BC**

Breakout Room #04

Breakout session #2c: **Oral Presentations: Public Health**

	Host: ***Jason Curran***
	
	Presentations are 15 minutes including time for questions
	
	   • *2:30-2:45 2c1:* ***Rural Community Responses to COVID-19 in British Columbia***
	
	   • *2:45-3:00 2c2:* ***What Is Missing from "Patient-Oriented Research?" A View from Public Health Systems and Services Research***
	
	   • *3:00-3:15 2c3:* ***Client engagement with iOAT (Injectable Opioid Agonist Treatment) sites before and during the COVID-19 pandemic***
	
	   • *3:15-3:30 2c4:* ***Appropriate Access to Healthcare for Rural and Remote Communities: A Community-Based Toolkit for Investigating Legal Approaches***

	Breakout Room #05 *Breakout session #2d:* ***Panel Presentation*** *Host:* ***Larry Mroz*** ***Connecting Experience to Research: A review of different approaches to patient engagement in BC***
	Breakout Room #06 *Breakout session #2e:* ***Panel Presentation*** *Host:* ***Dee Taylor*** ***"Water is at the Heart": Indigenizing Patient-Oriented Research to explore how Indigenous women living with HIV understand and support their health***
	Breakout Room #07 *Breakout session #2f:* ***Panel Presentation*** *Host:* ***Michelle Smith***

	Centering Lived Expertise and Equity in a Program of Research
	Breakout Room #08 *Breakout session #2g:* ***Panel Presentation*** *Moderator:* ***Lynne Feehan*** ***The Foundry Project:*** • *2:30-2:45 **The Experience Project: Centering the voices of youth with lived experience to improve evidence-informed care*** • *2:45-3:00 **Improving Treatment Together: Evaluating Youth Engagement in Co-Designing and Informing Health Services Interventions for Youth Who Use Opioids*** • *3:00-3:15 **Understanding Experiences and Needs of Parents and Caregivers of Youth Who Use Opioids***
	Breakout Room #09 *Breakout session #2h:* ***Panel Presentation*** *Moderator:* ***Danielle Lavallee*** *Host:* ***Amber Hui*** ***Recorded presentations with live interaction*** ***Methods Matters****:* • ***The Peer Models Network*** • ***Using Face-to-face and Virtual Deliberative Dialogue to Develop Consensus in Patient-Oriented Research*** • ***Development of the Valuation of Lost Productivity Questionnaire for Caregivers***

	• *Patient Oriented Predictive Modelling of Healthcare Utilization (POPMHU): Developing a Shared Language through a Collaborative Team Wiki Page*
3:30-4:30	*Plenary Room #P1* *Plenary Session:* **POR and Health Technology** *Host, Q&A support:* **Annie Moore** *Moderator:* **Paul Burgener** ***How do we engage people around integrating technology into healthcare? How do we use technology to engage people in patient-oriented research?*** *Beth Bourke, Fred Cameron, Dennis Hore, Christopher Horsethief, Sean Spina, Bruce Wallace*
4:30-4:45	*Plenary Room #P1* *Moderator:* **Dee Taylor** *Closing ceremony* **Elder Roberta Price**

Poster Session 11:30-1:00

Poster presenters will be available to present and discuss their posters. Presenters are welcome to stay in the room following the presentations for further discussion.

Time	Room/ Host	#	Author Name	Poster Title
	Lynne Feehan			
11:30-11:40	#02	1	Jennifer Brown	*Exploring Conflict and Compensation in Patient-oriented Research: A scoping review*

11:40-11:50	#02	2	Richard Sawatzky	Quality of life assessments to support person-centred healthcare for older adults living with frailty and their family caregivers: Development of knowledge translation resources
11:50-12:00	#02	3	Craig Settee	Wabishki Bizhiko Skaanj: A learning pathway to foster better Indigenous cultural competence within Canadian health research
12:00-12:10	#02	4	Lillian Hung	Hum along with the silent disco headphones: lessons learned in implementing the headphone program in a hospital unit
12:10-12:20	#02	5	Alanna Koopmans	Patient-Oriented Predictive Modelling of Healthcare Utilization (POPMHU): An Undergraduate Student's Experience and Insights with a Patient-Oriented Research Approach
12:20-12:30	#02	6	Jill Hidalgo	Promoting Self-Management: Addressing the Educational Needs of New Hemodialysis Patients
12:30-12:40	#02	7	Erin E. Donald	Towards equity-informed care: A co-development process for meaningful patient-reported evaluation of care for persons experiencing structural vulnerability and chronic illness
12:40-1:00	#02			Optional Q&A/discussion with Posters 1-7 authors.
	John Ward			
11:30-11:40	#03	8	Ashmita Rai	Involving Patients, Family, and Caregivers in Policy for Integration through Primary Health Care Teams
11:40-11:50	#03	9	Josie Geller	Lessons Learned in Tertiary Mental Health Treatment: Patient Experiences of Virtual Care during the COVID-19 Pandemic
11:50-12:00	#03	10	Riley Bizzotto	Culturally Safe Patient-Reported Experience Measurement (PREMs) to Improve Quality of Care Among Indigenous Peoples in BC
12:00-12:10	#03	11	Jim Mann	Flipping Stigma on its Ear: People with Dementia Doing Action Research
12:10-12:20	#03	12	Graham Pollock	KidneyLink and KidneyPro: Online resources to enhance patient engagement in kidney research
12:20-12:30	#03	14	Moira McMillan	Patient Partner Input for Research into Northwestern BC Medical Travel

12:40-1:00	#03			*Optional Q&A/discussion with Posters 8-14 authors.*
	Jenny Cartwright			
11:30-11:40	#04	15	Jennifer Davis	*Patient-Reported Outcome Measures (PROMs) to Support Adherence to Falls Prevention Clinic Recommendations: A Qualitative Study*
11:40-11:50	#04	16	Tsion Gebremedhen	*Understanding research participation experiences among persons identifying as African, Caribbean, and Black in the Greater Vancouver Area*
11:50-12:00-	#04	18	Jude Kornelsen	*Fostering Meaningful Rural Citizen Patient Partner Involvement in Research on Costs of Travelling for Care*
12:00-12:10	#04	19	Vanessa Fong	*A patient-oriented approach to examining the meaning of family quality of life: A cross-cultural comparison of Korean immigrant families and Canadian families of autistic children*
12:10-12:20	#04	20	Heather Noga	*Piloting Digital Storytelling for Endometriosis and Painful Sex: Ethical Considerations and Emotional Impact*
12:30-1:00	#04			*Optional Q&A/discussion with Posters 15-20 authors.*

Abstract title	Abstract Submitter	Affiliation	Abstract
Exploring Conflict and Compensation in Patient-oriented Research: A scoping review	Banner-Lukaris, Davina	University of British Columbia	Introduction and Background: Patient-oriented research (POR) is a new frontier in health research and represents a significant shift in the way research is funded, designed, and implemented. Through meaningful partnerships with patients, community members, patient advocacy organizations (PAOs), and others, teams work to undertake research that meets the values and priorities of patients and is relevant and impactful. Despite its increasing popularity, the approaches and methods underpinning POR are still developing, including a sense of how conflicts of interest (COI) and compensation are addressed in the context of POR. Although the financial compensation of patients that participate within research teams and related activities is becoming a commonly accepted practice, there has been emerging criticism around the lack of transparency of funding practices. While there are clear guidelines regarding COI and compensation for physicians and researchers, currently little is known about how conflict and compensation are managed within the context of POR. Our project seeks to critically explore how COIs are defined, managed, and understood within the field of POR by focusing on their implications for research teams, including patient and community partners. Methods: Our collaborative team of patient partners, researchers and knowledge users conducted a scoping literature review to examine compensation and COI in POR. A search strategy was developed and peer reviewed and our initial search of eight databases yielded a total of 20,640 hits, 184 of which passed title and abstract screening, and 61 of which passed full text screening. All title and full-text screens were conducted by two independent reviewers and the emerging data were extracted using a standardized template and then analyzed thematically Results/Findings: While there were few articles that addressed POR directly, studies were identified that have explored how COI and compensation is addressed and managed across the stakeholder groups typically engaged in POR. Five main themes emerged as part of this review:

			1) Defining COI in the context of health research, 2) Understanding what constitutes COI, 3) Policies, guidelines, and management of COIs, 4) Implications of industry-academia partnership, and 5) COIs in POR. Compensation and COI remained a contentious issues and varied strategies to address these were identified in the literature, including limiting the percentage of funding from certain stakeholders, implementing independent monitoring systems and review boards, and committing to public disclosure and transparency of COIs in patient-oriented and health research. Discussion/Implications From the analysis of the literature, we found that there were few studies that explored compensation and COI within the context of POR and that there was an overall lack of guidelines and directives that were targeted to patients and patient-organizations engaging in health research. Our team are currently undertaking engagement and priority setting activities to address this gap and to develop useful tools for use by those engaged in POR.
ED2Foundry: Building a partnership between the emergency department and community health services for youth and young adults with mental health and substance use care needs	Barbic, Skye	The University of British Columbia, Department of Occupational Science and Occupational Therapy	Introduction and Background. In Canada, there is a profound disconnect between the Emergency Department (ED) and mental health services for young people. More than half of Canadian youth and young adults presenting to the ED with mental health and/or substance use (MHSU) challenges report no previous MHSU related-contact with the health-care system. Across British Columbia (BC), there is an immediate need to improve the ED assessment experience and referral process for youth to prevent repeat ED visits and hospitalizations, and to promote overall health and wellness. Our purpose was to build a BC-based partnership between a network of Eds (BC Emergency Medicine Network) and an integrated youth health services network called Foundry. We coalesced stakeholders (youth with lived experience and families, care providers, and community champions) across BC to inform the development of a clinical care framework (ED2Foundry) designed to improve the care experience in the ED and the transition from the ED to community health services (when appropriate) for young people requiring support for MHSU concerns. Methods: In Phase 1, we conducted a scoping review of the literature to understand the gaps in the assessment, treatment and follow-up of youth

			presenting to the ED with MHSU concerns. We used results to develop an interview guide in conjunction with a youth advisory committee. Using purposive sampling, we recruited BC stakeholders to understand their experiences receiving/providing ED services (Phase 2). We asked participants to share their ideal ED experience and to inform the development of ED2Foundry. We used inductive exploratory analysis to organize data into a clinical framework to describe the ED-to-community transition. Results: We interviewed 30 participants. Key themes included (1) timely access to developmentally appropriate ED treatment spaces, education materials, assessments and interventions that are fit for purpose for the community, (2) immediate connection for youth and families to community resources through peer support (3) development of feedback mechanisms for ED providers to support ongoing improvement in care, and (4) empowering youth to be leaders in the co-design of clinical care guidelines, health services and policies. Discussion/implications: The clinical care framework consists of age-appropriate screening in the ED, within ED-referral and connection to Foundry services, and active follow-up from a peer support system to help young people find the care, connection, and support they need. ED2Foundry represents an opportunity to address fragmentation of services to provide a safe transition to age-appropriate community MHSU care. Dissemination plan/KT Approach: We will leverage the Foundry Network and the BC Emergency Medicine Network to summarize findings, coordinate a provincial webinar, and develop a clinical care guide to share across BC communities. Youth from across BC will co-develop all materials with careful consideration to age, gender, and community needs.
Bridging the Digital Divide: A scoping review to understand the barriers and facilitators youth face in accessing	Ben-David, Shelly	UBC Okanagan	Introduction Mental illness affects approximately 1 in 4 Canadian youth and young adults (Kessler, 2005). Foundry BC, worked closely with Canadian youth to identify the need to understand how to navigate online mental health information. Young people are more connected to the internet than any other generation, with nearly all youth living in BC reporting using the internet for accessing health information. The purpose of this scoping review was to identify and summarize the currently available literature on the digital divide for youth accessing digital technology for mental health

digital mental health technology			purposes. The digital divide refers to the separation between those who have access to digital information and communication technologies and those who do not. This area of study is also a timely as COVID-19 has dramatically affected the need for, and access to in-person mental health resources for youth and young adults (Moreno et al., 2020). Methods The review was conducted in accordance to the Arksey and O'Malley framework (Arksey & O'Malley, 2005).The research team led by Drs. Barbic and Ben-David, youth research ambassadors, graduate level students, and the help of a UBC librarian performed a thorough search of Medline, EMBASE, CINAHL, PsycINFO, and Cochrane databases. A five-stage methodological framework to complete this review was conducted. Articles were included if published in the last ten years, and sampled youth that were accessing digital technology for mental health purposes. Results/Findings Researchers screened 11,811 studies, and 335 met criteria. Eighty-three percent of the studies were conducted between the years 2014-2020. The majority of the studies were conducted in Australia, USA, across multiple countries, United Kingdom, and Canada. Twenty-one percent of the studies consulted youth during the research process. Only 6 percent of the studies focused on diverse population such as housing insecure, LGBTQ2IA+, and Indigenous youth. The majority of the articles focused on general mental health needs, while others focused on specific mental health disorders such as depression, and anxiety. The most popular study designs included randomized control trials, reviews, qualitative, mixed-methods, and surveys. Topics included outcomes of digital mental health technology interventions, understanding user needs, and the digital technology help-seeking process. Discussion/implications Gaps that emerged from this scoping review are the basis of an upcoming qualitative study to understand the digital divide among youth accessing digital mental health technology in British Columbia. Youth research assistants will be involved at every stage of the research process. Future youth mental health research should consider thoughfully engaging youth partners in the research process, as their expertise in the subject matter improves credibility of the study findings. Research is also needed among diverse samples of youth to understand their specific experiences utilizing digital mental health

			technology interventions. Dissemination plan/KT Approach Integrated knowledge translation activities will include the development and testing of digital health literacy curriculum for Foundry centres across British Columbia. The findings will also be disseminated in journal articles, conferences, and World Cafés. The results will be used to directly inform the care of young people receiving services across British Columbia.
Culturally Safe Patient-Reported Experience Measurement (PREMs) to Improve Quality of Care Among Indigenous Peoples in BC	Bizzotto, Riley	School of Population and Public Health, University of British Columbia	ABSTRACT Background: Patient-reported experience measures (PREMs) are used to help drive improvements in the BC health system (Patient-Centred Measurement Steering Committee, 2019), yet there is a critical lack of Indigenous voices and experiences captured by these measures (Anderson, 2009; Smylie & Firestone, 2015; Rotondi et al., 2017). As a result, improvements in safety and access to care for Indigenous Peoples is hindered by this dearth of knowledge. The overarching objective of this project is to investigate how to make PREMs culturally safe and describe the processes undertaken to ensure the methods are decolonized, empowering and meaningful to Indigenous patients and communities. Methods: The present study is led by the First Nations Health Authority, the first of its kind in Canada with the mandate to improve the cultural safety of healthcare for First Nations in BC. A technical committee of Indigenous experts and individuals with lived experience will guide all aspects of this project to ensure the research is grounded in cultural safety and includes, Elders, Indigenous patient partners, and service providers. This project aims to decolonize PREMs, and will use a Two-Eyed Seeing approach, integrating Western and Indigenous knowledge and methodologies. Phase I includes a Western scoping review and qualitative interviews to be completed by fall 2020. The review will search the extant literature for culturally safe and informed ways to measure Indigenous patient experiences. This will be enhanced by qualitative interviews that will probe the knowledge of Indigenous patient partners, Elders/knowledge keepers, and health system partners of how to assess patient experience in a culturally safe way that is inclusive of both Indigenous conceptions of wellness and patient perspectives. Phase II will include a one-day gathering in the spring of 2021 that will validate Phase I findings among First Nations and Indigenous

			communities in BC. Results : The Phase II gathering will give attendees the opportunity to ground the Phase I findings in Indigenous experience and ways of knowing. This will ensure that the outcomes of this project are culturally safe, relevant, and meaningful to the Indigenous Peoples' of BC, and guarantee this work is done in a good way. Discussion: The results of this project will contribute to the nascent evidence-base for culturally safe healthcare experience assessments and research within BC health systems. This is the first step of a larger research agenda that will drive the implementation of cultural safety and humility at the structural, systemic, provider, and inter-personal levels in BC. The findings generated by this research project will ensure that quality data on Indigenous Peoples' health care experiences is community-driven and action orientated. Dissemination/KT: A plain language narrative summary, community report and journal publication based on the findings from the review and interviews will be presented to community at the gathering. With prior informed consent of the events attendees, the de-identified and contextualized findings will be included in the final report.
Can a patient/family-oriented discharge process improve the patient and provider experience of discharge from hospital?	Black, Agnes	Providence Health Care	Introduction and Background: An effective transition from hospital to home or community is an important influencer of patient safety and care experience, and a lack of confidence and understanding about what to expect at home can lead to unnecessary hospital readmissions. Patients and families need support at discharge from acute care. Survey results in 2016-17 showed that at our hospital only 55% of patients felt adequately prepared at discharge. Methods: On two medical units at an acute care hospital, we tested an intervention to improve patients' preparation for discharge home from hospital, as well as clinicians' experience of the discharge process, and 30-day readmission rate. The intervention included: • A patient-oriented discharge summary form (PODS), created with patient/family member involvement and used by the entire care team. • Patient and family caregiver involvement in the discharge process. • Use of teach-back (educational method) with patients and families at discharge. • Post-discharge follow-up contact with patients. Results: Evaluation results show approximately 60% of patients are discharged using the new form and process, and 87% of patients

			who received PODS indicated it was helpful. Survey results also showed 79% of patients reported feeling adequately prepared for discharge; this compares to 38% and 62% on previous, similar survey questions before PODS was introduced. In overall hospital experience, 60% of patients reported the top two scores (scores of 9 or 10 of a possible 10), compared to 50% of patients in the 2016-17 survey. Patient and family member comments collected through post-discharge follow-up phone calls overwhelmingly illustrate patients' appreciation for these calls. More than half of providers (57%) stated that when using PODS they were more confident patients were adequately prepared for discharge. Providers also reported PODS helps them to be more effective in their job (53% Mar 2020, improved from 29% Sep 2019) and fewer providers report being dissatisfied with the discharge process (6% Mar 2020 vs 24% Sep 2019). After implementation of PODS, 30-day readmission rates on the project units showed a decrease in readmit rate for the 50-59 age group. Discussion: New interventions were developed with Patient Family Partner collaboration to support healthcare leaders to enhance person and family-centred care, improve the discharge process from hospital to home, and reduce readmission rates. Implementation of PODS has demonstrated a measurable improvement to the discharge process in an acute care setting, from the perspectives of both patients and providers. The PODS process offers an innovative and now proven approach, and is easily adaptable to other healthcare settings. Dissemination Plan: Members of our team have presented project findings to numerous groups within our organization. Additionally, we led a one-hour session at the Quality Forum conference in Feb 2020, and we will conduct an oral presentation at the Institute for Patient and Family Centered Care conference in August 2020. The PODS project was selected for the Partnership Award from the Institute for Patient and Family Centered Care in 2020. We are planning a publication.
Personal Health Records: Contrasting Views	Burton, Lindsay	University of British Columbia - Okanagan	Introduction: Rural Canadians have an increased prevalence of chronic disease multimorbidity. Personal health records (PHRs) have demonstrated benefits for patients with chronic diseases, such as diabetes and hypertension. With planned implementation of a PHR in primary care

of Rural Patients and Providers			networks in several rural communities in British Columbia, Canada, the purpose of this study was to explore patients' and primary care providers' perspectives on PHRs using focus groups to identify gaps responsible for slow uptake and ultimately optimize PHR implementation. Methods: Patient and provider focus groups were carried out in the Kootenay Boundary Region in British Columbia, Canada. Groups were asked questions about their understanding of PHRs, perceived values, and desired features of PHRs, and their interpretation and perceptions of the benefits of patient-generated data. A qualitative descriptive design was used to interpret patient and provider perceptions of PHRs without the imposition of a pre-existing framework. Results: Focus groups consisted of one patient- (n=9) and five provider- (n=17) focus groups. Patients and providers shared similar, but subtlety different views and understandings of PHRs based, in part, on their different contexts, exposures, and experiences with PHR features. Two central themes were identified: 1) patient-oriented focus, yet with differing orientations to types of patient-reported data valued and who had control over the PHR, and 2) information sharing while needing to identify boundaries in communication. Discussion: Findings from this study showed that patients and providers agreed on the patient-centredness and information sharing opportunities of the PHR but their orientations to patient-reported data, PHR control, and the nature of the boundaries differed. Considering the higher prevalence of chronic disease multimorbidity, unique obstacles, and documented lower PHR engagement in rural settings, understanding the views shared in this study can assist in optimizing implementation and use of upcoming PHR systems. KT Approach: Academic partners will share these learnings through regional and provincial academic presentations, publication of manuscripts, social media, as well as sharing through faculty websites. Interior Health and Kootenay Boundary Division of Family Practice will also share these learnings through their standard communications processes including monthly meetings, mailing lists, and community newsletters.

Virtual Health Use During COVID-19 by Rural Practitioners	Burton, Lindsay	Kootenay Boundary Division of Family Practice	Objective: COVID-19 has rapidly changed how healthcare is delivered in British Columbia. While virtual care is has been usedtilized to overcome geographical barriers andor for specific chronic disease management, the escalation in virtual care in order to protect the safety of patients and health care providers, during the COVID-19 pandemic is unprecedented. The purpose of this study is to evaluate virtual care use rates, experiences and challenges of physicians, nurse practitioners and midwives during the COVID-19 pandemic. Methods: Cross-sectional survey of primary care physicians, specialists, nurse practitioners and midwives within the Kootenay Boundary Health Region. The survey captured six dimensions: (1) provider demographics, (2) virtual care platform, (3) experience and satisfaction, (4) plans for future virtual care, (5) potential to facilitate increased patient attachment, and (6) patient use of other virtual health services. Results: Sixty-five practitioners completed the survey. Majority of practitioners used the telephone as their primary virtual care platform, however 60% used a combination of video and telephone. For approximately half of practitioners, patient preference and , comfort, and ease with technology, and reason for visit wereas the main deciding factors for use of video or telephone. Practitioners reported several value-adds of video including: specific visualization for physical exams, relationship building, and general assessment of patients. Other than minimizing COVID-19 risk and use of PPE, providers felt benefits of virtual care were largely for patients, including: no travel and more convenient times for patients. The majority of practitioners indicated that they would do more virtual health visits in the future once the COVID-19 pandemic is over. Discussion: Understanding practitioner use and challenges during rapid uptake of virtual care is critical to the sustainability of ehealth solutions. Practitioners were enthusiastic about virtual care and expressed interest in continued use past the pandemic response. Practitioners also saw benefits to their patients in utilizing virtual- care options. Results from this study will be used to provide supports and solutions for virtual care use in the KB region as well as the optimization of virtual care in rural communities. KT Approach: These findings will be disseminated by the Kootenay Boundary Division of Family Practice for

			project planning, project evaluation and improving the supports offered to Kootenay Boundary providers to support the utilization of virtual health. Results will also be submitted to peer-reviewed journal. Broader audiences will be reached through creation of an infographic.
Rural Community Responses to COVID-19 in British Columbia	Carthew, Christine	University of British Columbia	Background The Rural Evidence Review (RER) project, a Centre for Rural Health Research initiative, has funding under Canada's Strategy for Patient-Oriented Research and the Rural Coordination Centre of British Columbia (BC) to work together with rural patients to provide high-quality, useful evidence for rural healthcare planning in BC. The project was born out of a recognition for the importance of rural patient voices in health planning and a commitment to actualizing this principle through research. The RER is built on regular and reciprocal engagement with rural patients across BC. Three Rural Citizen Advisory Committees bring together rural patients (n=36) to support the project to understand and action rural healthcare priorities through research. The Committees were instrumental in conceptualizing the 'Rural Community Responses to COVID-19' survey study. During Committee meetings in March 2020, members spoke about their communities' experiences of COVID-19 and identified a gap in available information and knowledge: the experiences of other rural communities across BC, including community strength and innovation in response to the pandemic. Methods To address this knowledge deficit, the RER in partnership with the BC Rural Health Network (BCRHN) - a network of rural healthcare advocates (patients) across BC - implemented the targeted distribution of an online survey to learn from rural BC patients and communities about their experiences and responses to COVID-19. The survey was shared to Rural Practice Subsidiary Agreement communities through local newspapers and radio stations, community-specific Facebook groups, and local elected council and Chambers of Commerce. We received a total of 562 responses from patients across 144 communities, between April 17 and June 23, 2020. The data were analyzed using quantitative and qualitative methods, led by the RER and in collaboration with BCRHN key stakeholders. Findings The impacts of the pandemic on participating rural communities were physical, mental, social and financial in nature. For instance, respondents expressed fear and

			frustration in response to the threat of the coronavirus, and described feeling isolated as an outcome of concomitant public health protocols, including social distancing. At the same time, respondents explained that the pandemic led to a banding together of their communities to boost morale and to support those in need. Participants offered detailed accounts of the multiple activities and innovations that emerged in response to the pandemic, to support those at risk and to build community spirit. These included, for example, adopt-a-neighbour and senior watch programs, vehicle (drive-by) parades to celebrate community birthdays and to show appreciation for essential workers, delivery services for groceries and other supplies, virtual fitness classes, concerts, book readings, and more. Implications of Findings We recognize the importance of local ("ground up") solutions to address the healthcare challenges and priorities that rural BC communities are facing, including COVID-19. This survey study has rigorously captured and documented rural resilience and innovation in the face of a global pandemic. Knowledge Translation The findings will be shared across rural and remote BC communities to support and promote learning and collaboration.
Connecting Experience to Research: A review of different approaches to patient engagement in BC	Cheah, Stefanie	Island Centre	Engaging patients and public as partners across the health research continuum is core to Canada's Strategy for Patient-Oriented Research. Despite broad support for engagement across all stakeholder groups, there remains no clear gold standard for how it is done. Groups such as the BC SUPPORT Unit regional centres and the Patient Voices Network have developed strategies to best support stakeholders in effectively recruiting, training, and supporting patients to become part of a research team. REACH BC - a new online platform developed to provide British Columbians the ability to find and connect with health research opportunities, including COVID-19 specific research – further expands the possibilities for engagement. This panel presentation will review the different strategies employed by each group and compare early results from the launch of REACH BC on their existing activities. BC Patient Safety Quality Council | Patient Voices Network (PVN) A review of the historical processes in which PVN supported researchers and patient partners in patient-oriented

			research. These methods included, engagement planning support for health researchers, engagement record management, posting POR opportunities to the PVN membership, patient partner orientation, introduction to researchers, and follow-up on the engagement experience. REACH BC REACH BC is a new online platform for British Columbians to connect to health research opportunities as a research participant or patient partner. REACH BC raises awareness of POR and opportunities for patient partners through the public directory of active research projects in the province. A customized matching engine allows individuals with a REACH BC Volunteer profile to be notified of new research opportunities that match their health interests and eligibility. Early results show British Columbians are interested in becoming patient partners and are successfully using REACH BC to get connected to research teams conducting POR. Fraser Centre. The Fraser Centre is a collaboration of Fraser Health and Simon Fraser University. Our centre provides support services to all academic and health authority researchers working in the Fraser Valley, as well as members of the public interested in engaging with research. Activities include supporting researchers in developing patient engagement plans that cover how to recruit, train and support patients to become part of a research team, knowledge translation and research methods and navigation. The Fraser Centre has incorporated REACH BC as a tool to enhance existing strategies by supporting researchers with the posting of research projects that seek partnerships with patients in everything from setting research priorities and research questions, designing research methods, research governance, participating on research teams and publishing results. Island Centre Vancouver Island Centre connects researchers, clinicians, and health system decision makers with patients and families living in the area served by Island Health, and offers services to support and increase POR in the region. The Island Centre takes a hands-on approach to supporting teams to work together as partners throughout the research process. Training in POR, planning, recruitment, onboarding, and meeting facilitation are just some of the services offered. REACH BC is the newest support tool they've added to their arsenal!

The Tapestry Project: Methods for Supporting Diverse Patient Engagement in Research in a Diverse World	Cheung, Iva	UBC Department of Psychiatry	Introduction and background The BC SUPPORT Unit Patient Engagement Methods Cluster undertook an extensive consultation [1] involving patients, researchers, policy makers, health care service providers, health research funders, and other community stakeholders to identify compelling patient engagement research to support across our province. A prominent theme of that consultation was that patient engagement in research must embrace diversity. The consultation found that, among patient partners engaged in research, certain populations were routinely underrepresented. Knowing how to identify and address the barriers that these populations face in accessing research opportunities may help research teams increase diversity and equity among the patient partners that they engage. Methods Four teams, each including at least one patient partner as well as an academic researcher, were formed to create video-based educational modules to help research teams engage these underrepresented populations: (1) LGBTQ2S+ communities; (2) rural and remote communities; (3) Deaf and disabled communities, and (4) immigrant, refugee, ethnocultural, and racialized communities. The patient partners—and, often, the academic researchers—had lived experience as members of at least one of these underrepresented communities. A fifth team developed a module that would serve as a primer to the topic of diversity and equity in patient engagement in research. Teams performed environmental scans to find existing resources and identify knowledge gaps, then wrote scripts and developed storyboards for the educational videos. These videos will be hosted on the Tapestry platform, which presents them in thematically linked webs. Once complete, these videos will be evaluated for their engagement and knowledge transfer impact with academic and patient partner researchers. Results/findings The evaluation has not been completed, but by the time of the conference we will be able to share some of the educational videos and discuss the patient engagement process involved in their creation. Discussion/implications These videos offer a launching-off point to discuss diversity in patient engagement from the perspectives of underrepresented communities. They explore the barriers to patient engagement and some ways to overcome these barriers while issuing a call to action to research teams to more

			actively advocate for participatory equity at a systemic level. These educational modules acknowledge that they reflect some underrepresented perspectives but not all, but the Tapestry platform offers a flexible way to invite community co-creation of new resources for each module or new modules to continue the conversation into the future. Dissemination plan/KT approach After the modules have been evaluated, they will be launched to the public through social media and via the vast social networks of the project's team members.
Patient-Reported Outcome Measures (PROMs) to Support Adherence to Falls Prevention Clinic Recommendations: A Qualitative Study	Davis, Jennifer	University of British Columbia - Okanagan	Purpose: Our goal was to examine how patient-reported outcome measures (PROMs) may support patients' adherence to fall prevention recommendations in a novel primary care setting – the Falls Prevention Clinic. Patients and methods: Using a patient-oriented qualitative study design, patient partners were recruited to our study team and assisted in developing focus group prompts. A trained facilitator conducted five semi-structured interviews with a total of 21 Falls Prevention Clinic patient participants. Patient participants were prompted about: their views on the EuroQol 5 domain – 5 level (EQ-5D-5L) PROM, their preferences for administration and feedback, the presentation of questionnaire data, how useful comparative data and the EQ-5D-5L may be in improving adherence to recommendations, and any other information they would need to improve adherence. Patient participants' responses were coded according to the three stages of qualitative analysis: open, axial and selective coding using an iterative and comparative approach. Results: "Opportunity" and "Development" emerged as higher level themes for the patient participants' perspectives on how the EQ-5D-5L may be helpful for their appointments. "Frequency" described how often the patient participants' believed the EQ-5D-5L should be administered and provided with feedback. "Challenges", "Benefits", "Patients' Understanding", "Relevance of Data", and "Usefulness of Data" provided insight on how PROMs data presentation are viewed by patients. "Performance", "Resources", "Knowledge", "Role in Behaviour Change" highlighted the patient participants' ideas for the role of the EQ-5D-5L and additional information in supporting their adherence to falls prevention recommendations. Additional information that patient

			participants provided emphasized that patients' would value further support information to facilitate their adherence. Conclusion: This novel patient-oriented qualitative study among individuals at high risk of future falls, sheds light on the importance of timely, understandable feedback, integrated with other clinical feedback in supporting adherence.
Integrating Patient-Centered Measurement into Team-based Care Workflow	Davis, Selena	Patient Voices Network	Background: As BC transitions to a patient-centered mode of team-based care[1], methods to support shared care decision making with patients and their interdisciplinary team are needed. Patient-centered measurement (PCM) is one possible method and involves the integration of patient-generated data into regular care visits and decisions. Examples of patient-generated data include patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs), as well as patient's self-action plans. However, there continues to be conceptual, methodological, and logistical challenges in translating PCM into routine clinical practice [2-4]. Even when they are collected, patient-generated data may not be reviewed during regular care visits or tracked over time. Additionally, patient-generated data continue to be commonly collected through a paper-based format that limits its integration into electronic medical records and patient portals [5, 6].Providers also acknowledge being unable to effectively use and interpret these data due to a lack of technical and organizational resources [7]. Our PCM adoption methods aim to narrow these current gaps by offering a step-by-step guide on how PCMs can be integrated into the team-based care workflow. Objective: To develop new ways to incorporate patient-centered measurements into team-based clinical practice. Methods: We are employing an integrated knowledge translation (IKT) approach that actively involves patient partners, knowledge users, and researchers in all aspects of the study design. Across the planning, development, implementation, and evaluation phases, we are selecting from multiple study methods (mapping clinic workflow, interviews, document analysis, and practice reflection). Supported by a patient portal, PCMs for anxiety (GAD-7), depression (PHQ-9) and self-efficacy will be completed by patient participants. We will analyze how these patient-generated data can be integrated into clinic

			workflow to support patients' during, after and between their clinic visits. Synergies derived from this collaborative knowledge translation approach will enhance understanding of patients' and providers' context and needs, thereby enhancing the relevance of the generated research and increasing knowledge users' understanding of the research process, awareness of the research, and appreciation for how and when it can be applied [8]. Results: Challenges identified in integrating patient-generated data into practice included: limited resources to support quality improvement, current organizational changes in response to COVID-19, current fee structures, and patients' access to technology. We will present on how our IKT process is addressing these challenges by gaining patients' perspectives on their use of a patient-oriented portal, consulting with community quality improvement experts, and working with champions within a clinic setting. Conclusion: While the value of patient-generated data and the need for PCM methods of collecting, integrating, and using priority-driven patient-generated data in team-based care are well recognized, no actionable outputs exist. Through a collaborative effort we aim to address this gap and demonstrate how patient-generated data can be incorporated into clinical practice within a Canadian primary care team setting.
Using Face-to-face and Virtual Deliberative Dialogue to Develop Consensus in Patient-Oriented Research	DieBold, Andrea	Master of Social Work Student, University of British Columbia Okanagan	Introduction: To assist in eliminating existing gaps in the translation of knowledge to policy/ practice, the incorporation of integrated knowledge translation (IKT) ensures equitable engagement of knowledge users, including patients, as partners to generate applicable, useful and translatable findings 1 . As outlined by the BC SUPPORT Unit, patients include anyone with lived experience, family members and caregivers 2 . Consensus methods are identified as practical approaches to developing evidence-based solutions through the inclusion of priorities from various stakeholders. To produce effective patient-oriented outcomes, best interest solutions need to be co-created, agreed upon and supported by group members 3 . To better understand the utility of consensus methods for use in IKT and patient-oriented research, we are studying two consensus methods approaches; deliberative dialogue 4 (DD) and Delphi 5 , using both face-to-face and virtual modes of delivery. This presentation will focus on research

pertaining to the use of DD in face-to-face and virtual environments. Methods: To test the effectiveness of DD as a consensus method, both face-to-face and virtual sessions were conducted to elucidate findings within different contexts and issues. Prior to the DD, participating stakeholders were provided an evidence synthesis to inform and support the conversation. DD sessions took place over the duration of 2-3 hours using workshop style activities (e.g. small and large group discussion, priority setting) to discuss and identify appropriate actions to improve services and supports. To collect further feedback, a process evaluation questionnaire was dispersed to participants subsequent to the dialogue. Follow-up dialogues will take place to assess and re-prioritize stakeholder needs if applicable. Findings: One face-to-face DD and one virtual DD have been completed. Representation of researchers, stakeholders, decision makers and individuals with lived experience were present. Actions were developed from stakeholder priorities to improve service user care. Questionnaire results will help to further inform DD processes as a viable consensus method to use in health care improvements. Discussion: Testing DD in face-to-face and virtual contexts has allowed both researchers and knowledge-users to contribute and prioritize relevant needs. Furthermore, during the COVID-19 pandemic and social distancing, virtual DD has been identified as a practical solution to be able to bring together multi-stakeholder groups to act toward consensus on various issues, where a better understanding of how to best conduct effective dialogue is needed. Finally, stakeholder generated actions will contribute to informing policy/ practice within each of the organizations where DDs were held. Dissemination: This project works to study innovative research methods focused on consensus building in IKT. Engagement of patient-partners, researchers, decision makers, and health care providers through the DD process will facilitate outcomes that focus on patient-identified priorities. Results have been shared back with stakeholders involved in DD sessions through action reports for their validation and feedback. A final report will be completed and can be used by these groups to move actions forward. Results of the consensus process will be shared through presentations, and the development of easy-to-use tools

			for researchers, decision-makers, and patients to facilitate consensus building in the future.
EmPOwER: Engaging persons with cerebral venous thrombosis for meaningful outcomes and peer support	Dizonno, Vanessa	University of British Columbia, Vancouver Coastal Health	Background and Aim : Cerebral venous thrombosis (CVT) is a rare cause of stroke that most commonly affects younger women 1,2 . Although prognosis is "excellent" if using outcome measures from other stroke studies, this does not account for issues relating to chronic fatigue, headache, mood, and cognition that may significantly affect quality of life (QoL) 3-5 . We aimed to better characterize symptoms after CVT diagnosis and their impact on QoL to find patient-centered outcomes for future CVT trials. Method : The patient advisory committee was comprised of young stroke survivors, patient advocate, health economist, and healthcare providers and were consulted for their expertise and personal experience. The pre-forum survey was used to determine residual symptoms and effects on QoL in CVT patients; results informed the agenda and guided discussion during the patient forum. The forum was held on January 19 th , 2019 in Vancouver, BC for former CVT patients and their caregivers/loved ones. The following topics were discussed: a) CVT journey (personal objectives and peer support), b) Knowns and unknowns, c) Wellness (pharmacological and non-pharmacological strategies), and d) Online resources and website feedback. Results : The pre-forum survey was completed by 27 respondents, with almost all experiencing residual symptoms like headaches. Forum participation included 28 attendees comprised of CVT survivors and their loved ones, healthcare providers, and researchers. Uncertainty around the disease and recovery was discussed, and the idea of (re)defining normalcy was recognized. Patients shared their experience with exercise, mindfulness, and sleep as therapeutic strategies for wellness. Resources for patients, caregivers, and non-neurologists were lacking, necessitating a need for knowledge translation and lay language materials. Implications : The planning and dissemination activities of this project has widespread implications, impacting stroke research, clinical practice, and the public. Firstly, patients with a rare disease were connected in-person and online through the website for development of a peer support network. As was articulated during the forum, patients found it difficult to locate CVT-specific

			resources, so peer-to-peer knowledge exchange is both helpful and empowering. Secondly, the results from this project will inform outcomes for future Phase III trials (e.g., SECRET) that are both meaningful for patients and clinically relevant. Feedback from the advisory committee and study participants will be integrated into study design after completion of the feasibility pilot phase. KT Approach : EmPOwER has led to development of resources specifically for CVT including a website and lay language materials. The structure and objectives of the forum have been discussed as a model for future patient engagement in research by the Heart and Stroke Foundation, and an online educational module on Canadian Stroke Consortium website.
Towards equity-informed care: A co-development process for meaningful patient-reported evaluation of care for persons experiencing structural vulnerability and chronic illness	Donald, Erin	PhD(c), RN, School of Nursing and Institute on Aging and Lifelong Health, University of Victoria	Introduction and Background: People who face structural vulnerabilities (i.e., homelessness, poverty, criminalization, racism, and stigma) and who also have chronic illnesses (such as lung, liver, or kidney disease) face severe disadvantages as their health declines. These systemic and social inequities can lead to multiple unmet health needs, lack of trust in the health care system or its providers, and feeling judged related to intersecting vulnerabilities such as mental health issues or substance use 1–7 . Research that our team has done suggests that the perspectives of people who face such inequities are seldom considered, especially when they interact with health care providers 8–10 . Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) offer a potential avenue for making the needs and concerns of structurally vulnerable persons visible within the health care system. Though PROMs and PREMs have yielded benefits in other populations 11–14 , there is minimal empirical research informing how this could be accomplished with persons who are marginalized by the health care system. Methods: The aim of this study is to advance methods in the implementation of PROMs and PREMs with people experiencing structural marginalization and chronic illness. This three-phase research study engages persons with lived experience of homelessness and chronic illness as meaningful contributors throughout the research continuum. This presentation describes a patient-oriented co-development process for a phased study testing PROMs and PREMs in a population of

			persons accessing care at an inner-city community health centre in British Columbia. Findings: Over the course of eight two-hour meetings, a small advisory committee of persons with lived experience met virtually with two research team members and a co-chair with lived experience. Small group size and longer meeting times provided an opportunity for a close team relationship to form. Advisory committee members elaborated on the meaning of key PROM and PREM concepts, including quality of life and quality of care, in the context of homelessness, poverty, and intersecting vulnerabilities. Several existing PROM and PREM tools were discussed for relevance; and strengths, weaknesses, and opportunities for adaptation were proposed. Experience measures were identified as a top priority by advisory committee members; as were relational PROM and PREM measures including being listened to, being treated with dignity, having a trusting relationship with health care providers, and having overlapping health issues addressed at one site or in one visit. Implications: In Phases Two and Three, the advisory committee will continue to work with the research team as two to three PROMs and/or PREMs are selected and trialed at an inner-city community health centre. By identifying PROMs and PREMs that are relevant and meaningful, this study will assist knowledge users, researchers, and persons with lived experience trying to give voice to and make visible needs, experiences, and outcomes for persons experiencing structural vulnerability and chronic illness. KT Approach: In partnership with the advisory committee, local, national, and international knowledge translation strategies are planned. These include plain-language summaries, presentations and outreach to provincial and national clinicians and decision-makers, and publication in academic journals.
Improving Treatment Together: Evaluating Youth Engagement in Co-Designing and Informing Health	Ewert, Alayna	Foundry	Introduction and Background The goal of the Improving Treatment Together (ITT) Project is to improve experiences and outcomes of health and social services for young people who use opioids, their families, and the health service providers who deliver services. The project aims to achieve this goal by developing youth-centered and evidence-informed products for opioid use treatment services provided to youth in Alberta and British Columbia. These products will be implemented and evaluated cross-provincially in

Services Interventions for Youth Who Use Opioids			participating communities. The project utilizes a community-based co-design framework that positions these stakeholder groups as the experts in identifying and designing solutions to improve current-state treatment services. The presentation will explore findings from the evaluation pertaining to youth engagement including YTM involvement in the project planning and facilitation process as well as youth participation in the co-design sessions. Methods The ITT project held four workshops with youth (n=13) that incorporated elements of both community-based participatory research and human-centred design. Four YTMs supported the planning and facilitation of these sessions. The thirteen youth who participated in the session described their experience with youth substance use services to help identify specific needs or improvement opportunities in their community. The workshops concluded with a design component where participants developed products that would address the identified needs. As part of the evaluation, feedback surveys were administered to youth participants and in-depth, semi-structured interviews were conducted to learn more about the YTM experience contributing to the project. The Public and Patient Evaluation Tool (PPEET) was adapted and administered to all youth participants after the co-design session to collect feedback on their experience. Results/Findings A total of four YTMs participated in the evaluation, while two youth completed the co-design feedback survey. We will discuss learnings from the feedback received from youth participants and YTMs. Themes around diversity, solutions-focused activities, supporting youth in project-based work, and supporting youth participation in co-design will be explored. Discussion/implications The feedback from youth participants and YTMs will be shared and reviewed by the project team to improve the engagement of young people for Phase 2 of the project. Phase 2 involves the implementation and evaluation of the interventions emerging from the co-design process in Phase 1. Dissemination plan/KT Approach The evaluation findings from the ITT project will be summarized in a final evaluation report to be disseminated to project stakeholders and funders. This project represents one of several initiatives within Foundry that is building capacity to incorporate community-based design methods to inform

			ongoing service model design, implementation, and youth engagement improvement efforts in order to improve experiences and outcomes for our clients and their families.
A patient-oriented approach to examining the meaning of family quality of life: A cross-cultural comparison of Korean immigrant families and Canadian families of autistic children	Fong, Vanessa	Simon Fraser University	Introduction A number of measures exist to assess family quality of life (FQOL) in the context of raising a child with a disability. Recently, there has also been a growing number of studies translating and using these measures cross-culturally. However, despite the widespread use of these assessment tools, questions remain over the applicability and validity of these measures in non-Western contexts;(Ajuwon & Brown, 2012; Hu, Wang, & Fei, 2012). If FQOL measures and tools, which are primarily developed in Western societies, are to be used cross-culturally but do not include domains valued by diverse families, practitioners and service providers will fail to address the specific needs of such individuals and families. Thus, the current study sought to examine and compare conceptualizations and descriptions of FQOL from the perspectives of Korean immigrant and Canadian families of children with ASD. A patient-oriented approach was used to address the main research question with the Korean immigrant sample. Although this is one of the largest immigrant groups in Canada, they are a hard-to-reach community and highly underrepresented in autism research. An engagement approach was used, collaborating with a member of the Korean community to help bridge this gap, strengthen relationships, and promote shared ownership of the research. Methods: The current study engaged one parent partner from the Korean community who is a parent of an autistic adult and also the Executive Director of the non-profit organization, Here and Now. Here and Now supports families of children with disabilities by providing informational workshops for parents, programs and future planning, and networking opportunities for families to connect with resources and meet other families in their community. The Executive Director has been engaged in all aspects of the research process, including setting research priorities, developing the research question, recruitment, translating study documents, and implementing the study by co-interviewing participants. A qualitative design was used to answer the main research question. Semi-structured interviews were conducted with 13 Korean immigrant parents and 15

			Canadian parents of autistic children living in BC, Canada. Data were analyzed using NVivo software using a thematic approach. Results : For Korean immigrant families, three themes were identified: family cohesiveness, value orientation, and acceptance from society. For Canadian families, themes comprising family interactions, support, emotional well-being, individual characteristics, and comparisons to other families were essential elements in defining their FQOL. Discussion: The findings emphasize how differences in culture may impact how we understand and assess family functioning and quality of life. If research informing the development of these tools lacks cross-cultural perspectives, service providers and professionals may fail to address these families' unique needs. Dissemination plan: Researchers and our parent partner will collaborate in ensuring that participants' views and perspectives are accurately represented and will be invited to present at conferences and workshops alongside the researcher. Our parent partner will also be engaged in creating the poster presentation to increase the accessibility and relevancy of the research findings.
Patient Oriented Predictive Modelling of Healthcare Utilization (POPMHU): Developing a Shared Language through a Collaborative Team Wiki Page	Freeman, Shannon	Assistant Professor, University of Northern British Columbia	Introduction : Patient-oriented research brings together diverse individuals to inform and direct research. This heterogeneity is a strength but can also present challenges. Meaningful engagement in research is contingent on understanding and effective communication between all participants. For this, a shared language is necessary. Patient-Oriented Predictive Modelling of Healthcare Utilization (POPMHU) is a transdisciplinary research project involving members from the disciplines of health sciences and computer sciences and patient partners with backgrounds in fields of nursing, physiotherapy and engineering. To develop a shared language, our research team co-created a collaborative Wiki page. Background: Patient-Oriented research seeks to involve patients in research as equal partners. This differs from other approaches to research where power lies with the health expert or researcher, creating a hierarchy and divide between professional and patient (Lee & Garvin, 2003). This power difference can be sustained through the use of expert language or jargon, creating barriers to knowledge and information (Lee & Garvin, 2003). The Strategy for Patient-Oriented

			Research framework identifies the need for meaningful engagement of patients in health research in order for health research to meet the needs of Canadians (CIHI, 2015). A shared language is key to collaboration, an essential principle of patient engagement in research (Thomas & McDonagh, 2013). In healthcare, a shared language has been shown to lead to better interprofessional collaboration, higher quality of care and job satisfaction (Stuhlinger, Schmutz & Grote, 2019). The development of a shared language is a process requiring intentionality and time (Thomas & McDonagh, 2013). We used the development of a wiki page to generate dialogue and to promote understanding between team members which benefited the research process. Methods: A wiki, a website designed for collaborative use, was created for the POPMHU project using the MediaWiki software framework. Patient partners actively participated in an online tutorial on how to set up an account, navigate and edit the Wiki. Individual consultation was offered along with a step-by-step usage reference document. Patient partners were supported and encouraged to add to the Wiki page themselves, with the option to pass on their desired additions to a research assistant if preferred. In particular, they were encouraged to identify terms and abbreviations that require clarification to be added to the Wiki, e.g., as they emerged from reading material and team discussions. Findings : The website is accessible at http://popmhu.ca. Together, our team has assembled two pages of definitions for specialized vocabulary; currently the Terms page contains 33 entries, and Abbreviations contains 38. We continue to update and adjust the wiki based on team member input. Discussion/implications : The development of our wiki opened up dialogue around language we used as a research team. Patient partners were actively involved in this process. The POPMHU Wiki provided a practical and simple way for a shared language to be implemented by a transdisciplinary research team. Dissemination plan/KT Approach : The wiki itself will be used for knowledge translation moving forward. We will include a link to the website in communications about our project.
Understanding research	Gebremedhen, Tsion	Simon Fraser University	With the widespread social uprising against racial injustice, health researchers must stand in solidarity with, and listen to the needs of African,

participation experiences among persons identifying as African, Caribbean, and Black in the Greater Vancouver Area			Caribbean, and Black (ACB) communities. Racism is a social determinant of health and anti-racist practice is vital for public health equity. We have had difficulties engaging ACB communities in previous studies examining health for women living with HIV (WLWH) 1,2 ; local ACB leaders have suggested this is partly due to HIV stigma and unfamiliarity with research. This is an equity concern: ACB women comprise >35% of WLWH in Canada and may experience aging and comorbidities differently 3,4 . We must collaborate with ACB communities to better engage ACB WLWH in research; understanding research participation experiences, including barriers and facilitators to meaningful participation, is imperative to supporting research engagement and value. The findings of this project will help delineate individuals' experiences with research, explore potential ways to eliminate barriers, and establish future research priorities for ACB individuals and communities, thereby informing patient-oriented research. Methods: We are developing a survey by, with, and for ACB communities in the Greater Vancouver Area (GVA) to request community input on research experience, barriers to research engagement, recruitment strategies, approaches to lessen HIV stigma, and future research priorities. We will disseminate a workshop on research methods, participant rights, and explore potential benefits to participation to build research capacity for ACB WLWH . When piloting the survey, we will incorporate feedback from members of ACB communities, including our partners at the Afro-Canadian Positive Network of BC (ACPNet), to ensure that our questions can truly capture our communities' experiences. We anticipate that considerable recruitment will occur through word of mouth. The survey includes important educational information to support learning for participants, on the topic of HIV, for example the concept of Undetectable=Untransmittable (U=U). We will use descriptive statistics to summarize all study results, diagnostic statistics to draw correlations between questions with non-binary responses, 2-sample t-tests for binary responses, ANOVA analysis wherever we use t-tests, and finally Chi-squared tests for categorical data. We will engage community members at all stages of this project, through dissemination of the survey, data analysis, as well as ongoing knowledge translation and exchange (KTE)

			activities. Results: Persons who identify as ACB will indicate potential barriers and recruitment strategies for engaging ACB communities in research. We will identify themes among specific groups (ie: age groups) regarding barriers to, or experiences with research in general. Discussion: The findings will elucidate barriers to engaging in research that members of ACB communities face, while highlighting approaches to encourage future participation. Furthermore, the learning opportunities in this survey may facilitate future discussions and capacity building opportunities. These results will help researchers adopt anti-racist practices to better engage with members of ACB communities, and to build trusting and lasting relationships together. KTE Approach: All results will be shared with the community, researchers, and academia via community gatherings, abstracts, conference presentations, and a manuscript. KTE activities will be conducted on an ongoing basis, in collaboration with the community.
Development of the Valuation of Lost Productivity Questionnaire for Caregivers	Gelfand, Aaron	Centre for Health Evaluation & Outcome Sciences	Background: The Valuation of Lost Productivity (VOLP) questionnaire was initially developed to measure and value work productivity losses in terms of work time losses and associated costs in people with health problems. These losses include work stoppage, absenteeism and presenteeism (reduced work productivity while at work). However, people with health problems often require time from their family members or friends (caregivers) to take care of them. These caregiving responsibilities can affect the caregivers' work productivity. Existing questionnaires that assess the time spent by caregivers on caregiving responsibilities and caregiver work productivity losses have limitations. Also, it is important to involve caregiver partners in developing such questionnaires. Using a patient-oriented research approach, we adapted the VOLP into a caregiver version to capture time spent on caregiving and work productivity losses of caregivers. Methods: After reviewing the VOLP and other existing questionnaires measuring caregiver work productivity losses, the research team (including two caregiver partners) developed an initial draft of the questionnaire. This was improved using one-on-one interviews with caregivers, and circulated amongst the team once more, providing feedback on any changes necessary. It was converted to an online format using Qualtrics, and underwent further one-

			on-one interviews with caregivers to test and improve it. Interviewed caregivers were recruited through existing networks with the BC SUPPORT Unit, Family Caregivers of BC, posters at medical clinics, doctor offices, and large social gathering sites, including coffee shops and community centers. We defined caregivers as individuals currently caring for a family member or friend living with a chronic condition. Results/Findings: The first round of interviews involved 7 caregivers, while the second round involved 3. Participant demographics covered a diverse sample, including varying ethnicities (50% European, 10% Hispanic and 30% East Asian), and age groups (20% 30-39, 50% 40-49 and 30% 50-59). Major team discussion changes included the addition of volunteer activities, and lost job opportunities. Both rounds of interviews saw several issues brought up by multiple participants. Major issues during the first round involved recall periods, and quantifying time spent on emotional support. Our second round focused more on the ease of online use, and saw fewer issues with content. The most common issues involving work productivity loss revolved around their recall periods. Discussion/Implications: Participants had issues with workplace and volunteering recall periods, believing that asking for information on the past 7 days was not a good representation, compared to the average 7 days. We chose not to change our recall here to ensure consistency, as it would be impossible for us to know how each individual calculated this average 7 days. Participants had issues quantifying time spent on emotional support. This was expected as it can be subjective and potentially overlap with other fields. This was addressed by rephrasing the examples to better illustrate what we were interested in. Many issues brought up in the second round were addressed by formatting alteration, such as highlighting key phrases. Dissemination Plan: Knowledge dissemination will go through various organizations, e.g. BC SUPPORT Unit, CHÉOS, journal publication and conference presentations.
Preliminary Validation Results for the Valuation of Lost Productivity	Gelfand, Aaron	MSc student at the School of Population and Public Health	Background: The Valuation of Lost Productivity (VOLP) questionnaire was initially developed to measure and value work productivity losses in terms of work time losses and associated costs in people with health problems. These losses include work stoppage, absenteeism and presenteeism (reduced work

Questionnaire for Caregivers			productivity while at work). However, caring for people with health problems affects the work productivity of their caregivers. Existing questionnaires assessing caregiver work productivity losses have limitations, namely, their presenteeism measurement method, a 0-10 scale. This can lead to larger time loss estimates of presenteeism compared to direct time estimate methods. We adapted the VOLP into a caregiver version to capture work productivity losses of caregivers. Methods: After reviewing the VOLP and other existing questionnaires measuring caregiver work productivity losses, the research team developed an initial questionnaire draft. This was improved using one-on-one interviews with caregivers and converted to an online format using Qualtrics. The Work Productivity and Activity Impairment (WPAI) questionnaire for caregivers was included to test validity. The online version was administered to 400 caregivers in Canada, recruited through a market research company, using pre-defined quotas. We defined caregivers as individuals caring for a family member or friend living with a chronic condition. Main outcomes included VOLP and WPAI presenteeism and absenteeism, the latter measured using work time missed, differing in recall period (3 months vs. 1 week, respectively). VOLP presenteeism was measured using a direct hour estimating method. WPAI presenteeism was measured using a 0-10 scale method. Validation methods were similar to the VOLP patient version and interpreted using standard definitions. Results/Findings: Initial results found low correlations between VOLP and WPAI outcomes, observing a higher correlation between absenteeism (0.49) than presenteeism (0.36). Correlations between VOLP outcomes and time spent on caregiving responsibilities (caregiving hours) ranged from negligible to low, with a higher correlation for absenteeism (0.39) than presenteeism (0.22). Correlations between WPAI outcomes and caregiving hours ranged from negligible to low, with a lower correlation for absenteeism (0.27) than presenteeism (0.35). Controlling for care-recipients' condition severity resulted in illogical correlations trends. Dividing groups by severity resulted in negligible effect size. Dividing groups based on the median of caregiving hours resulted in small effect sizes. Discussion/Implications: Correlations between the VOLP and WPAI were higher than those between VOLP and

			other measured outcomes. However, the lower correlations between VOLP and WPAI presenteeism may reflect differences in measuring presenteeism. The findings are consistent with previous validation results for VOLP patient version. The stronger correlation between VOLP absenteeism and caregiving hours than WPAI absenteeism may be attributed to different recall periods. The weaker correlation between VOLP presenteeism and caregiving hours than WPAI presenteeism may again reflect their different constructs. The low discriminatory capability estimated by the effect size for condition severity, and the illogical correlation trends may be due to the small subgroup sample sizes or indicate the difficulty caregivers have in assessing the severity of their care-recipients' conditions. Dissemination Plan: Knowledge dissemination will go through various organizations, e.g. BC SUPPORT Unit, CHÉOS, journal publication and conference presentations.
Lessons Learned in Tertiary Mental Health Treatment: Patient Experiences of Virtual Care during the COVID-19 Pandemic	Geller, Josie	St. Paul's Hospital, Providence Health Care / Department of Psychiatry, University of British Columbia	Significance: There is great need to optimize virtual care delivery in Canada due to the COVID-19 pandemic. As face-to-face contact is dissuaded, the health research community across BC has been encouraged to learn effective ways of meeting patients' health care needs (MSFHR, 2020). This presentation provides preliminary findings from a new survey assessing patients' experiences of virtual care in a tertiary mental healthcare setting, the Provincial Adult Tertiary and Specialized Eating Disorders Program (PATSED). PATSED 's multidisciplinary team (e.g., Psychology, OT) treats individuals with severe eating disorders from across the province. Our research team conducts Continuous Quality Improvement research in collaboration with its Patient and Family Advisory Committee (PFAC). In the wake of COVID-19, all PATSED treatment was modified to be offered virtually, and its research infrastructure was adapted in order to assess patients' experiences of this new way of delivering specialized tertiary care. Methods: Patients enrolled at PATSED from March 16 to the present were invited to complete an online survey evaluating each virtual program component on the following dimensions: usefulness, satisfaction, and perceived benefit of continuing post pandemic. Participants were prompted to respond to open-ended questions on the benefits and drawbacks of each newly adapted component. Finally, they reported the degree to which they

			experienced virtual care-related challenges. Results: Preliminary results from 35 individuals indicated variability in responses across treatment types (e.g., assessments, individual and group treatment sessions), suggesting different aspects of care were more suited to virtual delivery. Individual treatment received higher ratings than group treatment, and psychiatric follow-up sessions were rated more positively than medical follow-up sessions. Patients cited main benefits of virtual care to be savings of time and money. Drawbacks included technology issues (30%) and concerns about confidentiality (21%). Patients also listed lack of privacy at home, and difficulty managing competing demands, such as child care, as other challenges. Data collection is ongoing. While this data was collected in a specialized eating disorders program, there may be value to adapting the survey for use with other populations. Components of virtual care that would be recommended for use post-pandemic, while others that may not, will be described. Finally, components that were possible to modify virtually and that were well-received by patients, will also be described. Patient engagement and the therapeutic alliance are known to be related to quality of care. These elements are particularly vital for psychologically based treatments and may be impacted by virtual care delivery. This study highlights a need for the development of data-driven approaches to guide virtual healthcare, with an inquiry into how mental health treatment in particular, can be facilitated. Knowledge sharing plan: This research will be presented to PATSED, PFAC , and will be shared with the Provincial Eating Disorders Network, which includes eating disorder professionals from across the province. Finally, our team was invited to present these research findings at the Interior Health's Eating Disorder Forum that brings together people from across disciplines, organizations and communities to network, learn and plan eating disorder services.
"Water is at the Heart": Indigenizing Patient-Oriented Research to	Gormley, Rebecca	Faculty of Health Sciences, Simon Fraser University; British Columbia Centre for	There are alarmingly high rates of HIV infection among Indigenous populations in Canada. Among Indigenous women living with HIV (IWLWH), such inequities extend to the similarly alarming rates of attrition across the HIV care cascade between initiating antiretroviral therapy to survival, compared to women of other ethnicities. Even when engaged in HIV care,

| explore how Indigenous women living with HIV understand and support their health | | Excellence in HIV/AIDS; AIDS Vancouver | IWLWH in Canada receive poorer quality-of-care than non-Indigenous women. However, negligent in these discussions is the strength and benefits that IWLWH gather from traditional ways of knowing, healing, and medicines ; and how such strengths can better support health care and outcomes for IWLWH. CHIWOS-Positive Aboriginal Women (CHIWOS-PAW) is a sub-study of the Canadian HIV Women's Sexual and Reproductive Health Cohort study (CHIWOS), focused specifically on the experiences of IWLWH. CHIWOS-PAW is developed, led, and facilitated by, with, and for IWLWH. This panel will take the attendees on a journey of how a collaborative team of IWLWH, Elders, and researchers practicing allyship came together to develop a strengths- and arts-based study to understand how IWLWH living on the Coast Salish Territories understand their health through traditional ways of knowing. This panel will describe the CHIWOS-PAW research process, including how the team Indigenized Patient-Oriented Research (POR) using Water Teachings and an interactive methodology rooted in Indigenous teachings. The panelists will demonstrate how they have maintained meaningful collaborations with participants while adapting to a virtual setting. Elder Sheila Nyman (Indigenous Elder) will open and close the panel, grounding us and teaching us about what it means to do our work in a Good Way. Valerie Nicholson (CHIWOS-PAW Lead, IWLWH, frontline warrior) will lead an interactive presentation, calling on attendees to immerse themselves in a novel presentation methodology to understand the transformative value of Indigenizing research. Using ceremony, grounding, and Indigenous teachings, she will ask attendees to reflect and share their histories throughout the presentation, creating a relational experience to what the IWLWH in CHIWOS-PAW experienced. Debbie Cardinal (CHIWOS-PAW Peer Research Associate, patient-advocate) will share her experiences as an Indigenous woman newly involved as a peer researcher, emphasizing the importance of conducting POR grounded in ceremony. Rebecca Gormley (CHIWOS-PAW Research Coordinator, POR advocate) will moderate the panel. Dr. Angela Kaida (Principal Investigator, CHIWOS) will contextualize the CHIWOS-PAW study, including the rationale for a study focused on the experiences of IWLWH, and why engaging in POR was critical to the success |

			of the project. Teaching/learning: - Interactive dialogue: engage with leaders actively involved in POR, while providing an opportunity for attendees to reflect, interact, and immerse themselves in an Indigenized approach to POR; - Visual: using imagery, understand the transformative nature of Indigenizing research. Audience Everyone interested in POR. Outcomes 1. Gain an understanding of new approaches to POR, including: a. Indigenizing the research process, as led by Indigenous patient partners; b. Transformative value of centring patient voices. 2. Experience an interactive methodology to share the process of conducting Indigenized, and strengths-based POR, led by IWLWH. 3. Imagine opportunities to engage patient populations meaningfully in virtual settings.
Measurement properties of the short-form Patient Engagement In Research Scale (PEIRS)	Hamilton, Clayon		Project title: Measurement properties of the short-form Patient Engagement In Research Scale (PEIRS) Authors: Clayon Hamilton, 1,2 Alison M. Hoens, 1,2,3 Annette M. McKinnon, 3 Shanon McQuitty, 3 Kelly English, 3 Lisa D. Hawke, 4,5 Linda C. Li 1,2 1 Department of Physical Therapy, University of British Columbia 2 Arthritis Research Canada 3 Arthritis Patient Advisory Board, Arthritis Research Canada 4 Centre for Addiction and Mental Health 5 University of Toronto Objective: The Patient Engagement In Research Scale (PEIRS) is a self-administered 37-item questionnaire completed by patient partners (including family caregiver partners) to determine their degree of meaningful engagement in research as an indicator of the quality of their engagement in a research project. We sought to shorten the PEIRS to its most essential items and evaluate its measurement properties for assessing the degree of patients' and family caregivers' meaningful engagement in research projects. Methods: A prospective cross-sectional survey with a test-retest component undertaken as a researcher-initiated collaboration with patient partners. A web-based survey was conducted across Canada and the USA, and a paper-based survey in Canada. Participants were patients or family caregivers who had engaged in research projects within the last 3 years, were ≥17 years old, and communicated in English. Results: 119 participants: 99 from Canada, 74 female, 51 aged 17–35 years and 50 aged 36–65 years, 60 had post-secondary education, and 74 were Caucasian/white. The original 37-item PEIRS was shortened to 22 items

			(PEIRS-22), mainly because of low inter-item correlations. PEIRS-22 had a single dominant construct that accounted for 55% of explained variance. Analysis of PEIRS-22 scores revealed: (1) acceptable floor and ceiling effects (<15%), (2) internal consistency (ordinal alpha = 0.96, Cronbach's alpha = 0.96, and average inter-item correlation = 0.55), (3) structural validity demonstrated by fit to a Rasch measurement model, (4) construct validity indicated by moderate correlations with the Public and Patient Engagement Evaluation Tool (PPEET), (5) good test-retest reliability (ICC2,1 = 0.86), and (6) interpretability from benchmarking scores across three levels of global meaningful engagement in research ("none to moderate", "very", and "extremely" meaningful). Consistent with our results from the Rasch analysis, we derived a meaningful patient and family caregiver measurement framework that mapped the essential items that partners experience to three levels: foundational, intermediate, and advance engagement. Discussion: The PEIRS-22 is a valid and reliable tool for assessing the degree of meaningful patient engagement in research and is likely to be completed in 4-7 minutes. It enables standardized assessment of patient engagement in research across several contexts. The new measurement framework indicates the essential aspects of meaningful engagement for each level, aspects which are required to achieve the specified level of engagement. Dissemination plan: These results will be submitted for publication in a reputable journal. This updated and validated version of the PEIRS will be communicated to current users of the questionnaire. We will work in collaboration with our institutional partners to promote the implementation of the PEIRS-22 to impact patient-oriented research.
The Peer Models Network	Harvard, Stephanie	University of British Columbia	In Canada's public health care system, policy-makers must choose what interventions and programs to fund, given budget limitations. To help make these choices, decision-makers often rely on information from health economic models, including statistical and simulation models. These models inform decision-making by providing information about costs and effects associated with different options. To build a health economic model requires making many social and ethical value judgments: deciding what treatments and outcomes to research, how many different options should be

			compared, how human participants in research should be 'categorized', and how much evidence is necessary before making conclusions are just some examples. 1 These judgments can influence healthcare funding decisions, so making them transparent, understandable, and open to feedback from patients and the public aligns with democratic principles. It also has the potential to improve how models are developed, since patients and the public may have knowledge and lived experience that scientists and model developers do not. To help make health economics models more transparent, understandable, and open for criticism and feedback, our research team has developed a website and Twitter account called the Peer Models Network. The website includes a new technical infrastructure called 'PRISM' that allows health economic models to be hosted online, making them accessible to everyone. The website also features 'model companion videos', short educational videos that aim to explain models to patients and the public, as well as interviews with modellers that give insight into the model development process. To invite patients and the public to give feedback to the research team and to model developers, the website includes a private message feature, as well as a discussion forum. The 'Peer Models Network Panel' is a group of patients and the public who wish to be contacted about opportunities to give formal feedback on models and educational videos. The Twitter account, @PeerModels, aims to raise awareness and start conversations about issues related to value judgments and public engagement in modelling. In this presentation, members of the Peer Models Network team, including a patient partner and two researchers, will describe the project and give a tour of the website and the social media page. The audience will learn about the philosophical rationale for the project, the technical specifics of PRISM, as well as the creative process for developing educational videos. The presentation will end with a discussion of potential next steps for ensuring the Peer Models Network serves the goals of patients and the public. This includes anti-racist goals prioritized by patient partners, such as making models more inclusive of diverse groups and experiences, addressing the presence of systemic racism in healthcare

			and society at large, and its negative impact on healthcare and health outcomes of racialized and marginalized groups.
Promoting Self-Management: Addressing the Educational Needs of New Hemodialysis Patients	Hidalgo, Jill	Providence Health Care - St Paul's Hospital	Patients with end-stage renal disease face many physiological and emotional challenges as they go through the treatment plan and lifestyle changes. Pre-dialysis education plays a key role in helping patients adjust to their kidney disease and adhere to treatment (Moattari et al., 2012; Parvan et al. 2015). Education programs are designed by clinicians with the goal to address patient needs. However, there is little evidence that shows patient involvement in the development of effective educational programs for new hemodialysis patients. The objectives of this study were 1) to investigate the educational needs of patients from their point of view and 2) to obtain patient and nurse clinician perspectives on facilitators and inhibitors of implementing an effective education program to promote self-management in new hemodialysis patients. This study was conducted at St Pauls Hospital Hemodialysis (HD) unit. The renal team is comprised of doctors, nurses, dialysis technicians, social workers, dietitians, pharmacists, and clerical staff who provide care to both inpatient (acute) and outpatient (chronic) dialysis patients. This study used a qualitative research design using the interpretive description approach. Procedures included collecting demographic data, conducting focus groups with nurse clinicians, and in-person and phone interviews with patient participants and CNLs. Patients expressed several learning needs such as explanations about Kidney disease, how the hemodialysis machine works, complications during and after HD, discussion of lab results and medications received during HD, and different treatment modalities. Nurse Clinicians and CNLs feel patient education is most effective when delivered in a standardized format with concise content tailored to the learning needs of the patient. Nurse clinicians recognize their role in delivering patient education. They highlighted the importance of continuing education in various patient education topics in order to address their own learning gaps, learn from other healthcare professionals, and gain confidence in teaching patients. All participants noted that having a dedicated patient educator would facilitate effective delivery of patient education. In the absence of a dedicated patient educator, CNLs suggest

			providing one-on-one patient education in the first three HD runs, assigning senior nurses who have more experience caring for new patients, and introducing new patients to a peer mentor/support on the unit. Identified themes will assist the health care team to better support hemodialysis patients with their learning needs and promote self-management on hemodialysis. In the future, the findings could also be used towards a follow-up research project wherein a structured patient education program can be developed and piloted in the Hemodialysis Unit at SPH. We plan to share the research findings with patients, clinical staff, and the Hemodialysis leadership team at SPH by sharing electronic copies of our research summary, displaying a poster on the unit, and by preparing a presentation to unit leadership to communicate our study findings and initiate discussions of how to improve education for new HD patients at SPH. We would like to share our findings at conferences and with key Renal organizations locally and nationally.
Hum along with the silent disco headphones: lessons learned in implementing the headphone program in a hospital unit	Hung, Lillian	University of British Columbia	Background: Silent disco headphones have been used among young people in concerts and parties; such headphones have extended distance coverage for broadcasting from a transmitter, features of noise cancelation, and three channels of music. Rather than using a speaker system, music is delivered by wireless headphones and facilitated by a DJ via a built-in microphone. No study has yet tested whether it is feasible to use such headphones to support well-being among older people in hospital settings. Methods: This study examined the feasibility of using silent disco headphones with older adults with dementia staying in a geriatric hospital unit. Three patient partners from CEAN (Community Engagement Advisory Network) actively involved in the design and plan of the research, as well as data collection and analysis. We employed a video-ethnographic design, including conversational interviews and observations, with video recording among ten patient participants in a hospital unit. Two focus groups were conducted with ten hospital staff across disciplines. Results: Thematic analysis yielded three themes: (a) "it just made me feel happy, "(b) "it brings him back alive," (c) "it unlocks dementia". Delivering music and meditation programs via the silent disco headphones in the hospital unit has the potential to be a

			beneficial intervention that can enhance mood and energy, support self-expression, and promote wellness. Disussion: Our findings suggested that witnessing the positive effects of headphones on patients changed the staff's view of how music could be used in the clinical setting to support patients' well-being. We identified enablers and barriers to implementing the headphone program in the hospital setting. Future research should further investigate how thes silent disco headphones may help to reduce stress and promote wellness for patients in the clinical environment, especially during and post COVID-19 pandemic time. KT Approach: A manuscript has been submitted for open access publication. Patient partners are co-authors. Along with the PI, a patient partner has presented the results at a regional virtual conference in April, this year. The findings were reported to the stakeholders at the local health authority. A podcast has been recorded at the United Kingdom and is available for public access.
Patient-Oriented Predictive Modelling of Healthcare Utilization (POPMHU): An Undergraduate Student's Experience and Insights with a Patient-Oriented Research Approach	Koopmans, Alanna	University of Northern British Columbia, School of Health Sciences	1. Introduction: As an undergraduate student majoring in Biomedical Studies at UNBC, I was invited to join the Patient Oriented Predictive Modelling of Healthcare Utilization (POPMHU) research team. At the time, I had little idea of what Patient-Oriented Research (POR) meant, nor how it was done. Through my supervisors' guidance, and the support of 6 patient partners, I adopted the role of POPMHU's Patient Engagement Team Coordinator. From an undergraduate perspective, I will discuss my observations and learnings to describe how my unique experience with POPMHU may help future undergraduate students or their supervisors when participating in POR. Background: POR involves patients, families and caregivers as active partners in the research process, leading to research priorities that are patient informed and lead to better healthcare (CIHR, 2019). 2. Methods: My role as the Patient Engagement Coordinator, during the COVID19 Pandemic, allowed me to connect with patient partners through email, telephone and Zoom. Some duties included: i) Introductory calls with prospective patient partners, facilitated by Patient Voices Network. ii) Acting as primary communicator with patient partners between monthly team meetings. iii) Sending monthly 'homework' assignments to patient partners and collating responses. iv)

			Drafting agendas and power-points for team meetings. v) Responding to patient partners' questions or directing them to relevant resources or individuals. 3. Results/Findings: · Build relationships: POR offers an opportunity to learn from and get to know individuals you may not interact with normally. · Sometimes, telephone trumps email: Take opportunities to connect via telephone instead of email. Not only are phone calls more personal, but they can be an effective use of time, as questions can be asked and answered simultaneously. · Stay organized: When possible, keep a record and take notes either during or after conversations with patient partners (with permission). Patient partners have valuable insights, and notes will help you remember specific contributions. · When you are unsure, ask: If you do not know how to proceed in a situation, supervisors or patient partners there to help. There were times where patient partners asked excellent questions, which I did not know the answer to. I was able to seek the assistance of my supervisors and the question was addressed. · Be receptive to feedback: Patient partners are supportive and willing to suggest improvements. I had a patient partner suggest that instead of group emails, I send emails individually, so the number of emails received by patient partners were reduced and greater privacy was maintained. · Find resources: There is helpful and clarifying information about POR, easily accessible online. For example, The Evidence-Informed Practices and Strategies for Patient-Oriented Research (POR): A 'Menu' for Research Teams (Kent, 2019). 4. Discussion/Implications: Conducting research using a POR approach has significantly shaped my research perspective. As an undergraduate student, I feel very fortunate to participate in a research project, that values and is informed by patients, developing meaningful and relevant research. 5. Dissemination Plan/KT Approach: A report of my experiences will be added to the team Wiki page, available at https://popmhu.ca.
Fostering Meaningful Rural Citizen Patient Partner	Kornelsen, Jude	Centre for Rural Health Research, UBC	Background: Four rural citizen patient partners from communities across BC were invited to work collaboratively with researchers from the Centre for Rural Health Research (CRHR) Rural Surgical and Obstetrical Network (RSON) initiative in order to develop a tool to better understand out-of-pocket costs

Involvement in Research on Costs of Travelling for Care			for rural citizens who have to travel for care. Methods: Successful applicants were selected based on personal experience of travelling for care and a motivation to improve rural residents' access to health services. Through dialogue with the patient partners, key themes of rural residents' experience accessing health service were identified and developed into a cost-analysis survey tool. Citizen patient partners were instrumental in recruiting survey respondents and distributing hardcopies of the survey to members of their home and adjacent communities, particularly elderly citizens who were unable to complete the online version of the survey. Throughout the process, patient partners continually gave feedback to the researchers so that the instrument could be adjusted to reflect survey participants' specific concerns and lived experiences. Findings: During the eight-month research period, collaboration and communication was maintained between the CRHR RSON research team and citizen patient partners through regular video conferences, webinars, and email updates. Acknowledging that members of the working group come from a wide range of personal and professional backgrounds, patient partners were encouraged to suggest any training or educational opportunities that were of interest. Based on these suggestions, webinars were held on ethics in research, policy development and workshop facilitation. Collaborative analysis has been completed and virtual workshops are tentatively planned for the fall, pending community readiness in the context of COVID-19. Discussion/Implications: This project has demonstrated the value-added collaboration of rural patient partners and the research team in developing, administering, analyzing and disseminating data from a provincial survey on costs of patient travel for health care. This process has yielded robust data essential to health care planning and also strategies for promoting inclusivity so that partners with a range of interests and capabilities are able to participate in a way that is meaningful for them. Knowledge Translations: Tripartite knowledge translation focused on community members, health care decision-makers and academic colleagues is currently underway and will be described in this presentation. We will also reflect on the importance of using a patient-centered framework in order to improve the validity of research studies and creating research-driven change.

| Rural citizen-patient developed resources to support rural women in the post-partum period: A feasibility study of community engagement (FINAL) | Kornelsen, Jude | patient partner/resident, Golden BC | Background: Post-partum depression affects at least 7.5% of women in Canada (1). At a population level, more than 15.5% of women in Canada were either diagnosed with depression or treated with anti-depressants (1), which attests to the prevalence of mental health challenges in the childbearing years. This creates vulnerabilities in the post-partum period for a significant number of women, a situation exacerbated for rural women in communities lacking comprehensive mental health services. It also creates challenges for patient-engaged research, due to the systemic marginalization of populations with mental health concerns and, reciprocally, the life circumstances that make participation by such individuals difficult. Methods: This pilot project evaluates the efficacy of a ground-up, citizen-patient developed tool for preparing for optimal post-partum mental health. 'The Hards Method' was created by a Golden resident in response to her need for mental wellness supports and has been shared throughout the community. This patient-directed project engages community members including patients and care providers to establish the utility of the Hards Method (through virtual 'think-aloud' sessions) but also the importance of community gate-keepers in facilitating true community involvement. Findings: This in-process project is demonstrating the efficacy of the patient-researcher team in rural fieldwork. Preliminary findings from the virtual 'think aloud' sessions demonstrate the capacity for meaningful input from people with lived experiences of mental health challenges and concerns. As Ms. Hards has observed, "There are very few people that have mental illness and are able to have a voice, advocate, and be of benefit to others on this scale in this scope".   Implications: The evaluation of The Hards Method framework has been taken up by an array of women from diverse demographics due to the patient partners important linkage to the community of more commonly disenfranchised pregnant women in Golden . Knowledge Translation: We will end by describing first steps towards working with regional key stakeholders for more wide-spread applications of the framework and the process of citizen-patient/researcher collaboration in the development of the evaluation of The Hards Methods across other rural BC communities. |

| Amplifying and Engaging with Patient Voice Using Recorded Audio as a Knowledge Translation Tool - Podcasts and Beyond | Lloyd-Kuzik, Nicholas | Rural Evidence Review, Centre for Rural Health Research, Department of Family Practice, University of British Columbia | Description of proposed content : Knowledge translation is about getting the right information to the right people at the right time and in the right way. Recorded spoken-word audio is an underused knowledge translation tool that can help make information more compelling and approachable either as a standalone knowledge translation product or as a complement to other approaches (e.g. plain-language summaries, news articles, etc.). Whether an ongoing podcast series or a one-off interview, recorded audio is an ideal medium for researchers and advocates to engage and amplify patient voice, and a powerful tool for citizen-patients to share experiences from their own perspectives in a format that is personal, easy to produce, and easy to share. The Rural Evidence Review (RER) is a Centre for Rural Health Research (CRHR) imitative with funding under Canada's Strategy for Patient-Oriented Research and the Rural Coordination Centre of BC. The RER works together with rural patients to provide high-quality, useful evidence for rural health care planning in BC. Since early this year, the RER and CRHR have been producing a podcast series focusing on amplifying rural and remote citizen-patient voices, sharing knowledge emerging from our patient-oriented research projects, and engaging stakeholders across the health policy ecosystem in BC. Our first series of programs showcased rural community experiences of resilience and ingenuity in response to COVID-19, and our most recent series explores citizen-patient involvement in health care and services planning in BC. Although the program is young, it has been met with enthusiasm and interest from patients and other health care stakeholders. The CRHR recognizes value of audio as a tool for knowledge translation and patient engagement, and the value of sharing its developed capacity for creating audio content with other groups aiming to amplify and engage with patient voice. Whether for storytelling, interviewing, providing plain-language summaries of research findings, or anything in between, audio recordings can be effective, affordable, and achievable. Teaching/Learning approaches : Led by the CRHR Podcast producer, workshop attendees will be guided through the process of planning for an audio recording session on a subject of their choice. Participants will consider aspects of planning unique to audio production including selecting recording equipment, recording place |

			setting, format and outlines for audio programming, and distribution strategies and platforms for finished recordings. Key considerations for patient engagement will be discussed. Target audience: This workshop is intended for anybody interested in expanding their knowledge translations toolkit. This may include, researchers, healthcare practitioners and administrators, policymakers, citizen-patients, health advocates, etc. Learning outcomes: Participants will improve their understanding of: applications of recorded audio in engaging and amplifying citizen-patient voices; common formats and conventions for audio programming; how to plan and coordinate audio recording sessions; techniques for recording and editing audio; how to publish recorded audio to common platforms and allow users to subscribe for future content; participants will also be provided a list of free resources for creating and sharing audio programming.
Stronger muscles start with stronger partnerships: Evaluating the patient engagement process using the Patient Engagement In Research Framework	Ma, Jasmin	Arthritis Research Canada/ University of British Columbia	Introduction and background: Engaging patients in research has the potential to improve the relevance and quality of research and ultimately health-care services. 1–3 However, our understanding of how to best engage patients as partners is evolving. 3–5 The Patient Engagement in Research (PEIR) framework was developed by both researchers and patients and is derived from empirical data highlighting what patients specifically define as meaningful engagement. 6 Improving Strength training and Tailoring in ARThritis (I START) is a patient-oriented research (POR) project that aims to identify barriers and strategies to support people with arthritis to participate in strength training. The purpose of this research is to evaluate the extent to which patients have been meaningfully engaged throughout the I START project to date. Methods: This study employed a mixed-methods, descriptive case study design. Members from Arthritis Research Canada's Arthritis Patient Advisory Board have been involved throughout the I START project including refining the research question and methods, developing and reviewing grant applications, recruiting participants, interpreting findings, and reviewing manuscripts. At one year post-project initiation, the PEIR Scale 7 was administered to evaluate the degree to which patient partners felt meaningfully engaged based on each of the PEIR framework components (benefits, feeling valued, research environment,

			team interaction, support, contributions, convenience, and procedural requirements). Responses were evaluated on a 5-point Likert scale ranging from 'strongly agree' to 'strongly disagree'. Patient partners also completed a semi-structured interview guided by the PEIR framework to identify barriers, facilitators and recommendations to improve the engagement process. Interviews were recorded, transcribed verbatim, and coded thematically. Results/findings: All seven patient partners (clinicians=2, males=2, rheumatoid arthritis=3; juvenile idiopathic arthritis=1, Raynaud's=1, ankylosing spondylitis=1, osteoarthritis=1, psoriatic arthritis=1) completed the survey and interview. Overall, patient partners indicated they 'strongly agreed' or 'agreed' the patient engagement process fulfilled all 8 domains of the PEIR, however, 5 items received at least one 'neutral' response related to having an appropriate number of patient partners, an understanding of the objectives and ethical responsibilities, receiving sufficient explanation and support, the opportunity to provide input on individual task selection, and project involvement having a positive impact on their life. Analysis of the semi-structured interviews confirmed the quantitative findings as well as identified further recommendations for improvement including clear reminders of the project purpose in communications and meetings, gaining a deeper understanding of 'outside of the box' patient partner skills that can be leveraged, opportunities for social activities, and proposing tentative research timelines. Discussion/implications : Recognizing that patient engagement is a dynamic and iterative process, these findings will be used to improve the patient engagement process as the I START project progresses. The PEIR Scale will be administered at the 2-year follow-up to examine the change in meaningful patient engagement over time. This case study serves as an example of how POR projects can reflect on and improve the patient engagement process. Dissemination plan/KT approach: Results have been shared amongst the project team and the POR process will be submitted to the Integrated Knowledge Translation Research Network Casebook.
Learning, unlearning and	Maiwald, Karin	BC ASHN Academic/postdoctoral	Learning, unlearning and relearning in patient-oriented research: A panel discussion The emergence of patient-oriented research has provided new

relearning in patient-oriented research: A panel discussion		embedded scholar within Interior Health Authority Research Department within BC SUPPORT Unit Interior Centre. Affiliated (honorary, external post doc) with Maastricht University, the Netherlands	opportunities to undertake research that more readily reflects the values and priorities of patients and the public. Alongside the widespread adoption of POR, is a growing focus upon the approaches and methods needed to foster meaningful patient engagement. In this panel, we will first discuss and share ' learnings and unlearnings' from patients and researchers perspectives engaged in POR. Second, we will reflect upon ' relearning ' more focused on authentic co-creation and will identify methodological and practical strategies to optimize successful and impactful POR. Methods: Panel members comprise two patient partners and three researchers, who work at diverse organizations/institutions across the province, engaged in POR research. Panel members will draw upon their experiences of undertaking POR from across British Columbia and will share their experiential insights, learnings, and partnership stories. Guiding questions will include: 1. What do patients, researchers and others need to learn and unlearn both to promote and support meaningful POR? 2. What does success in POR look like? Approaches and outcomes: Through this panel, we will identify and share approaches and methods that allowed for meaningful collaboration and partnership in the dynamic practice. Panel members will draw upon their own experiences of POR to identify ways that they were tasked with learning, unlearning and relearning as part of the POR journey in health research and how this contributed to impactful research which is useful for health authorities to help improve the delivery of health services and policy. During this fun and fast paced panel, audience participation will be encouraged through anonymous polling (if available) and time for questions will be included.
Patient Partner Input for Research into Northwestern BC Medical Travel	McMillan, Moira	Patient Partner, Northern Patient Travel Improvement Committee	Introduction In Northwestern BC, it is common for patients and families to leave home to receive care in a bigger centre. Travel can be difficult due to many factors such as long distances, 1 weather, 1,2 limited transportation, 2 and expenses. 1,2,3 There is minimal research into the patient experiences when travelling for care, particularly in the Canadian context. This study aims to better understand the medical travel experiences of patients and families living in Northwestern BC. By understanding the barriers patients face and what supports exist, recommendations can be made to improve the patient

			experience. Key to this research has been the inclusion of patient partners who have shared their lived experiences to guide the research. Methods The Northern Patient Travel Improvement Committee (NPTIC) was established in June 2019. The research committee is composed of patients and family members, healthcare providers, healthcare administrators, and researchers. Patient partners have played a significant role in directing the research by sharing their thoughts and experiences at in-person and virtual meetings and through emails and phone calls. A patient partner (MM) was selected as a co-chair for NPTIC. Approaches used for research include a scoping review, patient journey mapping and semi-structured interviews with patients and caregivers, semi-structured interviews with healthcare providers, an online survey for Northerners, and a collation of resources available in the North. Each of these tools received significant input from patient partners, ensuring the research approach and findings focus on patient priorities and are relevant to patients and families. Results/Findings The influence of the patient partners can be seen in the following: - Framing the scoping review approach - Participating in the analyses of patient journey mapping - Extracting the most relevant topics from the healthcare provider interviews. - Recommending and setting the direction of an online survey - Development of the Northern Patient Travel Guide, created by suggestion of the committee The ongoing meetings and training have helped patient partners grow in expertise and gain confidence to become research team members. This project will help inform future research in the Northwest. Discussion/Implications Patient involvement has been essential in this study. Sharing valuable perspectives throughout the research process has led to a study that has great potential to improve healthcare delivery and patient care. Patient partners have felt they have been given a voice to address an issue very important to them, and have learned a lot about the research process. As a result, they feel more informed and significant in an area where they previously felt they had nowhere to go with their concerns. Dissemination Plan/KT Approach Findings will be shared with the general public, healthcare providers, policy makers, and health services researchers in various ways, as determined by the committee. Based on research project

			findings, recommendations on how to improve the medical experience will be identified. Lay language reports for the public will be created and community forums will be organized. Reports will be written to guide planning and improvement of health services, including a Best Practices Guideline.
Coming of Age as a Pathway towards Wellness for Urban Indigenous Youth in Care	Mellor, Andrea	University of Victoria	Background : (Re)connecting to Indigenous coming of age teachings connects youth to spirit and identity through familial, hereditary, and cultural linkages 1 . These teachings are grounded in wisdom held by knowledge keepers and are shared through songs, stories, ceremonies, and rites of passage 2,3 . (Re)connecting with these teachings supports community healing, wellness, and resilience, and helps to prepare young people to carry this wisdom forward in a good way. This project brought together local youth, elders, and Indigenous and non-Indigenous allies, to discuss how urban Indigenous youth who are living away from home or in foster care can access culturally appropriate and relevant coming of age resources. This presentation will discuss the findings of our community consultations, specifically, those informed by two youth workshops. Methods: The workshops were guided by priorities identified by community knowledge keepers and explored the meaning of "Indigenous coming of age" in sharing circles and interviews with fifteen Indigenous youth-in-care. A thematic analysis of workshop transcripts identified five themes: self-continuity, self-awareness, empowerment, being part of something bigger, and the importance of support networks. Findings: The five themes provide evidence that engaging with culturally relevant coming of age teachings is protective to youth wellness and helps youth to learn about their Indigenous ancestry 2,4 . Coming of age is a convergence of individual, family, and community relationships that weave together like a three stranded braid. Like a braid, if one strand has too much tension, or another has too little, the balance between them becomes skewed. Maintaining this balance is part of a whole-istic model of Indigenous health and wellness that supports lasting connections between Indigenous youth and their communities. Implications: This project is part of a broader discourse of (re)writing narratives that celebrate the strength, leadership, and independence of the urban Indigenous youth community. Receiving

			traditional coming of age teachings is , this becomes part of active cultural preservation and revitalization. Revitalization is a larger movement that works to heal the wounds of colonialism by recovering traditional cultural practices, and undoing systems that cause harm to Indigenous peoples, families, land, and culture 5 . Research Dissemination: We engaged with visual storytelling to share our findings to make visible the depth, energy, and individuality of the Indigenous youth we had the privilege to work with. We used research storytelling to connect the project themes in a fictional story and graphic novel called "Becoming Wolf". The story follows Wolf's coming of age, when during a dream she learns to cope with changes in her family by (re)connecting to her ancestral teachings. We are also developing an infographic that illustrates the research themes through visual metaphors and text. The illustration takes us on a cyclical journey through stages of leaving one's childhood, towards the self-awareness that develops during adolescence, and the empowerment that can lead one back to their community as an adult, mentor, and leader. This project will culminate in a community feast where we will share our work, give thanks, and celebrate our time together.
Client engagement with iOAT (Injectable Opioid Agonist Treatment) sites before and during the COVID-19 pandemic	Metcalfe, Rebecca	School of Population and Public Health, University of British Columbia; Centre for Health Evaluation & Outcome Sciences	Introduction and Background Injectable opioid agonist treatment (iOAT) delivered under observation is expanding in Canada, either with hydromorphone or diacetylmorphine. 1 In the Vancouver Lower Mainland, individuals with opioid use disorder at risk of a wide array of health and social negative outcomes, can access this treatment currently in five sites. The overarching goal of our PORTIA (Program of Outcomes Research on Treatment with Injectables for Addiction) study is to identify client factors that inform program design to optimize iOAT uptake and effectiveness. With the advent of COVID-19, our work expanded to exploring how the pandemic influenced iOAT delivery and client experiences. Methods Before any data collection, we formed the PORTIA advisory committee to ensure research reflected clients' views meaningfully at each step of the research process. The committee is composed of clients from each of the iOAT sites in the greater Vancouver area. Semi-structured interviews and focus groups were conducted to understand what aspects of iOAT and iOAT delivery were most

			important to clients. As data collection was nearing completion the COVID-19 pandemic began in North America. In response to the pandemic, we adjusted our aim and methods to understand how changes required to limit the spread of COVID-19 influenced clients' experiences with iOAT and their needs. We conducted three interviews with each client across 6 months using a grounded theory approach. 2 Clients often spoke about the importance of their relationships with clinic staff, therefore interviews with nursing staff from each iOAT site were added. 3,4 Participants and advisory committee members will review results. Findings We identified three primary themes that underpinned clients' engagement with iOAT programs: building trust; creating and maintaining relationships and communication; and flexibility for personalized care. These themes built on one another. iOAT programs build trust by limiting demands on clients and trying to meet clients where they are, and this in turn builds trust. Clients often reported strong relationships with staff, founded in open communication. These relationships made personalized care possible and reinforced client trust in the iOAT program. The advent of the COVID-19 pandemic, reshaped site processes and profoundly impacted clients' ability to develop and maintain relationships with staff and other clients. For example, clients felt the sites were "hospital like" and missed the sense of community that used to exist. Moreover, changes due to the pandemic (e.g., physical distancing; self-isolation) brought back upsetting memories of past traumas (e.g., AIDS crisis; previous maltreatment by healthcare providers). Discussion Building trust and strong relationships is key to addressing the diverse needs and experiences of clients, and COVID-19 pandemic strained sites' ability to build trust and relationships. Together these findings indicate that consideration should be given to how to respond to future outbreaks without eroding trust and relationships. Dissemination plan Study findings will be shared with clients, sites, stakeholders, and professional audiences through journal articles and presentations, including co-presentations with clients and short videos, so that iOAT sites will be able to better understand, and ultimately address, their diverse client needs, including during future outbreaks.

Strengths and Challenges of Virtually Soliciting Feedback On Study Materials	Monkman, Helen	BC SUPPORT Unit Vancouver Island Centre	Introduction and Background Engaging patients as partners at all stages of the research lifecycle is an integral component of Canada's Strategy for Patient-Oriented Research (SPOR). Before conducting a study, consulting with people representative of future participants can improve the clarity and comprehensiveness of study materials. This study explores the strengths and challenges of garnering feedback on study materials virtually (engagement activity) from the perspectives of the Principal Investigator (PI) and the Engagement Facilitator (EF). Methods Grounded in core principles from the SPOR Patient Engagement Framework (CIHR, n.d.) and the International Association for Public Participation (IAP2), this work took a User Centred Design (UCD) approach (i.e., involving users in the design process; IDF, n.d.) to developing study materials. The consultation process applied Delaney and Associates' (n.d.) five step approach. We used the REACH BC platform to support recruitment and consultants ('patient partners', N =13) could select one of three different virtual sessions to accommodate date/time preferences. We provided the study information package in advance of the sessions for review. Sessions lasted two hours and capped at five consultants per session. Each session upheld principles of equity, diversity, and inclusion to facilitate a safe, welcoming, and productive atmosphere. The PI guided discussions while the EF took notes and monitored the chat. Both the PI and the EF watched for non-verbal consultant reactions. Consultants were offered an honorarium in appreciation for their time and expertise. Results/Findings Strengths of this approach: The five step approach proved to be a strength to engaging peop[;e in the initial stages of a research project. The virtual platform (Zoom) allowed consultants to join from across British Columbia. Early evaluation results indicate consultants felt the overall engagement process helped them to contribute meaningfully to the opportunity. They felt welcomed by the researcher; there were clear expectations; they freely and respectfully shared their views; their contributions were valued; their participation positively influenced the engagement objectives; their time was well spent; and their contributions will improve the patient experience within the health care system. Challenges of this approach: Using a five step approach to support the

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			consultation process can be difficult to navigate without adequate infrastructure (i.e., an EF to oversee logistics, onboarding and orientation, communications, providing compensation, etc.). Pairing this approach with a virtual platform also brought challenges including technical difficulties with video/audio and managing 'airtime' between consultants. Discussion/implications A five step approach for consultation proved to be a valuable method to improving study materials and increasing the likelihood of collecting valuable and valid data. Overall, this approach could be valuable in not just for future consultation efforts for study materials other research activities (e.g., knowledge translation) as well. Moreover, this initial activity built rapport between the PI and the consultants which could be leveraged in future work. There are definitely strengths to conducting consultation sessions virtually, but this medium had its drawbacks as well. Dissemination plan/KT Approach Consultants will be provided with the revised study materials. The PI will reconnect with consultants to discuss KT activities nearing study completion.
Piloting Digital Storytelling for Endometriosis and Painful Sex: Ethical Considerations and Emotional Impact	Noga, Heather	BC Women's Hospital + Health Centre	Introduction Endometriosis affects approximately 1 in 10 females, 50% of whom experience pain during sexual activity that negatively affects their quality of life and relationships 1,2,3 . Recognizing that people primarily seek health information online, the limited information specific to this condition undermines affected individuals' abilities to understand their condition, self-manage symptoms and seek appropriate healthcare. Throughout the development of a patient website for endometriosis and painful sex, our patient partners emphasized that online information neglected to accurately capture the lived experience in a way that was validating, honest and empowering. Methods Using a participatory patient-oriented research approach, this project implemented a co-creation method to creating digital stories on the impact of endometriosis-related painful sex and the ways in which people respond to and manage this condition. Members of the research team, story development experts, and patient partners collaborated to develop evidence-based, personalized stories through a digital storytelling workshop. The specific aims were to; i) assess the acceptably of the co-creation process, ii) understand the emotional

			impact of the workshop, iii) determine participant's willingness to share their stories and evaluate the impact of these stories on a broader audience. Qualitative data for the study were collected through workshop observations, reflective journaling and a focus group. Results / Findings The collaborative study design process illuminated numerous ethical concerns related to the participatory research approach and as such, our extensive team discussions centered on devising mitigating strategies. Ethical concerns arose from the dual role of participant and research team members, collecting observational data, appropriate remuneration, and ownership of digital stories produced through co-creation. The highly emotional nature of the storytelling process necessitated conversations about, and implementation of, appropriate emotional support. Preliminary results from the observations and reflective journals brought forth both the challenges and benefits of co-creating deeply personal stories. Discussion This pilot study will enable us to refine the co-creation process as it relates specifically to patient partner and participant experiences. It will also assist in determining a target audience and means of dissemination in preparation for a full-scale future study on storytelling for knowledge translation. Our ultimate goal is to develop an innovative and engaging way of creating and sharing information to empower women to live their best life while combating stigma and validating the lived experiences. Dissemination Plan As a pilot study that focuses on the methodological process of patient-oriented research, participatory research methods and digital storytelling, the dissemination plan is focused toward research teams and patient partners who are interested in undertaking digital storytelling. We have yet to determine whether or not the process of digital storytelling will achieve the desired result. If so, then an appropriate dissemination plan targeting the endometriosis patient population will be designed.
Flipping Stigma on its Ear: People with Dementia Doing Action Research	Phinney, Alison	Dementia Advocate	The purpose of this project is to refine and apply the concept of social citizenship to improve health and community services for people with dementia. Social citizenship is the idea that people with dementia are "entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life" (1, p.37). While this concept is

			gaining traction, the work has been done mostly by academics on behalf of people with lived experience. We address this gap by engaging people with dementia in the actual conduct of the research so it is their experiences and perspectives that shape the concept of social citizenship. This four-year project (2019-2023) has been designed according to principles and methods of action research (2) with a team comprising health care researchers, community partners, and people with dementia. We describe what we have learned about the development and evolution of an Action Group of people with dementia who have shared their expertise to direct the early stages of the research. METHODS The Action Group (n=9-12) was recruited using purposive sampling beginning in summer 2019. It includes men and women from different cultural backgrounds with a range of experience living with dementia. The group met at a community centre for two hours each month until March. Since then, they have been meeting online for 90 minutes every two weeks. Most meetings are an open discussion of topics related to social citizenship and experiences of living with dementia. These have been recorded and transcribed, along with field notes. Data have been analysed for preliminary themes, with exemplars coming back to the group for further discussion and evaluation. Now in year two, the Action Group is focusing on engaging broader cultural perspectives and sharing their ideas through knowledge translation activities. FINDINGS We have analysed strategies that have supported the development and evolution of the Action Group. " Letting the Group Lead " references the decisions and actions that have supported the group to take leadership and offer meaningful direction in the research. Subthemes with examples include: (1) putting dementia experience first (e.g. including a dementia advocate as a principal investigator); (2) trying new facilitation techniques (arts methods); (3) providing personalized support (e.g. managing family communications); (4) accepting pushback (e.g. expanding focus to confront stigma). DISCUSSION The Action Group is growing into a thoughtful and confident voice (made perhaps even stronger since moving online) that provides important conceptual and practical direction in this research. Building relationships and reciprocity between researchers and people with dementia has been an

			important influence underpinning the strategies associated with "Letting the Group Lead ". These factors also have implications for meaningful engagement of people with dementia in research based in other methodological paradigms. KT APPROACH To share early findings with community partners and the general public, the Action Group has divided into two working groups: one focused on a writing project and another on an arts exhibit. They are also overseeing development of a toolkit for supporting people with dementia in advocacy and leadership.
KidneyLink and KidneyPro: Online resources to enhance patient engagement in kidney research	Pollock, Graham	Can-SOLVE CKD Network	Background: Over recent years, there has been increasing support and traction for patient-oriented research. Yet health research remains enigmatic for many patients who are not familiar with research terms, practices and protocols. A lack of awareness of opportunities to take part in research studies presents a further barrier to participation. To empower patients to engage in kidney health research across Canada, as partners and/or as participants, the Canadian kidney research network Can-SOLVE CKD has developed two online resources: KidneyLink and KidneyPro. Methods: KidneyLink (kidneylink.ca) is a platform to learn about and get involved in research that responds to the needs and perspectives of patients. From a user-friendly website, patients can create an account, select topics of greatest interest, and receive up-to-date listings of kidney research opportunities across Canada. KidneyPro (kidneypro.ca) is an online training module that helps patients understand the foundational aspects of research in Canada, with a specific focus on kidney research. The self-directed module aims to support patient engagement in studies as partners and/or participants and empower them to take part actively and meaningfully. KidneyPro has integrated quizzes to verify the leaner's understanding of key points from the module. Results: Both platforms launched in November 2019 and have seen strong initial engagement. As of March 31, 2020, KidneyLink had recorded 279 registered users. Web analytics suggest users spend nearly five minutes on the site on average, suggesting authentic engagement with posts and research opportunities. As of March 31, 2020, KidneyPro had seen 295 users initiate the module to begin the training program. We are working on an evaluation strategy to better assess the completion rate and attitude

			changes resulting from the training. Discussion: These two platforms show promise as strategies to increase patients' involvement in all aspects of the research process by linking them to opportunities for participating in research and enhancing their understanding of patient-oriented kidney research in Canada. Dissemination plan: To ensure the success of these two platforms, we recognize the importance of building a large user base and ensuring continued engagement. The initial phase of dissemination has focused on raising awareness of KidneyLink among the Can-SOLVE CKD community. The next phase will be to work with partners to leverage entities like the Canadian CKD Clinic Network that can help raise awareness of the platform among patients and practitioners outside of the network's scope. Finally, we aim to use a range of marketing strategies to promote KidneyLink and KidneyPro to the general public.
Wabishki Bizhiko Skaanj: A learning pathway to foster better Indigenous cultural competence within Canadian health research	Pollock, Graham	Can-SOLVE CKD Network	Background: Can-SOLVE CKD is a kidney research network in Canada within which Indigenous patients, caregivers, researchers, and community leaders have created an Indigenous Peoples' Engagement and Research Council (IPERC). A key component of IPERC's work is the creation of a new learning pathway, Wabishki Bizhiko Skaanj ("White Horse" in Anishinaabemowin), that will help researchers build respectful partnerships with Indigenous peoples within the health research setting. Wabishki Bizhiko Skaanj aims to enhance researchers' knowledge of racial biases, Indigenous voices and stories, the impact of colonization, and culturally safe health research practices. Methods: A working group including members of the Can-SOLVE CKD Network, Diabetes Action Canada, First Nations Health Authority (BC), Provincial Health Services Authority (BC), and First Nations Health and Social Secretariat of Manitoba is leading the pathway's development. Two in-person workshops were held in October 2017 and March 2018 to develop the concept and identity of the curriculum, which consists of interactive learning exercises, facilitated online modules, and webinars. Several components of the pathway have been piloted and feedback is being gathered via surveys, pledges, and stories. Results: The pathway's content is designed to help participants understand, recognize, and correct the racism that occurs in health care and research, in some cases caused by their own

			conscious and unconscious biases. Through enhanced knowledge, self-awareness and strengthened cultural competency, Wabishki Bizhiko Skaanj aims to support all partners in health care and research to close the gaps in health outcomes between Indigenous and non-Indigenous communities. Conclusions: Wabishki Bizhiko Skaanj represents a novel learning platform for Indigenous cultural safety in Canadian health research. While Wabishki Bizhiko Skaanj was developed in the context of kidney health, the learning pathway can be adopted by networks and institutions across Canada, to help reduce and ultimately eliminate the racism that Indigenous people face within the health care system. Knowledge Translation Approach: The pathway will be disseminated to the broader health research community with the support of partners such as Diabetes Action Canada, First Nations Health Authority (BC), Provincial Health Services Authority (BC), and First Nations Health and Social Secretariat of Manitoba.
Involving Patients, Family, and Caregivers in Policy for Integration through Primary Health Care Teams	Rai, Ashmita	The University of British Columbia	Abstract Background : This patient-oriented research project is being carried out in four provinces across Canada including British Columbia(BC), Alberta (AB), Ontario (ON), and Quebec (QC). Data collection and analysis are performed in three phases: 1) cross-case policy analysis; 2) patient engagement in policy development for primary healthcare (PHC) teams; and 3) recommendations for policy change. This presentation will report on Phase 2 of the BC case study. Objectives : The main objectives of this study are to understand if and how patients with two or more chronic illnesses and their caregivers are involved in building, applying and evaluating policies related to PHC teams, and to develop recommendations and actions to support integration through PHC team-based care. Methods : The study involved patient partners throughout the research process and focused on patient priorities to support integration for patients with two or more chronic illnesses through PHC teams. Patient engagement in policy development related to PHC teams and integration was explored via semi-structured interviews with patient-participants and caregivers. An online deliberative dialogue session will be held in the fall to share the results of policy analysis and patient-participant interviews; discuss how patients and caregivers could be involved in policy development in the public health care

			sector; and create actions for involving patients and caregivers in these policy activities. Results : Preliminary results from patient interviews in BC provided us with important data on the key themes: patient focus, standardization of care through teams, information systems, financial management. All the participants in the study. regardless of their experience in policy level engagement, wanted to be involved in policy processes and advocate for people. Barriers to participation, such as tokenism, racism, ageism, patient's health condition, lack of awareness and accessibility were also identified. Discussion : An understanding of patient engagement in policymaking and implementation will facilitate better engagement of patients/caregivers. Communication, coordination and cohesiveness among patients/caregivers, policymakers, service providers, and community organizations are essential to bridge the gaps in services and create a team based integrated PHC system. Knowledge translation approach (KT) : We are using an integrated KT approach (CIHR, 2012) with knowledge users as a part of the research team and involved in all aspects of research. A national KT activity will be conducted to disseminate the results and garner feedback on the actions of patients, researchers, policymakers, decision-makers, and providers. We will share the results of the study with the participants and invite them to share their comments and feedback via online discussion and interactive webinar presentation of the final results to gather further feedback and to work together to create recommendations on policy for primary health care teams. The final report will ncorporate the feedback and comments, and will be shared with research team members, collaborators, and other interested individuals in each of the provinces, nationally, and internationally. We will conduct other presentations (e.g., conferences), and the results will be used in academic articles submitted for publication.
A Pandemic Pivot - Patient Oriented Research in Mental Health during COVID-19	Ridgway, Lisa	BC SUPPORT Unit - Patient Partner and Moderator	This panel presentation revives a "Five Days in May" Research event originally scheduled for May 1, 2020, sponsored by Island Health's Research and Capacity Building Department. The event was cancelled due to COVID-19 on March 15. The topic is now more timely than ever before, and the panel will present a focused, moderated discussion around patient oriented research (POR) and mental health research with five acknowledged experts,

| | | | emphasizing a path forward during and after COVID-19. The panel will be moderated by BC SUPPORT Unit Patient Partner Lisa Ridgway, who originally brought the panel together for the Five Days in May event.   Lisa has experience moderating discussions including BC SUPPORT Unit's COVID-19 TownHall and WHRI and CIHR – IHSPR workshops, plus 15+ episodes of SPORcast, the POR Podcast among other presentations. Lisa has lived experience of mental health concerns, including depression and anxiety. The presentation will draw perspective from each SPOR stakeholder groups. Minister Darcy can address public policy towards mental health care research (including the "Pathway to Hope" strategy) and its intersection with POR.   Lauren Fox can discuss the Mental Wellness Day program at Royal Jubilee Hospital at Island Health, its adaptations to COVID-19 and how research shapes and supports its services. Dr Song can address how POR helps guide the delivery of mental health services across Island Health. Dr Caruncho can articulate POR in translational neuroscience from a bench-to-bedside-scientist viewpoint. Dr. Barbic can describe how POR in mental health shapes delivery of mental health services to BC's youth, especially during COVID-19. The panel is already established and met with the moderator earlier this year during the Five Days in May preparation and has the full backing of Island Health's Research and Capacity Building Department. The panel presentation will begin with 2 minutes for self-introductions for each speaker, 40 minutes for discussion of a maximum of 3 pre-set questions followed by 10 minutes for Questions and Answers from the panel to the audience. The questions will be developed collaboratively with the panel with the following themes: 1.   The translation of mental health research into policy / practice at Island Health and across BC during COVID-19; 2.   The collective way that each POR stakeholder in mental health research deals with scarce resources and pressures of COVID-19; 3. How POR enhances recovery oriented practice and what it looks look like in mental health care during COVID-19. From each SPOR stakeholder group, this moderated discussion on POR in mental health research will identify critical priorities for patients, their families and those who provide mental health care during the pandemic and beyond. The panel will identify lessons |

			learned from the last five months in mental health care needs and how research into mental health can help solve some of the unintended consequences of the pandemic. Please note: Ministry Darcy agreed to speak at the original event, and we are awaiting final confirmation of her availability to speak on October 8th. All other speakers have confirmed attendance.
Quality of life assessments to support person-centred healthcare for older adults living with frailty and their family caregivers: Development of knowledge translation resources	Sawatzky, Richard	Trinity Western University School of Nursing; Centre for Health Evaluation and Outcome Sciences; BC SUPPORT Unit	This patient-oriented research and integrated knowledge translation (KT) project focused on developing KT resources to support use of quality of life (QOL) assessment tools, including patient-reported outcome and experience measures (PROMs and PREMs), in healthcare of older adults living with frailty at home and their family caregivers. Resources were informed by qualitative research and co-developed by an engaged team of knowledge users at different levels of healthcare, including: patients and family caregivers (micro), healthcare professionals (micro), healthcare leaders (meso) and government decision-makers responsible for healthcare policy (macro). Our research objectives were (a) to describe knowledge gaps and barriers and the need for supportive resources regarding use of QOL assessment tools by knowledge users, and (b) to formatively evaluate tailored KT resources that were co-developed to meet the identified needs of different knowledge users. Methods Researchers and knowledge users worked together via in person and online meetings to design the project, recruit participants and conduct qualitative interviews and focus groups, interpret analytical results, and co-develop tailored resources based on iterative rounds of feedback. Data were collected from 50 stakeholders (patients and family caregivers, healthcare professionals, healthcare leaders and government decision-makers) throughout Canada via 57 interviews and 3 focus groups. All data were recorded, transcribed, and thematically analyzed. NVivo 12 was used to organize and code data. Transcripts were re-read to generate an initial codebook, which was refined in an iterative fashion throughout the analysis. A formative evaluation involving 23 of the 50 stakeholders was conducted following co-development of prelimimary resources based on emerging results. Results There was a need to develop basic yet tailored resources about QOL assessments for each knowledge user

			audience. Older adults and family caregivers wanted understanding about how to complete use QOL assessment tools (e.g., how to respond to questions and assign a number) and how this information will be used to improve their care. Healthcare providers sought practical information on how to integrate QOL assessments to minimize burden and to inform person-centered care. Healthcare leaders desired information to understand how PROMs and PREMs could be used to evaluate and improve healthcare services, including quality improvement. Government decision-makers needed knowledge about how to access, use, and interpret PROM and PREM information for healthcare policy purposes. Formative evaluation was used to refine resources and revealed an overall positive response by all four knowledge user audiences. The participants highlighted the importance and noted potential benefits in the QOL KT resources developed. Discussion This project revealed the need to develop QOL assessment KT resources specific to the intended audiences. The tailored resources provide older adults living with frailty and their family caregivers, clinicians, healthcare leaders, and decision-makers with practical supports to enable person-centred healthcare. Knowledge translation KT resources developed included 8 infographic brochures, 1 whiteboard animation, 1 live action video, and a webpage. The resources are made freely available online at www.healthyqol.com
What Is Missing from "Patient-Oriented Research?" A View from Public Health Systems and Services Research	Shahram, Sana	University of British Columbia	Introduction and Background In Canada, the Canadian Institutes of Health Research (CIHR) Strategies for Patient-Oriented Research (SPOR) (2014) framework provides guidance for conducting POR. The SPOR Framework can be enhanced through incorporation of public health thinking and approaches that promote understandings of social position and situatedness, which are critical to recognizing and addressing power inequities that permeate research and healthcare relationships and should be a fundamental principle of POR (Commission on the Social Determinants of Health 2008; Sadana & Blas 2013). Methods This presentation will critically examine the CIHR SPOR framework from the perspective of a public health systems and services research lens. It will unpack the central SPOR concepts of "patient," "patient engagement" and "health research" and argue for an expansion of

			these concepts to enhance potential for improvements in health systems and services. Dominant underlying discourses will be critically interrogated alongside consideration for the application of a critical public health lens rooted in the concepts of health equity and social justice, which can help illuminate important differences in power between providers, policy makers and patients/communities that are central to authentic and meaningful participation in research. Results/ Findings In SPOR, the "patient" is the focus of engagement or involvement. Although patient is used as "an overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends" (CIHR, 2014), this definition implicitly revolves around individual patients, without sufficient attention to broader structural forces that shape health and participation in healthcare systems. This intentionally or unintentionally reinforces the dominant societal focus on individuals presenting with a health problem to be treated through biomedicine and acute or chronic healthcare services. Discussion/ implications From a public health systems and services research perspective, the SPOR framework is lacking recognition of the complex social, environmental, economic and policy conditions in which individuals, families, groups, communities and populations are embedded and that impact health through the social locations of individuals and collectives within systems of power and privilege. To address these limitations, the SPOR Framework should include attention to 1) expanding the language of "patient engagement" to community or public engagement, thus including individuals, families, groups and communities; 2) explicitly incorporating principles of community-based participatory research, particularly the importance of an action orientation; and 3) paying specific attention to decolonizing health research for the meaningful inclusion of Indigenous peoples, as well as Indigenous research methodologies and protocols. Additionally, the SPOR Framework could specify the full range of health research to explicitly include public health systems and services research, which would greatly enhance its potential to improve population health and reduce health inequities. Dissemination plan/ KT Approach This topic has been published in a peer-reviewed journal.

xaɢqanaɬ Ɂitkiniɬ (Many Ways of Working Together): Sharing Lessons Learned through Community-Driven, Culturally-Informed Co-Learning and Co-Creation of Knowledge	Shahram, Sana	University of British Columbia	Introduction and Background Ktunaxa Nation Council, Interior Health, University of Victoria and University of British Columbia- Okanagan have formed a partnership to support community-driven and culturally-informed co-learning processes in Ktunaxa ɁamakɁis (Ktunaxa traditional territory). The aim of the partnership is to reorient health systems to learn from Ktunaxa approaches to supporting wellness and inform decolonization of health research as well as health service delivery within Ktunaxa communities. Under the leadership of Ktunaxa Elders and Knowledge Holders, our team developed xaɢqanaɬ Ɂitkiniɬ (Many Ways of Working Together), a locally-specific, community-driven and culturally-informed approach to co-learning and co-creation of knowledge, as aligned with Ktunaxa protocols. Over the last two years, we piloted and validated xaɢqanaɬ Ɂitkiniɬ through a series of community gatherings, intergenerational land-based activities and ceremonial recognitions in Ktunaxa communities. Using xaɢqanaɬ Ɂitkiniɬ, we facilitated community dialogue around the question: Qapsin kiɁin Ɂakaɬxuniyam (What would a healthy community look like?). Based on these conversations, we then identified a number of shared values and priorities for community wellness through iterative refinement with Ktunaxa Elders and Knowledge Holders. Participants commented that this process was "really meaningful, really powerful" and that being able to talk and listen embodied what it means to be a healthy community. During this panel presentation, members of our team will share lessons from our experience, highlighting key principles that are the cornerstone of our research, including: community-driven partnerships led by elders and knowledge holders; culturally-informed processes grounded in local protocols, language and ways of knowing; and co-learning and co-creation of knowledge that advances mutual goals. Include a separate description for each presentation on your proposed panel This panel presentation will include a series of interrelated presentations from team members representing multiple stakeholder groups, including Indigenous community members, researchers, knowledge users and students. Specifically, the panel will consist of the following presentations: Hereditary Chief Sophie Pierre will share her experience revitalizing,

			preserving and restoring Ktunaxa language, traditional knowledge systems and knowledge sharing processes in research. Dr. Christopher Horsethief will discuss the significance of locally-specific and culturally informed methodologies in research; furthermore, he will discuss the role of research and intergenerational knowledge exchange for capacity building in Indigenous communities. Dr. Sana Shahram will share lessons learned from relational approaches to community-driven partnerships and decolonized co-learning and co-creation of knowledge to transform health research. Interior Health Knoledge User(s) will share their experience in participating on this project and how it has impacted their own work in the health system as well as those they work with.
What Happened to Me: Theatre-based Knowledge Translation for Changing Childbirth in BC	Solomon, Dana	Birth Place Lab; University of British Columbia	What Happened to Me : Theatre-based Knowledge Translation for Changing Childbirth in BC Additional non-presenting team members: The Steering Council for CCinBC, Jasmina Geldman, Kathrin Stoll, Winnie Lo, Alison Mclean, Paulomi Niles, Ana Carrizales, Jenessa Galbraith, Ivee Kang, Elle Reimer, Taryn Yoneda, and Saraswathi Vedam. Introduction "Doctors should hear these conversations […]. We are people and we're supposed to be getting care." In 2014-2015, the Birth Place Lab (BPL) collaborated with communities across British Columbia to design a study on families' experiences of care during pregnancy and/or childbirth. In the resulting Changing Childbirth in BC (CCinBC) survey, people across the province reported on more than 3,500 pregnancies. More than 130 people met in 20 focus groups in rural and urban settings to share additional experiences. [1] Methods To report on findings, the BPL team, in partnership with Theatre at UBC, created a theatrical production titled What Happened to Me . The script was composed of quotes from focus group and survey responses, with minimal adjustments to facilitate storytelling. Some characters talked about superb care and respectful, kind providers. Others related disturbing accounts of abuse, mistreatment, assault, and neglect. The play contextualized these experiences through the broader results of the CCinBC study. What Happened to Me was produced with a professional cast and director, based on the theories of ICE (Ideologically Challenging Entertainment); an interdisciplinary approach advocating presenting multiple

			perspectives in an entertaining narrative. ICE has been shown to have a measurable impact on audience responses. [2] Throughout the production process, the authenticity of the performance remained a priority, ensuring that every person working on the show remained cognizant of the real lives and experiences they embodied. Additionally, the lived experiences of cast and crew members informed the performances and supported the creation of the production. Results/Findings We performed What Happened to Me twice in Vancouver and once in Burnaby. After each performance we held "talk back" sessions during which audiences shared suggestions for future knowledge translation. Audiences included patients, health professionals, parents, researchers, and students. Feedback for the production was extraordinary, with many requests for broader dissemination of the play, extending it into a full-length production, and creating additional productions. Researchers specialising in related areas expressed surprise at how moving the production was, given their daily exposure to similar stories. Post-show discussions ranged from sharing frustration with a system that is not conducive to family-centred care, to connecting these perinatal experiences to the broader health care system. We discussed the roles of midwives, obstetricians, doulas, and trainees, the medical billing system, and health professional education. Further KT/Dissemination Participants proposed multiple strategies for improving patient-oriented care. This theatre-based knowledge translation program was an extremely effective mechanism for communicating the results of a patient-oriented research program, and re-engaging the community in developing responsive, pragmatic applications of the findings. Further KT will incorporate these proposals, developing a long-term KT strategy addressing policy, practice, and community needs, implemented in collaboration with consumers, providers, and policymakers.
Understanding Experiences and Needs of Parents and Caregivers of	Tallon, Corinne	Foundry	Introduction/Background In BC, we are now confronting a dual public health emergency that increases both risks and barriers to accessing services for people who use drugs. To reduce the prevalence of opioid use disorder and overdose deaths in Canadian youth, there is a clear need to adopt a patient-centered approach to opioid treatment services. The goal of the Improving

| Youth Who Use Opioids | | | Treatment Together (ITT) Project is to improve experiences and outcomes of health and social services for young people who use opioids, their families, and health service providers who deliver services to this population. It aims to do so by developing health service interventions for youth through a co-design process. In BC, this project is a collaboration between the Canadian Centre on Substance Use and Addiction (CCSA) and Foundry, a provincial integrated youth services initiative. A total of nine community-based workshops were held with these three stakeholder groups. This presentation will discuss the patient engagement methods and outcomes from three workshops hosted with parent and caregivers. Methods Between November 2019 and February 2020, the ITT Project worked closely with community partners to host three parent and caregiver workshops (n=27) in Prince George, Vancouver and Victoria. Our workshops incorporated elements of both community-based participatory research and human-centred design in order to understand parent/caregiver experiences with youth substance use services. These activities then informed the identification of specific needs for improving these experiences. The workshops concluded with a design component where participants prototyped solutions to address these specific needs. The project team conducted a community-specific thematic analysis of the workshop findings, summarized these findings in reports and shared them back with their community partners and participants for validation. Findings We will describe the themes that emerged from parent and caregiver experiences while accessing opioid treatment services for their young people. We will also share the collective needs, associated ideas and the final set of prototyped interventions from participants of the workshops. Discussion/implications Findings from these community-based workshops informed the selection of four unique solutions to improve experiences and outcomes of youth services in BC. The second phase of the ITT project now involves a co-design and implementation process of these prototypes. We are currently working with a group of parents and caregiver workshop participants to develop a handbook for parents of youth who use opioids, which was one of the prototypes that was selected. Dissemination plan Four community-specific reports, a provincial report, and a series of infographics |

			summarizing the findings of the workshops are currently being developed. The provincial report will also compare findings across-communities and stakeholders. All knowledge products will be made available through the Foundry webpage. The findings from these workshops will inform conversations between Foundry and community partners, as well as government, with the goal of leveraging prototypes solutions beyond the scope of this project. CCSA project team members will facilitate these discussions at a national level. We plan to present on our methodology, findings and associated policy implications from these workshops at conferences, and through a series of academic publications.
The Experience Project: Centering the voices of youth with lived experience to improve evidence-informed care	Turuba, Roxanne	Foundry Central Office	Introduction/Background: Mental illness and substance use affects approximately 1 in 4 Canadian youth and young adults. 1 Foundry centres provide services for youth between the ages of 12-24 and utilize a substance use integrated stepped care model (ISCM), involving a number of interventionists. While this model is evidence-informed, it has yet to be validated by youth and young adults. The Experience Project aims to inform this model by asking youth with lived and/or living experience what is important to them and asking peer support workers how they want to be utilized within the ISCM model. This project utilizes an innovative youth engagement framework co-developed with youth for youth, to ensure that the voices of youth with lived experience are centered throughout the project. The overall intention of the project is to develop new content for Foundry's youth peer support curriculum (Phase 1) and improve substance use services for youth and young adults (Phase 2). Methods: A project youth advisory committee was created with 12 youth with lived and/or living experience of substance use and 2 youth peer support workers, all between the ages to 17-24 years old. The youth engagement framework was co-designed with this group and ensures that their voices and perspectives inform every stage of the project. Meetings were held bi-weekly for youth to inform study materials and research activities. From this advisory, 5 youth research assistants were hired to support research activities for the first phase of the study. Survey design was guided by the youth engagement framework. The surveys were administered to the advisory committee and

			the youth research assistants throughout phase 1 of the project to seek feedback on current engagement methods and improve future engagement. This presentation will explore the co-development of a youth engagement framework for Foundry's research activities, the process of acquiring and responding to feedback from youth, including survey design and administration, and preliminary results. It will conclude by discussing lessons learned and the impact of empowering young people to be leaders in research and a central voice in informing their health services. Results/Findings: Important lessons were learned throughout the youth engagement process. Preliminary feedback from youth has highlighted the need to address the lack of diversity within the project team in order to holistically inform project activities and ensure study participants from diverse backgrounds feel safe and welcome. Although data is currently still being collected, we will be reporting on youth engagement experiences, including youth expectations vs. experiences, their comfortability in sharing feedback, whether they felt their feedback was incorporated into the project, and their experiences with professional development opportunities. Discussion/Implications: Our findings will help us improve future engagement activities of youth with lived experience and support the development of a far-reaching youth engagement framework within research. Dissemination plan/KT approach: Our youth engagement framework will be shared with the Foundry network across B.C. and project partners in Ontario. Youth Research Assistants will have the opportunity to support academic journal publications and conference presentations relating to their experience with the project.
Centering Lived Expertise and Equity in a Program of Research	Vedam, Saraswathi	Birth Place Lab at UBC	The Birth Place Lab at UBC specializes in centering the voices of health service users in every aspect of the research process. Our research highlights that disenfranchised populations are more likely to experience barriers and mistreatment when accessing or receiving care. Projects include Changing Childbirth in BC , a provincial study of women's preferences for and experiences of maternity care, and the CIHR funded RESPCCT Study to evaluate respectful maternity care in diverse communities across Canada. The Giving Voice to Mothers Study explored experiences of respect,

			discrimination, and inequities in quality of childbearing care among communities of color, and Giving Voice to LGBTQIA2S+ Families project has further adapted these measures to capture their unique pregnancy experiences. The Decolonizing Birth Research project, co-led by Indigenous researchers explores the applicability of these methods and measures in BC Indigenous communities. Introduction (5 min) : The moderator will briefly provide an overview of the BPL research program and the co-development of our participatory research process. Trust Building (10 min) : Two panelists (Olson, McLean) will describe intentional, relationship-based recruitment of community partners, knowledge keepers, and decision-makers, and how to adapt best practice methods to specific communities Community-responsive survey development (12 min): Patient Partners and Community Engagement Coordinators (McLean, Lo, Metellus, Wenzell) will describe their roles in item selection, an expert Delphi panel, Community Steering Council, to assure relevance, clarity, and importance of study measures. Centering the lived experience throughout the research process (12min): Researchers (Stoll, Niles) will describe engagement, training, and support for community researchers to participate in analysis and interpretation of data; a patient partner (Scott) and KT Specialists (Solomon, Tatum) will describe the community-led design and selection of images, social media tools, and plans for recruitment and KT Codifying equity approaches within the research unit (12min): PIs (Olson, Altman), community and patient partners (Tatum, Metellus), and BPL staff (Beer) will provide a taste of how the BPL strives to apply an equity process throughout study tool development, including continuous inclusion, attention to cultural safety, and reproductive justice training and support for community partners and staff. Talk Back (8-10min) : The moderator will summarize lessons learned and facilitate a discussion with the audience. Bohren, Mehrtash, Fawole, Maung Maung, Balde, Maya, Thwin, Aderoba, Vogel, et al. (2019) How women are treated during facility-based childbirth in four countries: a cross-sectional study with labour observations and community-based surveys, The Lancet, Volume 394, Evaluation of the Strategy for Patient-Oriented Research - Final Report, Canadian Institutes of Health Research, May 17, 2016 McBain B., Phelan L.

			(2016) Building Students' Communication Skills and Understanding of Environmental and Sustainability Issues Interactively and Cumulatively with Pecha Kucha Presentations. In: Byrne L. (eds) Learner-Centered Teaching Activities for Environmental and Sustainability Studies. Springer, Cham. Vedam S, Stoll K, Khemet Taiwo T, Rubashkin N, Cheyney M, Strauss N, McLemore M, Cadena M, Nethery E, Rushton E, Schummers L, Declercq E. The GVtM-US Steering Council. Giving Voice to Mothers: inequity and mistreatment during pregnancy and childbirth in the United States. Reproductive Health, 2019, 16:77 .
Working with research patient partners in conducting MRI study on Myalgic Encephalomyelitis: selection and set up of the functional MRI task	Zhang, Lan Xin	Fraser Health Student Research Assistant | University of Toronto Student	Introduction and Background Myalgic Encephalomyelitis (ME) is a devastating multisystem disease that affects over 580,000 Canadians. It is characterized by symptoms following even trivial physical or cognitive activities. It typically evolves into a long-term disabling condition where patients are unable to tolerate previous levels of activity and have substantial reductions in the ability to engage in various aspects of life. While ME lacks diagnostic tools and treatments, recent Magnetic Resonance Imaging (MRI) research has suggested a promising approach to better understand ME: looking at the brain's inflammatory response. In this project, our research team, which includes patient partners, aims to directly reveal brain metabolic and functional changes underlying neuroinflammation in ME. To do so, we developed a functional MRI task to 1) test differences in attention/working memory between patient and control group and 2) evoke brain activation for pre-post comparison of brain metabolic changes. In collaboration with the patient partners, we have chosen a working memory/attention task from the current literature and modified it to best suit our project. Methods A comprehensive literature search of well-established attention/working memory fMRI tasks was done using term sets including "fMRI", "N-back", and "ME/CFS". Upon task selection, various parameters such as type of stimuli, display and response durations, and total task duration were studied and optimized based on critical input from the patient partners. Currently, the task is being examined for implementation within the team and will then lead to finalization of detailed parameters such as text font, size, background brightness, etc. Results/Findings The N-back

			task was considered to be most suitable in reaching our objectives. The participants are presented a sequence of stimuli where they need to decide if the current stimulus is the same as the one presented N trials ago. Taking into consideration the fatiguing symptom of ME, two versions of the N-back task with different difficulty levels were prepared for testing and implementation, prior to the final application decision. These included a ~ five-minute interleaved two condition task and a ~ four-minute single condition task. Based on trials and critical input from the team including the patient partners, the finalized task will be the one most feasible for activating the brain with optimal level of difficulty. Discussion/implications This work serves as an important step forward with the experimental design. The thoroughly developed and tested fMRI task will be used in the MRI scans for identification of the hypothesized difference in fMRI activation. It is expected this project will yield evidence on the feasible and reliable detection of MRI brain changes in ME patients. This could potentially lead to future research regarding diagnostic biomarker and treatment for ME. Dissemination plan/KT Approach Study results and its link to clinical care will be published in scientific journals and presented at conferences. KT will be done in close partnership with patient partners and clinical healthcare team members to share with the ME patient community, raising awareness of both ME and MRI's role in ME research and perhaps most importantly, for improved ME patient care.