



Putting Patients First: Partnerships for Better Health Research



-  Researchers
-  Patients
-  Caregivers
-  Clinicians
-  Administrators
-  Policy makers

**“NOTHING ABOUT US
WITHOUT US!”**
 People most affected by
 health research should
 have a **VOICE** in
 shaping the research



 @BCSUPPPORTUnit
#PPF17

Date
November 9, 2017, 8:00am - 6:00pm

Location
Marriott Vancouver Pinnacle Downtown
1128 West Hastings Street, Vancouver

<http://bcsupportunit.ca/conference>

BC SUPPORT Unit
Advancing patient-oriented research

Strategy for Patient-Oriented Research
SPOR
 Putting Patients First 

BCAHSN
ACADEMIC HEALTH
SCIENCE NETWORK

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A Welcome from Our Leaders

On behalf of the BC SUPPORT Unit, we welcome you to our inaugural conference, *Putting Patients First: Partnerships for Better Health Research*. We're pleased to welcome a diverse audience from across British Columbia and beyond, from a variety of disciplines, to network and to learn from one another about patient-oriented research (POR).

The BC SUPPORT Unit, launched one year ago today, is part of Canada's Strategy for Patient-Oriented Research (SPOR) led by the Canadian Institutes of Health Research (CIHR). To learn more about the Unit, please visit www.bcsupportunit.ca.

We're excited to learn from our plenary presenters, Vikki Entwistle and Charlotte Loppie, about their experiences in POR, from the presenters of eight breakout sessions, as well as 24 poster session presenters. The conference program is designed to provide foundational learning across the four stakeholder groups that the Unit serves: patients interested in POR, health researchers, health care providers and health system decision-makers.

Please take some time to visit the exhibit tables during the breaks to learn about the Unit's operations and demonstration projects, along with affiliated programs.

We wish you a rewarding conference experience and hope that you find new collaborative POR opportunities through your networking time today.



Stirling Bryan
Scientific Director



Minnie Downey
Executive Director

Frequently Asked Questions (FAQ)

What's this I hear about networking? This is a networking and learning event where participants are encouraged to build new relationships in the interest of developing patient-oriented research. We encourage you to meet people outside of your own institutions at the breaks.



What hashtag should I use to tweet conference proceedings? Use #PPF17 and follow us on Twitter @BCSUPPORTUnit.

How can I give my feedback about this conference? A survey link will be sent to your email address after the conference – we appreciate your feedback and we'll use it to help improve future conferences.

Where can I see the poster session? Posters will be presented in the **Shaughnessy Salon** during the first breakout session at 11:00, and will continue through half of the lunchbreak to 12:30. See the program pages 14-37 for posters' abstracts. Please explore these POR projects to learn from other projects. Vote for your favourite poster! Winners will be announced at 3:35 in the ballroom.

How do I vote for my favourite poster? Ballots are included behind your name badge. **Colour in the number of the poster you** would like to vote for. The ballot box is located at the registration desk.

How do the breakout sessions work? 8 breakout sessions have been programmed: 4 from 11am-12pm and 4 from 2:30-3:30. The sessions will not be repeated. See the program on pages 9-12 for details on these sessions.

Where are the meeting rooms? Our day begins and ends in the ballroom, which will also serve as breakout session rooms **Pinnacle I & II** and **Pinnacle III** along with **Point Grey** and **Dundarave** Rooms. Lunch and refreshments will be served in the foyer. See page 5 for a site map.

Is the hotel wheelchair accessible? Yes, all hotel elevators will bring you to the third floor where meetings are held. All washroom facilities are wheelchair accessible. Washrooms are located on the third floor (beside the Pinnacle Ballroom) and additional washrooms are available on the lobby floor (beside the gift shop).

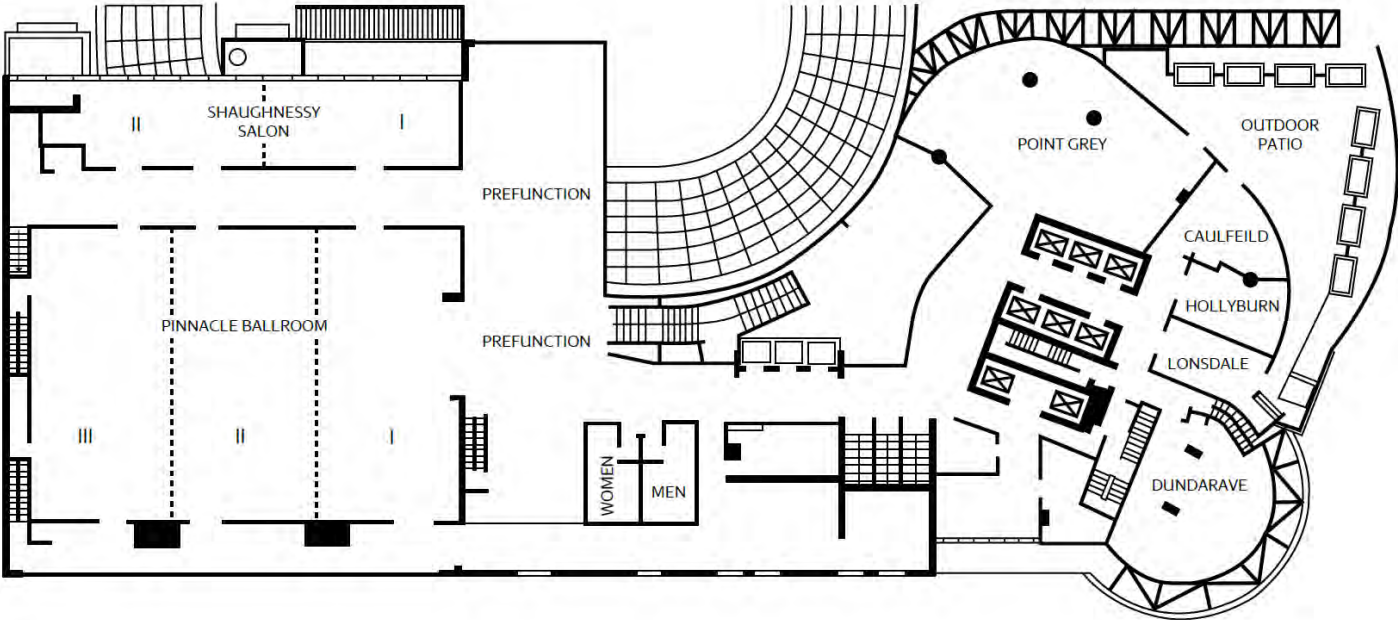
Is there wi-fi available? Wi-fi is available throughout the hotel. The code is **supportunit**.

Where are the washrooms? Washrooms are located just off the foyer near the registration desk.

Are there coat racks? Coat racks are located at registration – keep valuables with you.

Venue Map

THIRD FLOOR



Conference Agenda

Time	Event	Meeting Room
8:00-9:00	Registration and Networking Breakfast	Pinnacle Foyer
9:00-9:05 Plenary Session	Moderators' Remarks Norma McClelland; Rebecca Barnes	Pinnacle Ballroom
9:05-9:10	Opening welcome/prayer	
9:10-9:15	Welcoming Remarks: BC Academic Health Science Network (AHSN) Charles Jago	
9:15-9:20	Welcoming Remarks: Canadian Institutes of Health Research Karim Khan	
9:20-9:30	Welcoming Remarks: BC SUPPORT Unit Minnie Downey; Stirling Bryan	
9:30-10:10 Keynote Speaker	Doing a good thing well? Considering quality in patient-oriented research Vikki Entwistle	
10:10-10:30	Questions & Answers Kimberlyn McGrail	
10:30-11:00	Break: Nutrition & Networking	Pinnacle Foyer
11:00-12:00 Breakout Session	#1a (Re)Building Relationships with Indigenous Communities through Research to Support Revival, Renewal, and Reconciliation for Health Presenters: Leslie Bryant; Danielle Wilson Host: Deanne Taylor	Point Grey
11:00-12:00 Breakout Session	#1b Partnering with Patients and Community Members on Research Teams Panel: Jaime Ascher & Lynn Farrales; Donna Kurtz & Jessie Nyberg; John Chernesky & Ben Mortenson Moderator: Kent Cadogan Loftsgard Host: Colleen McGavin	Pinnacle I & II

Time	Event	Meeting Room
11:00-12:00 Breakout Session	#1c Engaging stakeholders to break the cycle of recurrent fracture Presenters: Sonia Singh; Larry Funnell Host: Rableen Nagra	Dundarave
11:00-12:00 Breakout Session	#1d Fostering Patient Engagement: A Focus on Digital/eHealth Methods Presenters: Erin Michalak; Sara Lapsley Host: Annie Moore	Pinnacle III
11:00-12:30	Poster Presentations <i>Remember to vote for your favourite!</i>	Shaughnessy Salon
12:00-1:00	Networking Lunch	Pinnacle Foyer
1:00-2:00 Plenary Session	Indigenous Perspectives on Patient-Oriented Research Moderator: Cindy Trytten Plenary Speaker: Charlotte Loppie	Pinnacle Ballroom
2:00-2:15	Questions & Answers Kimberlyn McGrail	
2:15-2:30	Break: Nutrition & Networking	Pinnacle Foyer
2:30-3:30 Breakout Session	#2a Can-SOLVE CKD: A patient-oriented research network to transform kidney care in Canada Presenter: Adeera Levin Host: Jenny Cartwright	Pinnacle III

Time	Event	Meeting Room
2:30-3:30 Breakout Session	<p>#2b Why does the BC SUPPORT Unit have Methods Clusters? What are they doing? How can I get involved?</p> <p>Presenters: Stirling Bryan; Alison Hoens</p> <p>Panel of Methods Cluster Leads: Linda Li; Hubert Wong; Leanne Currie; Nick Bansback; Erin Michalak</p> <p>Host: Alison Hoens</p>	Pinnacle I & II
2:30-3:30 Breakout Session	<p>#2c The Power of Lived Experience: Informing Culturally Safe Care for People Who Use Substances</p> <p>Presenters: Bernie Pauly; Karen Urbanoski; Elizabeth Hartney</p> <p>Patient-partners: Fred Cameron; Conor Rosen; Troy Haddad, Jack Phillips; Paige Phillips; Grant Myster</p> <p>Host: Lupin Battersby</p>	Point Grey
2:30-3:30 Breakout Session	<p>#2d Re-imagining Research: Dismantling colonial knowledge structures</p> <p>Presenters: Sheona Mitchell-Foster; Lucy Duncan; Maria Brouwer</p> <p>Host: Rachael Wells</p>	Dundarave
3:30-3:35	Room shift	
3:35-4:30 Poster winner announcement & Wrap up panel discussion & Plenary Session	<p>What is your vision for patient-oriented research over the next 5-10 years?</p> <p>Moderator: Cindy Trytten</p> <p>Panelists: Stirling Bryan; Vikki Entwistle; Adeera Levin; Charlotte Loppie</p>	Pinnacle Ballroom
4:30-6:00	Networking wine & cheese reception (cash bar)	Pinnacle Foyer

Morning Breakout Session Information

11:00AM - 12:00PM

#1a (Re)Building Relationships with Indigenous Communities through Research to Support Revival, Renewal, and Reconciliation for Health



This presentation will describe relational approaches for re-building relationships between Interior Health and the Indigenous communities in the interior region of BC, which falls within the traditional and unceded territories of the Dākelh Dene, Tsilhqot'in, Stl'atl'imc, Ktunaxa, Syilx, Secwepemc, and Nlaka'pamux Nations. We will share examples of how research is supporting revival, renewal, and reconciliation, including the ways in which cultural safety is being systematically integrated into the health system through education and performance management. We will also share insights and learning about the process of fostering allies within the health system as a means of transformation.

Meeting Room: Point Grey
Presenters: Leslie Bryant; Danielle Wilson
Host: Deanne Taylor

#1b Partnering with Patients and Community Members on Research Teams



Lynn Farrales and patient research partner, Jaime Ascher, will describe The Hummingbird Project: An Intersectoral Collaboration to Support Families Who are Pregnant After Stillbirth in a Primary Health Care Context. Donna Kurtz and community elder, Jessie Nyberg will describe A Collective Vision for Urban Indigenous Community-Centered Care in the BC Interior. Ben Mortensen and consumer research partner, John Chernesky, will describe a clinical study investigating vibration therapy that enabled Chernesky to take his first few independent steps since a car crash in 1993 left him with a spinal cord injury.

Meeting Room: Pinnacle I & II
Panel: Jaime Ascher & Lynn Farrales; Donna Kurtz & Jessie Nyberg; John Chernesky & Ben Mortenson;
Moderator: Kent Cadogan Loftsgard
Host: Colleen McGavin

#1c Engaging Stakeholders to Break the Cycle of Recurrent Fracture



This session highlights a patient-oriented research team’s project to address a gap in osteoporosis care identified by patients and health providers. Sonia Singh and patient partner Larry Funnell will discuss their research and implementation journey that brought together a group of leaders, health care providers and patients from Fraser Health’s Emergency, Surgery, Older Adult, Home Health and Primary Care units. Their aim was to develop a health care model that would prevent additional breaks in patients admitted to hospital with an initial fracture. Bringing together literature and experiential and clinical expertise led to the development and testing of a new program. Results were so impressive that local decision makers found a way to fund the program on a permanent basis. The duo will describe the process of bringing the patient-oriented research team together, securing funding from multiple sources, and creating a sustainable impact.

Meeting Room: Dundarave
Presenters: Sonia Singh; Larry Funnell
Host: Rableen Nagra

#1d Fostering Patient Engagement: A Focus on Digital/eHealth Methods



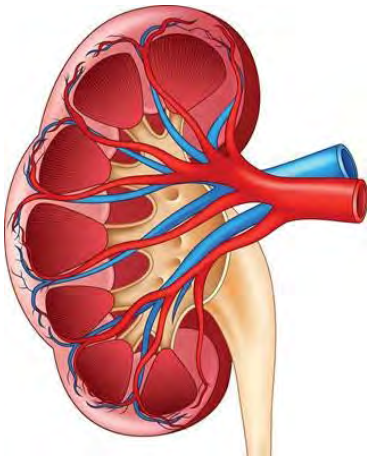
In this session, Erin Michalak and her colleague, Sara Lapsley, will talk about supporting patient engagement in research and knowledge exchange in the digital and eHealth realm. Practical examples of digital engagement methods will be described (for example, social media, online blogging, video production, webinars, telehealth). Findings from a recent study exploring the impact of various online engagement strategies will be presented, and lessons learned and new opportunities explored.

Meeting Room: Pinnacle III
Presenters: Erin Michalak; Sara Lapsley
Host: Annie Moore

Afternoon Breakout Session Information

2:30 – 3:30PM

#2a Can-SOLVE CKD: A Patient-Oriented Research Network to Transform Kidney Care in Canada



Can-SOLVE CKD is a unique pan-Canadian patient-oriented research network that places patients at the centre. Building on three years of priority-setting exercises with patients, their families, care providers, and policy-makers, we have developed a set of 18 research projects that intend to transform kidney care in Canada. These projects, informed by the lived experience of patients, will: enable earlier identification, triage and treatment of kidney disease in vulnerable populations, specifically emphasizing Indigenous peoples; offer novel treatments and strategies to people with inherited and acquired specific kidney diseases; and develop patient-friendly tools and methods of delivering care that are aligned with 21st century technology and ethical principles. This presentation will provide an overview of the processes used to build and launch the network, including its research projects and the core infrastructures necessary to ensure sustainability.

Meeting Room: Pinnacle III
Presenter: Adeera Levin
Host: Jenny Cartwright

#2b Why does the BC SUPPORT Unit have Methods Clusters? What are they doing? How can I get involved?



Methods Clusters are the primary ‘science’ pillar of the BC SUPPORT Unit. The mandate of the clusters is to advance the evidence base of scientific methods, within the context of patient-oriented research, by fostering a community of BC-based methodologists and other stakeholders to undertake methodology-focused projects. Thus far, we have moved to establish five clusters: Knowledge Translation & Implementation Science, Real-World Clinical Trials, Health Economics & Simulation Modelling, Data Science & Health Informatics, and Patient Engagement. There will be a sixth cluster, in Patient-Centred Measurement, to be taken forward later in 2017. The session will provide an overview of the rationale for BC’s approach in establishing methods clusters, and give some examples of projects being taken forward. The leads of all clusters will be at the session, and will form a panel to answer questions and engage in discussion with session participants.

Meeting Room: Pinnacle I & II
Presenters: Stirling Bryan; Alison Hoens
Panel of Methods Cluster Leads: Linda Li; Hubert Wong; Leanne Currie; Nick Bansback; Erin Michalak
Host: Alison Hoens

#2c The Power of Lived Experience: Informing Culturally Safe Care for People Who Use Substances



Societal attitudes related to substance use often permeate health care intentionally and unintentionally. The result is that people often feel unsafe to share their history or current use of substances when accessing health care. While primary care is considered an essential service for every British Columbian, many people who use substances do not have access to primary care and may avoid or delay accessing health care due to concerns and fears about how they will be treated. Patient-oriented research provides a unique opportunity to bring forth the unique perspectives of people with past or current experience with

substance use and primary care to inform strategies for creating culturally safe primary care. In this presentation, we will share the process of designing and implementing a patient-oriented research project composed of people with lived experience, researchers, policy and practice partners drawing on principles of community based participatory research. We will identify both critical considerations in undertaking patient-oriented research in this context as well as key challenges and how they may be addressed in the research process.

Meeting Room: Point Grey

Presenters: Bernie Pauly; Karen Urbanoski; Elizabeth Hartney; Fred Cameron; Conor Rosen; Troy Haddad; Jack Phillips; Paige Phillips; Grant Myser

Host: Lupin Battersby

#2d Re-imagining Research: Dismantling Colonial Knowledge Structures



Existing research structures and health systems in Canada are inherently colonial in nature and this limits genuine engagement from Indigenous and marginalized people in clinical and community health research, bringing unique challenges in patient-oriented research. Using an example from approaches to engaging Indigenous women struggling with substance-use during pregnancy in northern BC, the session will include a short didactic and narrative portion followed by small group discussions on incorporating decolonizing methodologies in strategies for patient-oriented research.

Meeting Room: Dundarave

Presenters: Sheona Mitchell-Foster; Lucy Duncan; Maria Brouwer

Host: Rachael Wells

Poster Presentations

Poster Number	First Author
1	Victoria McCutcheon
2	Iva Cheung
3	Amanda H.X. Lee
4	Janie Venis
5	Harpreet Chhina
6	Clayton B. Hamilton
7	Parisa Ghanouni
8	Laura Nimmon
9	Jim Mann
10	Christina Cassady
11	Davina Banner
12	Marie-Louise Bird
13	Ellen Randall
14	Helen H.L. Chiu
15	Louisa Edwards
16	Laura Ralph
17	Saraswathi Vedam
18	Jenny Leese
19	Lindsay Burton
20	Jenny Leese
21	Adeline Cui
22	Kendall Ho
23	Y. Ingrid Goh
24	Laurie J. Goldsmith



Poster Abstracts

Poster #1: Paediatric Elbow Fractures from a Child's Viewpoint: A mixed-methods study

Victoria McCutcheon^{1,2}, Harpreet Chhina², Ian Pike³, Mariana Brussoni^{3,4}, Damian Duffy⁵, Anthony Cooper^{1,2,5}

¹ Faculty of Medicine, University of British Columbia. ² Department of Orthopaedics, BC Children's Hospital. ³ BC Injury Research and Prevention Unit, Department of Paediatrics, BC Children's Hospital. ⁴ The School of Population and Public Health, University of British Columbia. ⁵ Department of Paediatric Surgery, BC Children's Hospital.

Victoria McCutcheon is a second-year medical student UBC.

Introduction and Background:

Supracondylar fractures of the humerus (SCH) are the most common fractures sustained following a fall among children. The most severe injury types can result in a disruption to the nerves and blood supply resulting in limb threatening injuries and potential life-long disability. Better understanding of mechanism of injury and child-related factors that influence injury, especially for severe cases, is crucial to identifying best practices and informing policy.

Methods:

A prospective, mixed-methods pilot study. Our approach links narratives from photo elicitation interviews (PEI) to mapped images of the locations of injury using geo-tagged photographs children have taken themselves. Quantitative data includes incidence and classification of SCH fractures, bone density and nutritional status, as well as treatments and outcomes to ultimately identify those at risk of long term or irreversible complications.

Preliminary Results:

15 patients recruited. We aim to recruit and interview 20-30 for the pilot portion of our data.

Discussion:

We are exploring why some children sustain more severe fractures than others using their viewpoints of their injury. This is a unique multidisciplinary team collaboration between the Department of Orthopaedics, the School of Population and Public Health, the BC Injury Research and Prevention Unit, and the Office for Paediatric Surgical Evaluation and Innovation, aiming to examine all patient-oriented aspects of this category of fracture.

Dissemination and Knowledge Translation Approach:

Incorporating quantitative and qualitative data provides a measurable view of the patient population and support an enriched view of injury. Spatial analysis of injury locations can also influence injury prevention strategies and neighbourhood planning. This knowledge can be shared with clinicians, patients/care-givers, community-based health teams, and local policy-makers to make timely and impactful improvements.

Poster #2: Increasing understanding of patients' rights under the Mental Health Act

Iva Cheung¹, Sandra Dawson², Jessica Wang², Vanessa Bland³, Laura Johnston⁴, Kimberly Miller⁵, Erin Michalak⁶

¹PhD candidate, Simon Fraser University, ²Patient Partner, ³Clinician knowledge user, Vancouver Coastal Health. ⁴Legal expert, Community Legal Assistance Society, ⁵Senior Leader, Clinical Education and Special Projects, Sunny Hill Children's Centre, ⁶Professor, Department of Psychiatry, University of British Columbia

Introduction and background:

BC's *Mental Health Act* authorizes health facilities to detain people who have a mental disorder and treat them without their consent. But the legislation also sets out rights that must be explained to patients when they are admitted. Giving patients rights advice may have important therapeutic value, giving them a sense of control that encourages them to take an active role in their own recovery. This research engages patient partners and a clinician knowledge user to improve the rights-advice process.

Methods:

This project includes four phases: The first invited people who have experienced involuntarily hospitalization to user-test the effectiveness of the current rights-advice document (a government form) as a communication tool. In the second phase, patient partners will co-create a suite of communication tools that better meets the needs of patients. The third phase will use participant observation and interviews of front-line staff to determine clinicians' barriers and facilitators to providing effective rights advice. These results will inform the fourth phase, in which our research team will develop and deliver a rights-advice training program for clinicians, which will include an implementation plan to help clinical staff use the suite of communication tools.

Results/Findings:

The first phase of research found that participants would like to receive rights information in several formats, participants identified legal language as an impediment to understanding and participants wanted more information about how to exercise their rights. Other phases will be carried out over this next year.

Discussion/Implications:

Our hypothesis is that a rights-advice program focusing on patient empowerment and co-created by stakeholders will increase patients' understanding of their rights and shift clinicians' attitudes about the therapeutic value of rights advice.

Dissemination/KT Approach:

The research team will use an integrated KT approach that aims to generate relevant communications for patients in a context compatible with clinicians' training and workflow.

Poster #3: Motherhood after spinal cord injury: lactation, breastfeeding and autonomic dysreflexia.

Amanda H.X. Lee BSc¹, Theodor Holmgren MD², Shea Hocaloski RN, B.TechN³, Stacy L. Elliott MD^{4,5,6}, Claes Hultling MD, PhD² & Andrei V. Krassioukov MD, PhD, FRCPC^{1,3,4,6}.

¹Experimental Medicine Program, Faculty of Medicine, University of British Columbia, Canada, ²Spinalis SCI Research Unit, Karolinska Institutet, Department of Neurobiology, Care Science and Society, Division of Neurodegeneration, Neurorehabilitation Section, Stockholm, Sweden, ³GF Strong Rehabilitation Centre, Vancouver, BC, Canada, ⁴International Collaboration on Repair Discoveries, Vancouver, BC, Canada, ⁵Departments of Psychiatry and Urological Sciences, University of British Columbia, ⁶Department of Medicine, Division of Physical Medicine and Rehabilitation, University of British Columbia, Vancouver, BC, Canada

Introduction and Background:

Lactation dysfunction following spinal cord injury (SCI) has been described.^{1,2} However, little is known regarding its extent and consequences on breastfeeding. Only 10% of women with SCI found information from obstetricians on postpartum care to be adequate, and obstetricians report insufficient confidence in caring for this population.³ It is imperative to understand the SCI-related barriers to breastfeeding from patient perspectives.

Methods:

We conducted a multi-center (ICORD, Vancouver; Karolinska Institute, Stockholm) study using two online questionnaires for women who breastfed with SCI ($n = 52$). A follow-up study is in progress with expanded questionnaires and sample size ($n = 100$). An expert panel of researchers, health care professionals and women with lived experience (participants) developed the questionnaires. Participants identified specific SCI-related complications to breastfeeding to be researched, and will help develop guidelines.

Results/Findings:

78% of women with high-level SCI reported insufficient milk production versus 35% of women with low-level SCI. 39% of women with high-level SCI experienced Autonomic Dysreflexia (AD) triggered by breastfeeding. AD is transient hypertension triggered by any stimulus below injury and contributes to declines in vascular health and cardiovascular events.^{4,5} Exclusive breastfeeding duration was shorter ($p < 0.05$) in high-level injury (3.3 months) compared to low-level SCI (6.5 months).

Discussion/Implications:

These results confirm impaired lactation and breastfeeding after SCI which is associated with shorter breastfeeding duration, particularly in high-level SCI. AD as a breastfeeding complication is more common than previously suggested and must be addressed. Clinicians must also be aware of patient needs that differ with SCI level.

Dissemination/KT Approach:

Patients on the expert panel drive the research by identifying breastfeeding complications and collaborating with researchers to develop questionnaires. Study participants continue to work with researchers and clinicians on knowledge translation by developing evidence-based guidelines and recommendations for both clinicians and other mothers with SCI.

Poster #4: Feasibility and Acceptability of an ICU Palliative Approach Screening Tool Research in Progress

Janie Venis, RN, MSN¹, Peter Dodek, MD, MHSc², Paddy Rodney, RN, PhD³, Vininder K. Bains, RN, MSN, CNCC(C)⁴, Cara Connaughton, RN, BSN¹, Sim Sunner, RN, BSN¹, Kim Cockburn, RN, BSN¹, Sarah Ho RSW, MSW⁵, Sylvie Galindo, MD⁶, Margaretha Smits⁷, Anne Tuppurainen, SHP, DTh⁸, Sabira Valiani, MD⁹, Kathryn Dunne, MSc, PGeo¹⁰

¹Intensive Care Unit Staff Nurse, St. Paul's Hospital, Vancouver, B.C., ²Center for Health Evaluation and Outcome Sciences and Division of Critical Care Medicine, St. Paul's Hospital and University of British Columbia, Vancouver, B.C., ³ Associate Professor, University of British Columbia (UBC) School of Nursing; Faculty Associate, UBC Centre for Applied Ethics; Research Associate, Providence Health Care Ethics Services, ⁴Critical Care Clinical Nurse Specialist, St. Paul's Hospital, Vancouver, B.C., ⁵Intensive Care Unit Social Work, St. Paul's Hospital, Vancouver, B.C., ⁶Department of Medicine Staff Physician, Lion's Gate Hospital, North Vancouver, ⁷Hospital Volunteer, St. Paul's Hospital, Vancouver, B.C., ⁸Spiritual Care Worker, Holy Family Hospital, Providence Health Care, Vancouver, B.C., ⁹Department of Critical Care Staff Physician, Saskatoon Health Region, ¹⁰Public research team member, Independent Consultant Geologist

Due to an aging population and increasing possibilities of treatments and technological interventions in acute care, hospitalized patients are sicker than ever before. Improving palliative care has become a national priority and according to the Institute of Medicine (IOM), improvement in the palliative approach is necessary to meet present and future health care challenge. Implementation of the palliative approach has a positive impact on patients, their families and the health care team.

The palliative approach prioritizes: an early and clear disclosure about prognosis; sensitive elicitation of patient and family members' values about quality of life and their preferences regarding treatment options. When ICU clinicians integrate the palliative approach into their usual care, patients and families can become partners in care and make more informed decisions that incorporate quality of life goals.

Tools or models that include criteria or 'triggers' to identify patients and their families who may have unmet palliative needs can help ICU clinicians with early implementation of the palliative approach. Using a mixed methods approach, we are developing and testing a 'trigger tool' to help with early identification of patients who might have unaddressed palliative needs such as: understanding of illness/prognosis; treatment options; patient values (what health means to them and what outcomes of treatments are expected or tolerated) and risks/benefits of life sustaining treatments.

Our multidisciplinary research team includes 2 members of the public to ensure relevancy of our subject to patient and family outcomes. We completed 2 interdisciplinary focus groups. The first focus group explored participants understanding of how the palliative approach is used in SPH ICU. The second focus group followed a survey with the aim to develop a palliative approach screening tool. The tool will be tested by ICU nurses and revised. This tool is developed and revised by the St. Paul's Hospital ICU team with the aim to build into daily ICU care.

Poster #5: Development of a cross-cultural patient-reported outcome instrument to measure the health-related quality of life of children and adolescents with lower limb deformities

Harpreet Chhina¹, Anne Klassen², Jacek Kopec³, John Oliffe⁴, Anthony Cooper^{1,5}

Harpreet Chhina is a doctoral student in the department of Experimental Medicine at UBC.

¹Department of Experimental Medicine, Faculty of Medicine, UBC, ²Department of Pediatrics, Clinical Epidemiology & Biostatistics, McMaster University, ³School of Population and Public Health, UBC; Arthritis Research Canada, Vancouver BC, ⁴School of Nursing, UBC, ⁵Department of Orthopaedics, UBC; BC Children's Hospital, Vancouver BC

Introduction and Background:

Lower limb deformities (LLD) describe a range of debilitating congenital and acquired conditions such as limb length discrepancy, limb deficiency, joint abnormalities and associated angular and rotational deformities. LLD cause difficulties in physical functioning, leading to discomfort, pain, and gait disturbance. The abnormal appearance, function and the resulting dissatisfaction are associated with psychological problems. All of these problems along with complex treatment procedures can have a considerable effect on the health-related quality of life (HRQOL) of these children. Our systematic review has indicated the lack of a patient-reported outcome (PRO) instrument to measure the HRQOL of children with LLD.

Aims:

To engage children with LLD and their caregivers to gain an understanding of the HRQOL of children and adolescents with LLD and to develop and validate a patient-reported HRQOL instrument.

Methods:

Mixed methods approach following international guidelines.

Phase 1 involves content development based on the systematic review and qualitative interviews. Face-to-face interviews are being conducted with the children with LLD and their caregivers across Canada, Ethiopia, India and USA. Items will be translated and culturally adapted. Cognitive debriefing interviews with children will provide feedback on items. Items will be shown to clinicians for feedback. **Phase 2** involves field-testing of the HRQOL instrument in Canada, Ethiopia, India, USA. **Phase 3** involves evaluation of measurement properties of the instrument.

Preliminary Findings:

Forty-five interviews to date have been conducted across Canada, USA and Ethiopia.

Discussion/implications:

This instrument will be used by health care professionals and families to examine the effectiveness of treatments in improving patient HRQOL. This process will help develop new, or modify current treatments, health care services and target care, to improve HRQOL for children with LLD.

Dissemination/KT Approach:

We aim to engage with the psychologists, social workers and child life specialist in providing support to this patient population and their families.

Poster #6: The Meaningful Patient Engagement in Research (PEIR) Framework – an Empirically Based Conceptual Framework

Clayton B. Hamilton PhD,¹ Alison M. Hoens BScPT MSc,^{2,3} Catherine L. Backman PhD,⁴ Annette M. McKinnon,³ Shanon McQuitty,³ Kelly English,³ and Linda C. Li PhD⁵

¹Post-Doctoral Fellow, Department of Physical Therapy, University of British Columbia, Vancouver, BC, and Arthritis Research Canada, Richmond, BC, ²Clinical Professor, Department of Physical Therapy, University of British Columbia, Vancouver, BC; Methods Cluster Knowledge Translation Specialist, BC SUPPORT Unit, Vancouver, BC, ³Patient Research Partner, Arthritis Patient Advisory Board, Arthritis Research Canada, Richmond, BC, ⁴Professor, Department of Occupational Science & Occupational Therapy, University of British Columbia, Vancouver, BC, and Senior Scientist, Arthritis Research Canada, Richmond, BC, ⁵Professor, Department of Physical Therapy, University of British Columbia, Vancouver, BC, and Senior Scientist, Arthritis Research Canada, Richmond, BC, Canada

Background:

Patient engagement in research is promoted to improve the relevance and quality of health research, but has little conceptualization derived from empirical data. A conceptual framework would link a comprehensive set of concepts to propose what makes patient engagement in research meaningful. We aimed to develop a conceptual framework for *meaningful* patient engagement in research from a patient perspective, with the intended practical value of it being useful to guide the planning, implementing, and evaluating of patient engagement in research.

Methods:

We conducted a qualitative secondary analysis of in-depth interviews with 18 patient partners from a research centre-affiliated patient advisory board. Data analysis involved three phases: identifying the themes, developing a framework, and confirming the framework. Thematic analysis was conducted to identify and explore the emergent themes. Directed content analysis was conducted to derive concepts from 18 publications related to patient engagement in research to supplement, confirm or refute, and extend the emergent conceptual framework. The framework was reviewed by the four patient partners on our research team.

Findings:

Participants' experiences of working with researchers were generally positive. Eight themes emerged: *Procedural Requirements, Convenience, Contributions, Support, Team Interactions, Research Environment, Feel Valued, and Benefits*. These themes were interconnected and formed the Patient Engagement in Research (PEIR) Framework to explain the phenomenon of meaningful patient engagement in research from a patient perspective.

Implications:

The PEIR Framework provides guidance on aspects of patient engagement in research to operationalize for engagement to be meaningful. It could be particularly useful when patient-researcher partnerships are led by researchers with little experience of engaging patients in research.

Dissemination/KT Approach:

This paper has been submitted for publication. The PEIR Framework is being used to develop an outcome measure for evaluating patient engagement in research. A workbook on the PEIR Framework for researchers is planned.

Poster #7: Stakeholders' perspectives in developing a virtual reality program for children with autism: A community-based participatory research.

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Introduction and background:

Children with ASD have difficulties in communication, thus affecting their social participation. There is a growing use of assistive technologies among therapists to support social participation of children with ASD; however, the technology is often developed without consulting with children or their parents, thus not fully meeting their needs.

This project aimed to explore the perspectives of end-users on their priorities for the content of a virtual-reality platform aiming to facilitate social participation of children with ASD.

Methods:

We interviewed 23 multidisciplinary stakeholders, including 12 parents of children with ASD, seven experienced clinicians working with individuals with ASD, and four high functioning youth with ASD (13-17 years old). Participants were asked to identify issues around social participation and how to address them via assistive technologies.

Results:

Thematic analysis resulted in several themes on barriers to social participation, including "financial barriers", "stigmatization and social barriers", and "lack of existing social opportunities". Participants set priorities on socio-emotional skills and expressed their ideas on potential features of assistive technologies, including "clinical utility", "generalization of skills", and "motivation" to support children with ASD.

Discussion and implications:

This study bridges the existing gap between families and various clinicians in the field of ASD, using a community-based participatory approach to support children's social participation. Valuing stakeholders' ideas and incorporating the identified needs into a virtual-reality program will provide therapists with a client-centered tool to facilitate social participation and improve quality of life among ASD.

Dissemination / 'KT' Approach:

Using integrated and end of grant KT approaches, we involved stakeholders from initial stage of the project to understand their needs. We will use open-access publications and technology-based methods to disseminate findings.

Poster #8: The Power of the Patient: Exploring Inflammatory Arthritis Patients' Perceptions and Expectations of Team Based Care.

Laura Nimmon¹, Linda Li², Catherine Backman³, Raheem B. Kherani⁴, Joyce Ma⁵, Shanon McQuitty⁵, Sharan Rai⁵, Annette McKinnon⁵, Wendy Hartford⁶, Matt Hume⁶

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Introduction and Background:

A critical factor in improving prognosis of chronic disease and decreasing healthcare costs is patients' perceptions of control and ownership over their own healthcare. However, patients' active participation may be compromised by power dynamics associated with healthcare team negotiations around the patients' healthcare. Our aim is to generate insights into the phenomena of healthcare team power negotiations from the perspective of arthritis patients and their multidisciplinary team members.

Methods:

We are purposefully sampling inflammatory arthritis (IA) patients diagnosed within the past five years. Patients are recruited through our research team's social media outlets and health professional networks. Patients participate in 1-hour in-depth interviews, and complete demographic and social network surveys, and journals. Members of patients' healthcare teams are interviewed separately in 20- 30 minute interviews. Our qualitative approach uses a three-tiered analytic strategy: (1) item analysis, (2) pattern analysis, and (3) structural analysis to create an overall picture of the phenomena under exploration.

Results/Findings:

Currently, we have interviewed 15 patient participants (2 male; 13 female; aged 20-70 years) and 15 healthcare team members. Preliminary analysis suggests few patients experience healthcare delivered by what they envision as a multidisciplinary team. Notions of "healthcare team" composition and "power dynamics" vary between patients and healthcare providers. Four themes from the patients' perspective have emerged: (1) ways to gain power, (2) unstable sense of empowerment, (3) knowledge is empowerment, and (4) conduit of communication.

Discussion/implications:

IA patients' experiences with power negotiations and multidisciplinary care are heterogeneous, complex and context dependent. Awareness of patients' perceptions and expectations of multidisciplinary team based care may enhance IA treatment and promote patient empowerment.

Dissemination/KT Approach:

A short instructional video describing healthcare team dynamics has been created for professional training and patient information. We are exploring the use of scripted theatre pieces based on our research for performance presentations within the medical community.

Poster# 9: Involving Patients to Co-Develop Person-Centred Dementia Care in Acute Wards

Jim Mann¹, Lillian Hung^{2,3}

¹Patient Advocate, Alzheimer Society, ²Clinical Scientist, School of Nursing / University of British Columbia, ³Clinical Nurse Specialist, Vancouver General Hospital

Staying in the hospital can be a very stressful experience for patients with dementia. This patient-oriented research took a participatory action approach to involve patients with dementia, families and a large team of interdisciplinary staff in Vancouver General Hospital to co-develop person-centred dementia care education. The aim of the research is to improve the aspects of care environment that matter to patients with dementia.

Jim Mann who is living well with Alzheimer's disease served as a public advisor and worked closely with a nurse researcher to support the development of staff education. Seven patients with dementia in a medicine ward were involved to co-produce patient story videos for staff education. An action research approach, specifically called Appreciative Inquiry was used. The ethical framework developed by the Alzheimer Society of Canada guided the involvement of people with dementia in this project. This poster will present how the ethical framework was operationalized in this research project. Patients and the public advisor in this project provided invaluable advice and useful insights, which helped to shape research outcomes and created a more responsive research impact. In the beginning, the advisor also provided an education workshop for staff, which inspired tremendous interest and engagement of staff in the dementia project. Many innovative research outputs and knowledge translation tools were developed in a year of time, including an interactive education brochure, pocket cards, a communication tool - This is Me, etc. The study suggests that there is a great and untapped potential to involve people with dementia in research and health service development. Meaningful involvement of people with dementia can contribute to making care services in the hospital more responsive to patients' needs.

Poster #10: Spinal Cord Injury Research Evidence (SCIRE) Community: Development of an online knowledge resource for people with spinal cord injuries

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Introduction and Background:

People with spinal cord injuries (SCI) and their families are increasingly seeking health information online but most online SCI resources are not based on current scientific evidence. The *Spinal Cord Injury Research Evidence (SCIRE) Project* is a current resource that provides synthesis of research evidence for a professional audience. We are aiming to expand the scope of this project to include an audience of people living with SCI by developing a consumer module for the SCIRE Project website called *SCIRE Community*.

Methods:

A series of 3 focus group sessions involving SCI consumers and stakeholders (n=19) were conducted to determine priorities, preferences, and feedback on the resource. Qualitative methodology was used to analyze data from the focus groups and the results were used to develop the resource.

Results/Findings:

Nineteen consumers and stakeholders participated in the focus groups. Themes determined through the focus group sessions were used to inform and direct the development of the resource. This has resulted in the creation of a free online resource for the community which is publicly available at www.scireproject.com/community. Evaluation is planned for when the resource has established an online presence.

Discussion/Implications:

By engaging different groups within the community in a collaborative development process, SCIRE Community aims to help address gaps in knowledge for consumers and helps contribute to greater knowledge sharing within the community.

Dissemination/KT Approach:

Dissemination of SCIRE Community is planned to involve a social media and online strategy, partnerships with community organizations, presentation at relevant conferences, and scholarly publications.

Poster #11: Listening and Learning for Improved Stroke Care in Northern and Rural British Columbia: A patient-researcher partnership

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Introduction and Background.

Stroke is a major public health issue, contributing to high morbidity, mortality, healthcare expenditure and personal costs. In concert with population ageing and rising chronic disease, rates of stroke are projected to rise sharply. While this is problematic in urban communities, its impact in rural and northern communities will be profound due to the more limited availability of healthcare services and supports. Understanding experiences of stroke and stroke survivorship can assist healthcare providers and researchers to understand the concerns, needs, and priorities of patients.

Methods.

As part of a broader initiative exploring priority setting for stroke in northern British Columbia, we undertook patient journey mapping to highlight the experiences and priorities of those that have experienced stroke. This was initially undertaken as a series of qualitative interviews and mapping exercises. Through this iterative process, a patient-researcher partnership emerged and led to the creation of an interactive painting to explore stroke survivorship.

Results.

In this poster, we explore the development of this patient-researcher partnership and the eventual creation of an interactive painting. Throughout this process, we engaged in sustained activities aimed at supporting relationship-building and mutual trust, establishing sensitive expectations and timelines, and engaging in mutual discovery and creativity.

Discussion/Implications.

Through this collaborative process, we co-developed patterns of working that fostered meaningful engagement and partnerships. The co-creation of an interactive painting has provided a therapeutic vehicle through which to share experiences of illness and survivorship and to engage with other community members, healthcare providers and researchers about stroke and stroke care in rural and northern settings.

Dissemination/Knowledge Translation (KT) Approach.

This work is underpinned by an integrated KT approach and engages stakeholders, patients and researchers as equal partners in the research process. A number of KT approaches have been utilized, including arts-based KT through the co-creation of an interactive painting, knowledge user reports and summaries, and traditional peer reviewed outputs.

Poster #12: An integrated knowledge translation approach to improve opportunities for participation in community based exercise for people after stroke.

Marie-Louise Bird¹, William B. Mortenson¹, Francis Chu², Angela Wright², Nicole Acerra⁴, Karen Hayley³, Eric Bagnell³, Jennifer Yao⁴, Janice J. Eng¹

¹University of British Columbia, ²Patient Partner, ³Community, ⁴Vancouver Coastal Health

Introduction:

Exercise delivered in community centres may enhance recovery for people living in the community after stroke; however, stroke survivors commonly reduce their physical activity during the first year. Successful implementation of exercise programs to address this requires broad-based input to effect system-wide changes in exercise delivery for people with specific health needs. This study identified implementation factors to optimise adoption commitment and explore program characteristics, processes to access the programs (including navigation in and out of programs) and the range of people needed to ensure success.

Methods:

Using an integrated knowledge translation approach, this project is managed with the guidance of a stakeholder advisory committee (n=8) which includes people living with stroke. We conducted a series of focus groups with representatives from knowledge user groups including stroke survivors, care partners, community organisations (e.g., stroke support groups, community centre staff), healthcare providers and exercise deliverers. Focus groups were recorded, transcribed and thematically analysed.

Results:

Forty-two stake-holders participated. Based on the themes, a new implementation model was developed that defines relationships between community centres and the health authority and includes the voice of patients in the development of local implementation teams.

Discussion/Implications:

Our findings expand on previous frameworks by involving stakeholders throughout the development process. The implementation model supports the capacity of the community sector to offer ongoing services in partnership with the health authority and people after stroke, addressing issues of sustainability and implementation fidelity.

Dissemination/KT Approach:

We learned that the development of partnerships facilitates the implementation and delivery of programs for people after stroke. This message will be shared with a range of knowledge users (i.e. community centres, clinicians and people with stroke), using a range of strategies (i.e. web based resources, plain language summary and scholarly publications), aiming to build awareness and potential replication of the model more widely.

Poster #13: Understanding patients' long-term perspectives on satisfaction with knee replacement surgery: A qualitative investigation

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Introduction and background:

Total knee arthroplasty (TKA) is the highest volume joint replacement surgery in Canada. With up to 20% of patients not satisfied with their results, there is a need to better understand TKA patient satisfaction. This study seeks to learn: *What factors are associated with long-term patient satisfaction following primary TKA surgery?*

Methods:

Using a patient-centred care lens and grounded theory, we conducted semi-structured interviews with 27 patients about long-term TKA satisfaction, roughly 3.5 years post-surgery. Purposeful sampling criteria included sex, satisfaction, and pain and function scores, with over-sampling of not-satisfied patients. Analysis included identification of key categories and their relationships.

Findings:

Patient satisfaction was shaped by patients' ability to adapt to their replacements within their life context. Adaptation was influenced by multiple factors, including expectations, physical outcomes, personal beliefs, and system support. Different types of adaption emerged, e.g.: easy assimilation of an implant that brought full symptom relief and renewed functionality; willing acceptance of improvement, despite less than perfect outcomes; de-emphasis on TKA relative to more pressing life circumstances; ongoing focus on TKA because of severe unresolved knee-related issues.

Discussion and Implications:

Learning first-hand what matters in assessing satisfaction revealed a broader panoply of factors than typically measured in satisfaction surveys—expanding beyond isolated outcome measures to a holistic assessment of how TKA affects experience of life. Setting reasonable pre-surgery expectations about what TKA can do in patients' particular circumstances will help with post-surgery satisfaction. Greater post-surgery support could facilitate adaptation.

Dissemination/KT Approach:

Study findings will be disseminated using various avenues: sharing results with study participants, academic presentations, journal papers, and formal and informal presentations with key stakeholders.

Poster #14: Listening, Learning, Leading: Partnering With Patients To Transform Kidney Research In Canada

Helen H.L. Chiu^{1,2}, Nicolas Fernandez³, Leah E. Getchell⁴, Elisabeth A. Fowler⁵, Mila Tang¹, Heather A. Harris¹, Braden J. Manns⁶, Adeera Levin^{2,7} on behalf of the Can-SOLVE CKD Network

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Introduction and Background:

Partnering with patients in research challenges the traditionally investigator-driven research culture. The Can-SOLVE CKD Network is a patient-oriented kidney research initiative that addresses the most important unanswered research questions across the spectrum of kidney disease.

Methods:

The James Lind Alliance methodology was used to develop a comprehensive research program, constructed around the top priorities as identified by patients, researchers and health care system decision makers. The infrastructure required to facilitate a national research network was determined. A patient-led Patient Council and Indigenous Peoples' Engagement and Research Council were formed to guide the development and outcomes of the Network. The partnership experience was evaluated with a survey to patient partners.

Results/ Findings:

A patient-oriented research program in kidney disease involving three themes (early identification, access to novel therapies, optimal care) was developed. The national Patient Council of >30 members has grown to be the core driver of the Network. Quantitative and qualitative survey results demonstrated that the patient partners are highly engaged, appreciative of the participatory opportunities, and feel empowered through their involvement in research. These results and ongoing feedback led to further strategies to enhance the researcher-patient partnership in the Network.

Discussion/ Implications:

Partnering with patients in research has led to the identification of important research themes to guide a major national research Network. Patient partners are making a unique and important contribution in the research process, demonstrating that researcher-patient partnership is feasible on a national level.

Dissemination/ KT Approach:

As researchers and patients are empowered to lead in kidney research together, including dissemination and implementation of findings along the way, a transformative change in kidney research will ensure impact in the health and care of those living with kidney disease in Canada and beyond.

Poster #15: The PREFeR (PRioritiEs For Research) Project: Building capacity for patient-oriented primary care research in British Columbia

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Introduction:

Primary care is where most patients first consult for health needs. Much of primary care research focuses on understanding patient needs and gaps in care, but patients are infrequently included in prioritizing research ideas. Patient and clinician priorities may significantly differ. PREFeR (PRioritiEs For Research) aims to identify patient-generated priorities for primary care research in British Columbia, and compare patient and clinician perspectives.

Methods:

BC patients will be recruited to an advisory group. Framed by the Dialogue Model and using Nominal Groups Technique, this group will explore experiences of primary care. Patients will review, discuss, and individually rank the themes that emerge. Pooled results will then be used to construct an online survey that will be administered province-wide to capture patient and clinician ratings of each theme's importance. Rapid literature reviews will be carried out. A dialogue event will bring patients and clinicians together to share the survey and review results, aiming for consensus on the top 5-10 patient topics.

Results:

Ten of 11 members recruited to the patient advisory group provided over 70 experiences of 'what stood out' in BC primary care. These were grouped into 19 themes, with *patient-provider communication*, *accessibility difficulties*, *electronic medical records/information sharing*, and *diversifying care* as frequently-cited topics. A rank-ordered list of the top 10-15 priorities identified will be forthcoming.

Discussion:

Involving patients in primary care research priority setting is important to patients, feasible, and fruitful. Similarities in patient and physician priorities may result in greater intervention uptake and engagement. Involving patients in research prioritization ultimately benefits the intended end-users, leading to more efficient use of resources.

Dissemination/KT approach:

Patient group members will contribute to papers and conference presentations, press releases and the final report, which will be made publicly available. Ultimately, patient priorities will drive future funding applications.

Poster #16: Perinatal Outcomes based on Patients' Values of cOmpleXities (POP VOX): a mixed methods study

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Introduction and background:

Optimal labour management requires clinical decisions that occur through shared decision-making by both patient and provider, informed by objective outcomes data. The most accepted outcomes measure is the Adverse Outcomes Index (AOI), composed of ten adverse perinatal outcomes, scored and weighted by severity based on expert opinion. The AOI helps care facilities identify areas for improvement and guide decision making but lacks patient perspectives on outcome prioritization. This study aims to revise the AOI based on patient values.

Methods:

The POP VOX study is a mixed methods study using qualitative (grounded theory) and quantitative (statistical analysis) methods. It is approved by the UBC Research Ethics Board (h16-02688). *Phase 1 (Approaching completion):* Develop instrument for patient survey by creating descriptions of adverse outcomes, written at appropriate (grade 8) reading level. Revise paragraphs based on (a) expert feedback for medical accuracy (via focus group with BC Perinatal Council members), (b) patient feedback for readability and evoked emotion (via interviews with postpartum patients). The qualitative data is then coded and analyzed in order to guide final survey development. *Phase 2:* The final survey will be used to collect patient opinions regarding prioritization of outcomes. This will allow a revision of the AOI based on patient weighting of outcomes. Sampling methodology will need to reflect the spectrum of patient opinion.

The results of the survey will be compared to the weighting of the original AOI. This will allow a new look at labour outcomes that reflect the perspective of mothers.

Results/Findings:

We will present original AOI parameters alongside our adverse event descriptors. Preliminary results from the patient and expert groups (phase 2) will be shared at the BC SUPPORT Unit conference.

Discussion/Implications:

Improvement of maternal healthcare relies on patient input. Including patients' opinions at the level of administrative quality assessment will provide a valuable way for achieving this goal.

Dissemination/KT Approach:

Dissemination of the POP VOX index to the medical community will utilize standard approaches of conference presentation and peer review publication. This will encourage uptake by health authorities. Broader public dissemination will utilize social media.

Poster #17: Patient-oriented Maternity research: Women measure Autonomy and Respect in North America

Saraswathi Vedam¹, Kathrin Stoll¹, Kelsey Martin¹, Ganga Jolicouer², and members of the Changing Childbirth in BC Steering Council³

¹ UBC Midwifery Program, Department of Family Practice, ² Midwives Association of BC, ³community members (including members from: BC Women's Foundation, Women in2 Healing, Immigrant Services Society, UBC School of Population and Public Health, Women's Health Research Institute, Strathcona Midwifery Collective, Access Midwifery, Pomegranate (Midwifery))

Introduction and Background:

Women of colour experience adverse perinatal outcomes despite socio-economic status and access to quality prenatal care¹. Very little is known about how marginalized women experience maternity care, their perspective on relationship-based care, or preferences for care. We describe the development and expert validation of two new quality measures that can be applied at the provider or institutional level to assess patient experience.

Methods:

Through an extensive content validation process including community consultations with over 1300 women, the team developed a cross-sectional online survey and focus group questions, exploring topics including: women's perceptions of reasons for interventions, and experiences of autonomy, respect, or discrimination when participating in a decision-making process. The team completed descriptive, psychometric, and mixed-effects analysis of quantitative data and thematic analysis of qualitative data.

Results/Findings:

Diverse groups of women from across the province (n=4087) provided survey data, and participated in 20 focus groups (n=203). Two new scales utilized in the survey, one measuring autonomy in decision-making (the Mothers Autonomy in Decision Making scale: MADM), and one the experience of respectful care (the Mothers on Respect index: MORi) displayed reliability and construct validity. Women who felt pressured to accept interventions had significantly lower MADM scores as did women who reported racial discrimination and difficulties communicating with their care providers.

Discussion/implications:

Women identified that the most important factors in maternity care are having a respectful and trusting relationship with provider(s), enough time to discuss options for care, and no pressure during decision-making.

Dissemination/KT Approach:

KT working groups, comprising women already engaged with us, and others who expressed interest will be organized to develop and implement targeted KT plans.

Poster #18: Partnering in Research: Maximizing Benefits & Minimizing Risks in Patient- Researcher Relationships

Jenny Leese^{1,2}, Graham Macdonald^{1,2}, Bao Chau Tran, Lianne Gulka², Alison Hoens^{1,2}, Sheila Kerr^{1,2}, Wendy Lum^{1,2}, and Linda Li^{1,2}

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Background:

Patient engagement in research has become a requirement of many research funding organizations. The principle of justice is central, indicating an ethical imperative for people affected to have a say in what and how research is undertaken, if they choose. Little empirical evidence to better understand ethical issues encountered in everyday practice of engagement exists, particularly from patients' perspectives. Our objective is to understand benefits and risks within patient-researcher relationships from the perspectives of arthritis patients with experience engaging in the research process.

Methods:

Participants were invited to participate in an in-depth, semi-structured interview. Eligible participants were current or past members of Arthritis Research Canada's Patient Advisory Board. An iterative thematic analysis was conducted, using a relational ethics framework to explore benefits and risks in patient-researcher relationships.

Findings:

22 participants (from 26 to 68 years old) were recruited. Twenty-one (95%) were female, with time spent as a board member ranging from 1 month to 10 years. 2 themes emerged: 1) "Being Heard": Being heard involved patient and researcher perspectives being taken seriously and acted upon, and required patients and researchers to value different ways of knowing (e.g., lived experience, objective fact); 2) "Being with Supportive People": Participants valued researchers who actively supported them in managing physical and emotional impacts of engagement.

Implications:

Findings provide insight into values and behaviours for fostering ethical patient- researcher relationships in engagement, from patients' perspectives.

Dissemination/KT Approach:

The research team is developing resources to guide researchers and patients who have chronic illness to anticipate and manage benefits and risks that may arise in engaging with each other.

Poster #19: Needs Assessment: Critical to Designing Rural Atrial Fibrillation Care to Rural Communities

Lindsay Burton¹, Camille Galloway¹, Kathy Rush¹, Frank Halperin², Nicole Gorman³, Linda Hatt¹

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Introduction and Background:

Atrial Fibrillation (AF) is a serious heart dysrhythmia that, left untreated, can lead to other health complications. Specialized care for AF is limited in rural communities. The aim was to use patient perspectives to needs assessment to inform development of rural AF care model.

Methods:

AF patients and physicians from three rural communities were invited to participate. Focus groups and surveys were administered, focus group data were thematically analyzed based on AF needs, AF problems, and long-distance care experiences. Survey data were used for descriptive purposes.

Results/Findings:

The most salient theme was the need for more information and education on AF. The other pressing needs identified included timely access to health care professionals (HCP) and support for self-management while on anticoagulants. Participants supported the idea of a credible AF website and were open to videoconferencing, provided they received adequate technological assistance. Physicians agreed that an integrated virtual cardiac clinic would be beneficial to the community. Seven health services were identified by the majority of participants as unavailable or unknown.

Discussion/Implications:

Both patients and physicians emphasized the importance of AF education for self-management and confidence. The local ED is not a suitable replacement as an alternative to the lack of timely access to HCPs. It is clear that the implementation of long distance care would be well utilized in rural communities.

Dissemination/KT Approach:

A one-page plain language summary of findings will be prepared and shared with rural advisory and other stakeholder groups (physicians, health administrators, local health services, clinics, older adults with AF) in each community.

Poster #20: Supporting participation in heart treatment decision-making with health professionals: A qualitative study examining patient information needs and preferences

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Background:

Diabetes can narrow arteries and reduce blood flow to the heart. Studies indicate that patients treated with Coronary Artery Bypass Surgery live longer and suffer fewer cardiac events than those who have stents only. However, patients often don't have the information they need to support them in participating in treatment decisions. We aimed to examine patient perspectives on information needs and preferences to improve heart treatment decision-making with health professionals.

Methods:

Participants were invited to participate in focus groups or one-to-one semi-structured interviews. They were eligible if they had coronary artery bypass surgery or stents, had supported someone who undergoing these treatments or were similar in age to patients with diabetes or heart disease. Heart treatment experiences and what people needed and wanted to participate in informed heart treatment decisions with their doctors were discussed. Using thematic analysis, two researchers independently coded verbatim transcripts. Themes were refined with research team members.

Findings:

Five focus groups of 2-4 people and 4 interviews were completed with 19 patients. 63% were male, and 89% were between 50-80 years old. Most had undergone heart treatment or cared for someone undergoing heart treatment (89%). Two major needs were identified: 1) Involving patients: Personalizing information to support patients in choosing treatments with doctors; 2) Being prepared: Enabling patients to weigh benefits and risks that matter to them in deciding between treatment options.

Implications:

Information gained informs strategies to support shared decision-making in heart treatment, in ways that align with patient priorities.

Dissemination/KT Approach:

Findings will be used in co-creating web-based information resources by patients for patients to support coronary revascularization heart treatment decision-making.

Poster #21: Engaging Members of Underserved Communities in Health Research: Best Practices and Approaches

Adeline Cui¹, Sue Mills², Sophia Park³, Daisy Au⁴, Nancy Clark⁵, Connie Davis⁶, Maylene Fong⁷, Mina Perez Flores⁸, Cheryl Koehn⁹, Sharon Koehn¹⁰, Clayon Hamilton¹¹, Shannon Holms¹², and Diane Lacaille¹³

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Introduction and Background:

Understanding how to involve underserved communities in research processes is an essential, but largely missing part of the patient-engagement and patient voices strategies shaping BC health research and care. These groups face barriers to accessing and receiving high quality care, and involving them in research processes is essential for better serving their needs. We conducted a literature review to determine current knowledge on best practices. Underserved communities included: racial/ethnic minorities, refugees, immigrants, Indigenous Peoples, and low-income and homeless individuals – all living with arthritis and other chronic conditions. This project was the first stage of a larger action-oriented study to understand the barriers to self-management support for underserved populations and potential solutions.

Methods:

Our literature search protocol included grey (Google) and academic literature searches (Medline/PubMed, CINAHL, and Web of Science). Inclusion criteria were English articles published after 2011, under the jurisdiction of Canada, USA, Australia, or Europe that provided significant information on how to partner with underserved communities in research. The final sample included 65 documents and relevant information was extracted and analyzed for common themes. The findings were compared, and contrasted, with other relevant models in the field.

Results:

Key areas for engaging underserved populations in research include: inclusion, population, motivation, pre-engagement, nature of participation, barriers and solutions, training, meaningful engagement, remuneration, and post engagement. Our findings support other models developed in the field but provide some more detailed 'how to' insights into some essential elements for involving these communities in research studies.

Discussions/Implications:

Our literature review findings provide an important starting place for a draft model that can be used to stimulate discussion and help us to better understand what patient engagement means for underserved communities.

Dissemination/KT Approach:

We plan to translate our draft model into 3 languages and disseminate it to community based organizations serving underserved populations for review and further refinement.

Poster #22: TEC4Home: Tele-monitoring to support the transition of Heart Failure patient care from hospital to home

Kendall Ho¹, Helen Novak Lauscher², Jennifer Cordeiro³, Craig Mitton⁴, Hubert Wong⁵, Ehsan Behzadhar⁶, Amrit Bhullar⁷, TEC4Home Health Innovation Community

¹Professor and lead, Digital Emergency Medicine, UBC Department of Emergency Medicine, ²Associate Lead, Digital Emergency Medicine, UBC Department of Emergency Medicine, ³Research Coordinator, Digital Emergency Medicine, UBC Department of Emergency Medicine, ⁴Professor, UBC School of Population and Public Health, ⁵Associate Professor, UBC School of Population and Public Health, ⁶Post Doctoral Student, UBC School of Population and Public Health, ⁷Research Assistant, Digital Emergency Medicine, UBC Department of Emergency Medicine

Introduction and Background

TEC4Home evaluates the efficacy of home health monitoring to support the transition of Heart Failure (HF) patients from hospital to home. At discharge, patients receive blood pressure cuff, weight scale, pulse oximeter and tablet in order to submit measurements and answer questions about their HF symptoms daily for 60 days. A monitoring nurse reviews the data and provides support to by phone. We hypothesize that TEC4Home will reduce ED/hospital readmissions, and improve quality of life and self-management behaviours for HF patients.

Methods

Sixty-nine participants were recruited from Vancouver General Hospital (VGH), St. Paul's Hospital (SPH) and Kelowna General Hospital (KGH) from November 2016 to July 2017. They filled out an enrollment (pre-) survey and a completion (post-) surveys 30 days after monitoring finished.

Results/ Findings:

Twenty-two patients (12 from VGH, 2 from SPH, and 8 from KGH) who completed monitoring and all surveys were included in this preliminary analysis. 12 ED/hospital readmissions were avoided (5 in VGH, 1 in SP, 6 in KGH). Significant improvement in participants' health-related quality of life (+22.3 at VGH/SPH and +32.0 at KGH out of 100) and in self-management behaviour (+20.5 at VGH/SPH and +15.5 at KGH out of 100) were demonstrated.

Discussion/ implications

Preliminary findings suggested cost savings for health system and improved quality of life for patients with improved ability to self-manage. The full evaluation of the 69 patients will be done in January 2018, and the results will guide the 18-month randomized controlled trial in 22 BC communities in 2018-2019.

Dissemination/ KT approach

Iterative KT will occur through results sharing with health authorities, Ministry of Health, and clinicians, patients and family in all research sites. The patient advisory committee with members from the 22 communities will guide dissemination of results to the public. Academic publications, presentations at research and policy forums will be pursued. Spreading TEC4Home to other communities over time will be done with health authorities.

Poster #23: Pediatric Rheumatology Patients and Caregivers Have Research Ideas Too!

Y. Ingrid Goh, PhD^{1,2}, Jennifer S. Takuski, MSc^{1,2,3}, Brian M. Feldman, MD, MSc^{1,2,3}

¹Division of Rheumatology, The Hospital for Sick Children; ²Child Health Evaluative Services, SickKids Research Institute; ³Department of Medicine, University of Toronto.

Introduction and Background:

Researchers typically design studies and then ask patients/caregivers to participate. This approach results in the omission of patients'/caregivers' input into the creation of research projects, which may affect the feasibility of the project. The recent movement towards patient-oriented research can potentially bridge this discord.

Objectives:

The primary objective of this quality improvement project was to identify research topics that are of interest to SickKids' rheumatology patients and their caregivers. The secondary objective was to identify individuals who would be interested in co-producing research.

Methods:

All patients and their caregivers attending the SickKids rheumatology clinic from July-August 2017 were asked to complete a one-time, anonymous survey. The survey asked them for their research ideas, as well as their interest in collaborating with the research team to develop future research.

Results/Findings:

360 surveys were distributed to patients and their caregivers. 335/360 (93%) surveys were returned, of which 230/335 (69%) contained responses. 118/230 (51%) surveys contained research ideas which included disease-specific research questions (22%) and research in alternative treatments (18%). Respondents also used this survey to provide feedback on clinic operations and request support in managing their condition. 91/335 (27%) respondents indicated that they were interested in developing research.

Discussion/Implications:

This is the first time we formally asked patients and caregivers for their research ideas and interest in collaborating to develop research. We plan to ask stakeholders to prioritize these suggested ideas. Collaborating to identify these priorities will enable us to develop meaningful pediatric rheumatology research projects.

Dissemination/KT Approach:

Findings will be disseminated to various stakeholders through our website, papers, and presentations.

The results from this project will directly influence the direction of future research in our Division and potentially other pediatric rheumatology institutions.

Poster #24: Lessons Learned about Patient Engagement in Designing Research to Improve Patient Satisfaction with Total Knee Arthroplasty

Laurie J. Goldsmith¹, Nitya Suryaprakash²

On behalf of the Engaging Knee Arthroplasty Patients (EKAP) team

¹Faculty of Health Sciences, Simon Fraser University, ²Centre for Clinical Epidemiology and Evaluation, Vancouver Coastal Health Research Institute

Introduction/Background:

Total knee arthroplasty (TKA) is the most common joint replacement surgery in Canada. However, up to 20% of patients report dissatisfaction post-surgery. Our research team has previously documented multiple areas for improvement for TKA patients. We are using patient engagement to plan follow-up research on interventions to improve patient satisfaction with TKA surgery.

Methods:

We recruited 15 former TKA patients (the “Patient Partners Group;” PPG) from earlier research and a clinical registry. We purposefully recruited patients of varying age, genders, ethnicities, and TKA experiences. Four research team members (2 researchers, 2 patients) met twice with the PPG to consider interventions suggested by previous research and to suggest other interventions for improving patient experience and satisfaction after TKA. We reflected on our experience with these meetings to provide suggestions for effective patient engagement.

Results/Findings:

Although we developed our plans for PPG meetings following standard patient engagement guidelines, we underestimated the time needed for developing a foundation for co-building activities. Welcoming and using constructive criticism to refine our work and approach allowed for quick course correction. Subsequently allocating significant time for getting to know each other and to ensure full learning from all was key to success.

Discussion/Implications:

Effective patient engagement not only relies on the CIHR guidelines of operating with respect and inclusiveness, providing support, and engaging in co-building. Effective patient engagement requires that teams be open to constructive criticism from any team member and that teams quickly learn and recover from missteps.

Dissemination/KT Approach:

We will disseminate our learnings about patient engagement through the BC SUPPORT Unit, interactions with knowledge users, including our end-of-project knowledge translation webinar, and academic journals and conferences.

Plenary and Breakout Session

Presenters' Bios

Jaime Ascher is the President of Still Life Canada: Stillbirth & Neonatal Death Education, Research & Support Society (SLC) and a member of the SLC Research team. As a bereaved mother of two stillborn sons, Jaime is a Community Partner (patient partner) who has participated in a Community-Based Participatory Research project whereby parents affected by stillbirth conducted research within their community to improve care and support. Jaime is also part of the research team as a Community Partner on a new 3-year project that Still Life Canada is collaborating with Fraser Health and the South Community Birth Program (Vancouver). It is a Participatory Action Research project that will focus on supporting women/families in subsequent pregnancies after they have experienced a stillbirth.

Nick Bansback is a Methods Cluster Co-Lead for Health Economics and Simulation Modelling for the BC SUPPORT Unit. He's an Assistant Professor at the School of Population and Public Health at the University of British Columbia (UBC), and the Program Head of Decision Sciences at the Centre for Health Evaluation & Outcomes Sciences (CHÉOS), one of the core partner organizations of the BC SUPPORT Unit. He holds a PhD in health economics from the University of Sheffield (UK), and completed his postdoctoral training at UBC. Currently a Canadian Institutes of Health Research (CIHR) New Investigator, his research is focused on using decision science to maximize the value patients and the public gain from health care.

Rebecca Barnes currently fills several roles, all with the common thread of enhancing health research capacity, through sustainable and standardized systems and processes. She is responsible for overseeing Research Engagement and Outreach for the Vancouver Island Health Authority, she is the Lead for the BC SUPPORT Unit Vancouver Island Centre, and she is the Program Leader for the Canadian Tissue Repository Network. Rebecca has worked in health research and biobanking for over 12 years. She holds a Bachelor of Science (Biology) and a Master's degree (Environmental Toxicology/Carcinogenesis).

Stirling Bryan, as the BC SUPPORT Unit's Scientific Director, develops and oversees the Unit's methods clusters and leads the planning and implementation of science-related aspects of all Unit operations including the Provincial Hub's services and the regional centres. Additionally, Stirling is Director of the Centre for Clinical Epidemiology & Evaluation (C2E2), and full professor in the Department of Medicine at UBC. He is also an honorary professor at the University of Birmingham (UK), and an Associate of the UBC Centre for Health Services & Policy Research (CHSPR). In 2005/2006, he was a Commonwealth Fund Harkness Fellow in Health Care Policy, based at Stanford. He sits on the UK Medical Research Council's College of Experts, the Scientific Committee of the International Health Economics Association, and the Editorial Board of Health Economics, a journal for which he is also an Associate Editor. Stirling's research interests span the areas of economic evaluation and health technology assessment from applied and methodological perspectives, including preference elicitation and outcome measurement, and the use of economic analyses in decision-making.

Leslie Bryant, Regional Practice Lead, Research & KT, Indigenous Populations, Interior Health. Leslie's research interests lie in the areas of health service delivery, Indigenous health, knowledge translation and application within healthcare and research capacity building. Leslie is working on developing key relationships with Indigenous communities and academic researchers across Canada to enable collaboration and networking opportunities. She is engaged in the measurement of KT activities, particularly the measurement of relationship building and its influence on knowledge transfer.

Kent Cadogan Loftsgard has been a Patient Partner to the BC SUPPORT Unit since the summer of 2016. In addition to his lifelong cerebral palsy and asthma, as well as his endless efforts as a patient advocate and caregiver, Kent contributes his diverse professional expertise in health media production, health specialty journalism, interdisciplinary health care education, and health research to complement the collaborative development and growth of the Unit.

John Chernesky is a C-6/7 incomplete quadriplegic. He was injured in a car accident in 1993. Following his injury, he travelled extensively, engaging a variety of rehabilitation techniques in order to maximize his recovery. He is very active in the SCI community and involved in numerous sports including para-rowing, wheelchair rugby, wheelchair tennis and downhill skiing. John is also highly involved in SCI research, having participated in many studies and is the co-author of a recent study on vibration platforms and their effect on muscle spasticity. He is currently employed at The Rick Hansen Institute as their Consumer Engagement Lead.

Leanne Currie is the Methods Cluster Lead for Data Science and Health Informatics (DaSHI) for the BC SUPPORT Unit. Her research focuses on the thoughtful application of information communication technologies in health care; this technology supports patients and their families by improving access and ensuring they get the best care they can. She is particularly interested in how design can support the effective re-use of data to support patient and clinician decision making. Prior to joining the BC SUPPORT Unit she collaborated with Vancouver Coastal Health in areas of student practice education, clinical education and guidelines for treating Chronic Obstructive Pulmonary Disease in Vancouver's Downtown Eastside. Her work helped to improve the coordination of nursing students' clinical training programs within the Lower Mainland. Leanne has received more than \$11.8 million of grant funding in research projects from organizations such as the Canadian Institutes for Health Research (CIHR), the Michael Smith Foundation for Health Research (MSFHR) and the Canadian Cancer Society Research Institute, National Science and Engineering Research Council & the US National Institutes of Health. She presents her findings to international audiences and is routinely published in peer-reviewed journals.

Minnie Downey, as the BC SUPPORT Unit's Executive Director, provides operational leadership and oversees the implementation of the Unit's business plan. In her most recent position with the Fraser Health Authority she worked in the strategic projects division of the Office of the CEO. In this role she championed Community Action and Resources Empowering Seniors (CARES), a collaborative project that spanned BC and Nova Scotia, and proactively engaged with seniors to delay or reverse frailty. Previously she was program director for Fraser Health's Cardiac Services, providing leadership for the development and execution of services across the health authority's 13 facilities and community programs. This work led her to receive the 2015 Golden Apple Innovation award from the Health Employers Association of BC for her leadership in the regionalization and standardization of the Implantable Cardiac Electrical Devices (ICED) project. Minnie holds a Master of Arts in Health Leadership from Royal Roads University, Bachelor degrees in Technology and Business Administration from Memorial University of Newfoundland, and a Diploma in Medical Laboratory Technology Science from the College of the North Atlantic. She also completed a fellowship in Executive Training in Healthcare Improvement with the Canadian Foundation for Healthcare Improvement, and is a Certified Healthcare Executive with the Canadian College of Healthcare Leaders.

Vikki Entwistle re-joined the Health Services Research Unit in 2013 as Professor of Health Services Research and Ethics. Vikki started her academic career in health services research as a research fellow at the NHS Centre for Reviews and Dissemination at the University of York (1994-1998). She then joined the Unit on a Leverhulme Trust Fellowship relating to patients' participation in treatment decision-making. Vikki spent 2003-2004 as a Harkness Fellow at Harvard School of Public Health developing work on patients' contributions to healthcare safety. She worked in the Unit, as Senior Research Fellow then Reader, until September 2005 when she moved to the Social Dimensions of Health Institute at the Universities of Dundee and St. Andrews as part of the Alliance for Self Care Research. She was promoted in 2007 to Professor of Values in Healthcare. Vikki has served on various research/policy committees. She was Editor of Health Expectations from 2007-2010 and is currently co-co-ordinator of the International Network on Feminist Approaches to Bioethics.

Lynn Farrales is a Family Physician and a Clinical Assistant Professor in the Department of Family Practice at the University of British Columbia on Coast Salish Territories. Her areas of research interest include Refugee Health and Stillbirth. As a clinician, she is a Family Physician with a focus on immigrant, refugee and student health. Lynn holds a Master's Degree which introduced her to qualitative health research with first generation women of colour prior to medical school. As a mid-career Family Physician, she returned to pursue her research interests within the Clinician Scholar Program at UBC's Department of Family Practice where she conducted a community-based participatory research project with bereaved parents whose babies were stillborn. She began her studies within the PhD program in

Family Medicine at Western University in 2016. She is currently Site Faculty for Scholarship in the UBC Family Practice Residency Program.

Larry Funnell is a long-time volunteer with Osteoporosis Canada (OC), and is a past Chair of the Canadian Osteoporosis Patient Network and a former member of OC's National Board of Directors. He sits on the Guidelines Committee of OC's Scientific Advisory Council, is a member of the COPN Executive Committee, and recently accepted an appointment as a Research Ambassador for the Institute of Musculoskeletal Health and Arthritis of the Canadian Institute of Health Research. Larry was diagnosed with osteoporosis in 1998 after suffering his eighth fracture. Effective treatment and lifestyle changes have kept him fracture free for more than 17 years.

Alison Hoens is the Knowledge Translation Specialist for the Methods Clusters at the BC SUPPORT Unit. She undertook her undergraduate and postgraduate education in Physical Therapy at UBC and Curtin University in Australia respectively. Alison is currently seconded to the BC SUPPORT from her positions as Knowledge Broker to the UBC Faculty of Medicine Department of Physical Therapy and as the Research, Education and Practice Coordinator for Physical Therapy at Providence Health Care.

Karim Khan is Scientific Director of the Canadian Institutes of Health Research's Institute of Musculoskeletal Health and Arthritis. He is a professor and clinician-scientist in the Department of Family Practice and School of Kinesiology at UBC, where he has taught since 2000. He is currently co-director of UBC's Centre for Hip Health and Mobility, a \$40-million centre funded by the Canada Foundation for Innovation. On the international stage, he took a two-year leave in 2014 to serve as the Director of Research and Education at Qatar's Aspetar Orthopedic and Sports Medicine Hospital – the first of its kind in the Gulf Region. He has also taught at universities in Australia and Norway. Karim has achieved international recognition for studies promoting greater mobility among vulnerable seniors, and is a respected leader in the field of tendon injuries, osteoporosis, fall prevention and exercise promotion for health. He has a track record of over 300 highly cited peer-reviewed publications, and has, since 2008, been the editor-in-chief of the high-impact British Journal of Sports Medicine (BJSM), a leading international journal that focuses on the role of physical activity for health. He is also the co-author of the best-selling textbook Brukner & Khan's Clinical Sports Medicine. Karim is passionate about knowledge translation and patient engagement, and was responsible for establishing the BJSM's social media accounts, podcast and blog that have reached millions of viewers and listeners. His association with CIHR began 16 years ago, when he received funding as a CIHR New Investigator from 2001 to 2007. Karim earned his medical degree and PhD at the University of Melbourne, and his MBA at UBC.

Donna Kurtz is an Associate Professor in the UBC Faculty of Health and Social Development School of Nursing, and is a nurse educator and qualitative researcher. She is of Métis and European heritage, and uses decolonizing Indigenous methodology approaches to Indigenous, community-led, multi-sector participatory research partnerships for equitable and improved access to health promotion and chronic disease prevention across generations that benefit communities and foster respectful non-racist, non-discriminatory health care provision and policy change. She is involved in cultural safety curriculum development and undergraduate, graduate and non-profit organization education, and Indigenous health science student recruitment and retention programs. Donna is a member of a campus-wide initiative in addressing the Truth and Reconciliation Calls for Action. She currently holds a CIHR Institute of Aboriginal Health grant for integration of Traditional and Western approaches in diabetes and obesity services for urban Indigenous communities. Although her work is mainly focused in Western Canada, she's also an Adjunct Professor with Federation University Mt. Helen, Australia. She is the past Co-Chair of the International Network of Indigenous Health Promotion Professionals.

Sara Lapsley has a Masters in Counselling Psychology from the University of British Columbia. She works at the BC Forensic Psychiatric Hospital providing group and individual counselling to patients with severe and persistent mental illness. She is a longstanding network member and peer researcher with the Collaborative REsearch Team to Study Psychosocial Issues in Bipolar Disorder (CREST. BD). She has published and presented in the areas of bipolar disorder,

patient-centred care in forensic populations, peer support, and military mental health. Sara is a musician who loves gardening and is a volunteer broadcaster with the UBC campus radio station.

Adeera Levin is a Professor of Medicine and Head of the Division of Nephrology at the University of British Columbia. She is the Executive Director of the BC Provincial Renal Agency, which oversees the care, planning, and budgets for kidney services in BC. In this capacity she has leveraged her epidemiological training, clinical knowledge, and health outcomes research expertise to develop an evidence-based transparent system which enhances the care of patients across the continuum of care. Her major research areas of interest include non-traditional risk factors for cardiovascular disease in CKD patients (with a particular focus on anemia, phosphate, and vitamin D, and progression of CKD variability), as well as models of care. She has nearly 300 publications in peer-reviewed journals, and has mentored clinicians, researchers, and academics. Adeera is a co-principal investigator of Can-SOLVE CKD, a \$40-million national network that aims to transform treatment and care for Canadians living with, or at risk for, chronic kidney disease. Adeera has won numerous awards for teaching and research. She is a recipient of the Order of Canada and has received the Kidney Foundation of Canada Medal for Research Excellence, and the Aubrey J. Tingle Prize in recognition of a body of work which has impacted patients in BC and elsewhere. She was inducted in the Canadian Academy for Health Sciences in 2014, and elected President of the International Society of Nephrology 2015-17.

Linda Li is the Methods Cluster Lead for the Knowledge Translation and Implementation Science Methods Cluster for the BC SUPPORT Unit. Linda Li is Professor, Harold Robinson/Arthritis Society Chair in Arthritic Diseases, and Canada Research Chair in Patient-Oriented Knowledge Translation at the Department of Physical Therapy, University of British Columbia. She is also a Senior Scientist at the Arthritis Research Canada. Linda earned a BSc in Physiotherapy at McGill University, an MSc at the University of Western Ontario, and a PhD in Clinical Epidemiology at the University of Toronto. Funded by Canadian Institute of Health Research (CIHR), she completed a post-doctoral fellowship in clinical epidemiology/knowledge translation at Ottawa Hospital Research Institute. Linda is currently a Michael Smith Foundation Health Research (MSFHR) Career Investigator, and a past recipient of the American College of Rheumatology Health Professional New Investigator Award, and the CIHR New Investigator Award.

Charlotte Loppie is a Professor in the School of Public Health and Social Policy at the University of Victoria, and the Director of the university's Centre for Indigenous Research and Community-Led Engagement. The Centre provides a supportive environment for students, researchers and communities to engage respectfully in research activities aimed at addressing the health disparities experienced by First Nations, Inuit and Métis peoples in Canada. Charlotte's guiding principle is to be of service to the Indigenous communities who will benefit from her research. To that end, she has made it her life's work to bring Indigenous peoples into research projects that touch their lives. Her goal is to empower communities, build research capacity, and tackle the health disparities faced by Indigenous peoples. She partners with First Nation communities, regional and national Indigenous organizations, health charities and government bodies on a range of projects. Her research interests include Indigenous health inequities, Indigenous HIV/AIDS, barriers to accessing the social determinants of health, racism and cultural safety, cancer among Indigenous peoples, research capacity-building and the sexual and reproductive health of Indigenous women, among others. Charlotte is the CIHR Gold Leaf Prize winner for Transformation: Patient Engagement.

Norma McClelland is a retired nurse with a graduate and postgraduate degree in health care. She has experience as a caregiver to both her parents and as a patient herself. She has volunteered with Patient Voices Network since 2011. Her volunteering opportunities include Hospice, End of life Care, Patient Advisory Council (Vancouver Island) TORCH (Towards Optimal Residential Care Health) and Advancing Patient-Oriented Research with the BC SUPPORT Unit.

Kim McGrail is the Data Lead for the BC SUPPORT Unit. Concurrently she is a faculty member at the UBC Centre for Health Services and Policy Research, Scientific Director for Population Data BC, an associate professor at the University of British Columbia School of Population and Public Health, and an associate with the Centre for Clinical Epidemiology and Evaluation (C2E2). Kim's current research interests are in evaluation of health system policy interventions, aging and the use and cost of health care services, and governance of access to data for research purposes. Kim was the 2009-10 Putting Patients First: Partnerships for Better Health Research (2017)

Commonwealth Fund Harkness Associate in Health Care Policy and Practice. She holds a PhD in Health Care and Epidemiology from the University of British Columbia, and a Master's in Public Health from the University of Michigan.

Erin Michalak is the Patient Engagement Methods Cluster Lead for the BC SUPPORT Unit. A professor in the Department of Psychiatry at the University of British Columbia, her background is in psychology with a PhD from the University of Wales College of Medicine in the United Kingdom. Her research expertise lies in patient-engagement in research, Community Based Participatory Research, knowledge translation, bipolar disorder, quality of life, eHealth/mHealth and implementation science. Erin's research has been well supported by the Canadian Institutes of Health Research (CIHR) and the Michael Smith Foundation for Health Research, amongst others. She is the founder and leader of the 'Collaborative REsearch Team for the study of psychosocial issues in Bipolar Disorder' (CREST.BD), a CIHR-funded Canadian network dedicated to collaborative research and knowledge exchange in bipolar disorder, and Program Director for the Asia Pacific Economic Cooperation (APEC) Digital Hub for Mental Health. She has published over 100 scientific articles and several books and book chapters. Erin is also a fan of work-life balance. She and her husband Richard are avid mushroom hunters where they live on the Sunshine Coast, breeders of Giant Schnauzers, and minions to their Bengal cats.

Sheona Mitchell-Foster is a practicing Obstetrician Gynecologist and Assistant Professor with the Northern Medical Program based in Prince George. After medical school at the University of Calgary, she completed her specialty training and Clinical Investigator fellowship in Vancouver at the University of British Columbia as well as a Masters of Public Health at John Hopkins Bloomberg School of Public Health. Sheona has a keen interest in the reproductive health of marginalized populations and has worked extensively in East Africa on cervical cancer prevention using HPV self-collection for screening, and continues to work on innovative approaches to cervical cancer screening in Indigenous women in northern Canada. Other areas of current research include perinatal substance-use in northern British Columbia with a focus on Indigenous and underserved populations in rural and remote geographies. She is the academic lead on a new holistic and culturally safe housing initiative dedicated to women struggling with substance-use during pregnancy and post-partum in northern BC.

Ben Mortenson is an assistant professor in the Department of Occupational Science and Occupational Therapy at the University of British Columbia. He is a principal investigator at the GF Strong Rehabilitation Research Program and International Collaboration on Repair Discoveries. He is the recipient of the prestigious CIHR New Investigator career scientist award, and an experienced mixed-methods researcher with over 50 peer reviewed publications. His work is centered on four main populations: assistive technology users, informal and formal caregivers, individuals with spinal cord injury, and residents in long-term care. Examples of his current research include studies to a) evaluate the outcomes of scooter skills training, b) identify barriers and facilitators to mobility and participation among people who use different types of mobility devices, c) develop novel technologies to help informal (family) caregivers, and d) improve self-management skills among people with spinal cord injury through the use of a mobile app.

Jessie Nyberg is a Shuswap Elder registered to the Canoe Creek Band and currently lives in Kelowna. Her Shuswap name, Busy Ant, was given to her by her grandmother when she was just one year old because she did not like to stay still and kept very busy. Jessie is a wife, mother of two, and grandmother of three. After practicing for 45 years she is also a retired registered nurse with a Bachelor of Science Degree. Since 2003 she has been Elder Advisor of the Aboriginal Steering Committee of the Human Early Learning Partnership Population Health research project. Jessie has been involved as a Board member with the Vernon First Nations Friendship Centre and Ki-Low-na Friendship Society, School District 22 Aboriginal Educational Committee, and the Okanagan Aboriginal Health Research Action Group, and the Vernon and Ki-Low-Na urban Elders Group. She is an Elder for Aboriginal Community Action for Children's Health (Kelowna), and Elder advisor for a UBCO research project on diabetes and obesity in Urban Aboriginal Peoples, and an Adjunct Professor at UBCO. Elder Jessie states, "I am, and always will be, a strong advocate and activist for my People. I believe that we must work together with the society in which we exist to help eradicate racism, discrimination, and assumptions that still exist and make it especially difficult for my People to access health care and receive adequate and

appropriate care and education. I also believe that we, especially our children, must be viewed holistically. Poverty, poor housing, poor nutrition, poor health, and unsafe drinking water and loss of language, culture, tradition impact health. Early childhood development programs, family, and extended family and community, all contribute to the development of our children. We must work to identify and then fill the gaps so we will ultimately have equity with rest of the population.” Jessie remains very passionate about cultural safety and is frequently invited to do presentations to community groups. She received the BC Aboriginal Childcare Society’s Aboriginal Child Care Award (2007) and was instrumental in the development of the Primary Care Centre in Vernon. In 2012 she was awarded the Queens Diamond Jubilee Medal for service to and advocacy for Urban Aboriginal People, and in 2015 she co-published Herstory a book sharing the words of Residential School survivors.

Bernie Pauly is an Associate Professor in the University of Victoria (UVIC) School of Nursing and a Scientist at the Centre for Addictions Research of British Columbia. Currently she is a University of Victoria Provost’s Community Engaged Scholar and holds the position of Island Health Scholar in Residence. Her research focuses on understanding the structural determinants of substance-use and related harms, and application of a health equity lens in the development of programs and policies for people who use substances. Her current research focuses on the implementation and impacts of managed alcohol programs for people with several alcohol use and homelessness, improving access to primary care for people who use substances and enhancing public health responses that promote health equity and prevent substance-use related harms. Drawing on principles of community-based research she works collaboratively with people who use drugs, and other community based organizations, health authorities and governments to promote health equity and reduce harms of substance-use. She has been recognized as an Honorary Citizen of Victoria and is a recipient of a UVIC Community University Leadership Award, a Queens Diamond Jubilee Medal, and a BC Community Achievement Award for her work.

Sonia Singh is a hospitalist physician and osteoporosis consultant based at Peace Arch Hospital in White Rock, as well as the Regional Medical Director for Research development in the Fraser Health (FH) Authority. She has been an early adopter of patients as research partners in research addressing care gaps in osteoporosis management, and in participatory action research around health of Elders with First Nations communities in the Fraser Canyon, BC. She has been actively involved in the Strategy for Patient Oriented Research (SPOR) SUPPORT Unit development in BC, as a core member of the original business plan writing team and more recently in the development of the SUPPORT Unit’s Fraser Regional Centre. She is a clinical assistant professor in the Dept. of Family Practice, UBC and the Assistant Dean Research Fraser Health in the UBC Faculty of Medicine. She is a member of the Scientific Advisory Committee of Osteoporosis Canada (2013). In 2015, she was awarded a Fraser Health Above and Beyond Award for Evidence Based Practice.

Cindy Trytten is the Director of Research and Capacity Building, Island Health, and has a diverse and lengthy career in leading change in the health system through health research in both the public and private sectors. She’s a member of the Canadian College of Health Leaders and holds a Certified Health Executive designation which enables her to better navigate the complexities of integrating research and research evidence into care. Cindy is a passionate lifelong learner, an amateur photographer and a practitioner of mindfulness. She’s grateful to be part of this exciting era when the health system is enabling patients and families to drive priorities and improvements that matter to them.

Karen Urbanoski is a Scientist with the Centre for Addictions Research of British Columbia and Assistant Professor in Public Health and Social Policy at the University of Victoria. She holds the Tier 2 Canada Research Chair in Substance Use, Addictions and Health Services Research (2015-2020). Prior to coming to the University of Victoria in 2015, she was a Scientist at the Centre for Addiction and Mental Health in Toronto, Ontario, where she still holds a position as a Collaborator Scientist. She also worked as a Research Fellow in the Department of Psychiatry at Harvard Medical School after completing her PhD. Karen draws from her training in epidemiology and behavioural research to study the social determinants of substance-related problems and addiction, and how these affect access to health care and addiction treatment. She is particularly interested in the effectiveness and implications of coercion and compulsory addiction

treatment. She studies the ways people recover from substance problems both with and without treatment, and considers how insights generated from this research can be used to inform a more equitable and efficient treatment system. As much of her research is based on large populations or whole treatment systems, she works to support the ongoing development and improvement of structures for system-level data collection, needed for rigorous addiction services research, performance measurement and quality improvement.

David Whitehurst is a Methods Cluster Co-Lead for Health Economics and Simulation Modelling for the BC SUPPORT Unit. He's an economist who has specialized in the areas of health and health care throughout his career. Prior to his appointment as Assistant Professor at SFU he held research positions at UBC and at the Universities of Birmingham and Keele in the UK. David is also an Associate Scientist at the Centre for Clinical Epidemiology & Evaluation (C2E2), a core partner organization to the BC SUPPORT Unit. His current research is focused on the assessment of quality of life in the context of economic evaluation, and he works across a broad range of clinical areas, including spinal cord injury and care for seniors.

Danielle Wilson is a member of the Tla-o-qui-aht First Nation and works for Interior Health as a Practice Lead in Aboriginal Health Program since 2011, having worked with the First Nation Inuit Health Branch of Health Canada for 12 years prior to this. Danielle has a B.Sc. from the University of Victoria and a Masters Degree in Public Health from the University of Waterloo. She has participated in research projects such as diabetes, tobacco cessation, and chronic disease obstructive pulmonary disease with Interior region First Nation partners.

Hubert Wong is the Methods Cluster Lead for Real-World Clinical Trials for the BC SUPPORT Unit. He is also an Associate Professor at the School of Population and Public Health at UBC, Program Head of Biostatistics at the Centre for Health Evaluation and Outcome Sciences (CHÉOS), and Associate Head of Methodology and Statistics at the Canadian Institutes of Health Research (CIHR) Canadian HIV Trials Network (CTN). His research focuses on clinical trial design and foundational issues in statistics, and he collaborates extensively with fellow researchers in diverse areas including HIV/AIDS, mental health, intensive care, emergency, neurology, orthopaedics, and rheumatology. He received two degrees at UBC: a BAsC in Engineering Physics in 1992, and a PhD in Statistics in 2000.

About Us

What's Health Research?

An organized way of collecting and analyzing information to understand and improve our health. We're changing health research to become more patient-oriented.

What's Patient-Oriented Research?

Research that:

- Is done in partnership with patients.
- Answers research questions that matter to patients.
- Aims to improve health care.

If you'd like to learn about the Strategy for Patient-Oriented Research (SPOR) definitions, please visit <http://www.cihr-irsc.gc.ca/e/41204.html>.

Who We Are

The **BC SUPPORT** (Support for People and Patient-Oriented Research and Trials) Unit is a multi-partner organization created to support, streamline and increase patient-oriented research throughout British Columbia.

The Unit is one of **10 SUPPORT Units** established across the country as part of Canada's **Strategy for Patient-Oriented Research** (SPOR) led by the **Canadian Institutes of Health Research (CIHR)**. It's also part of the **BC Academic Health Science Network (BC AHSN)** with the network's **board** providing governance and oversight.

About the conference

This conference will be of interest to patients, health researchers, health care providers and health system decision-makers interested in patient-oriented research (POR).

Why is this conference important to patients?

Patient-oriented research is more than just a buzzword. It's an approach to health research that emphasises meaningful patient engagement in every part of the process. This ensures health research focuses on questions relevant to patients. This conference will help patients understand what patient-oriented research is, and how they can become involved.

Why is this conference important to researchers?

Patient-oriented research is one way of increasing the impact of health research. By working collaboratively with patient partners, research questions, methods and findings are strongly aligned with patient preferences and therefore more likely to be adopted into practice – making a real difference to patients, families, communities and the health care system. This conference will help researchers learn more about how to engage and collaborate with patient partners on patient-oriented research.

Why is this conference important to health care providers?

Patient-oriented research addresses questions relevant to patients that can impact the delivery of care, which means providers also need to be meaningfully engaged in the research process. This conference will help providers learn about how research works and how they can meaningfully contribute to the research process to help findings be more easily incorporated in to care delivery.

Why is this conference important to health system decision makers?

Key research findings guided by patient and provider involvement still require system-level support to ensure they are adopted and implemented. Engaging decision makers in the research process helps identify and address issues to aid implementation. This conference will help decision makers learn about the impacts of patient-oriented research, and how it can help them make system level decisions to improve the quality of care for everyone in BC.



Conference goals and objectives

Conference Goals

Attending the conference will help you meet these goals:

- Learn about patient-oriented research and why it's important to health research
- Connect patient-oriented researchers with research-oriented patients, including how to use virtual tools beyond the conference
- Network with patients, researchers, decision-makers and health care providers interested in patient-oriented research
- Enhance knowledge and skills in conducting patient-oriented research and working within a patient-oriented research team

Learning Objectives

Are you a researcher? Upon completion of the conference researchers will be able to:

- Define patient-oriented research and articulate research objectives consistent with patient-oriented research
- Understand the elements of patient-oriented research, and how to work collaboratively to ensure patient partners are integrated into the research team
- Develop and maintain connections with other researchers in BC who are moving in similar directions to incorporate a patient-oriented research focus into their research activities

Are you a clinician? Upon completion of the conference clinicians will be able to:

- Understand how patient-oriented research can impact clinical practice
- Involve patient partners in research activities
- Participate in patient-oriented research and learn about available resources and support

Are you a policy- or decision-maker? Upon completion of the conference decision-makers will be able to:

- Understand patient-oriented research and how it can inform policy decisions
- Design policies informed by patient-oriented research
- Develop connections with researchers, clinicians and patient partners

Are you a patient? Upon completion of the conference patients will be able to:

- Understand the need for and role of patient partners in patient-oriented research
- Describe ways that patients contribute to patient-oriented research activities
- Develop connections with research teams, organizations and others who support patient-oriented research

Notes

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