



Putting  
Patients  
First 2022

March 10 - 11, 2022

# CONFERENCE PROGRAM

Presented by:



In partnership with:



The BC SUPPORT Unit would like to thank:



We acknowledge with respect and humility that our event takes place on traditional, ancestral and unceded Indigenous territories. As guests to this beautiful land, we are thankful and consider it a privilege to do our learning here.



# Putting Patients First **2022**

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Share your conference experience on social media using the hashtag **#PPF22** and follow us on Twitter at **@BCSUPPORTUnit**.



# Welcome from our leaders

On behalf of Michael Smith Health Research BC and the BC SUPPORT Unit, we welcome you to our fifth annual conference, Putting Patients First (#PPF22). This year's theme is "Listening, Learning, Collaborating and Changing". It reflects the opportunity we have to look back on what we've accomplished during the first five years of the BC SUPPORT Unit and to begin exploring what's possible as part of Health Research BC.

The conference line-up includes approximately 60 presentations and 20 posters by health care providers, researchers and patient partners from around the province and beyond. The depth and breadth of the presentations highlight how far we've come in advancing patient-oriented research in this province in the past five years.

The work of the BC SUPPORT Unit is based in relationships — with researchers, health care providers, and patient partners, our colleagues in the health authorities and universities, and our funding partners. Together, we've built capacity to conduct and implement patient-oriented research, increased the quality and impact of the patient-oriented research that is conducted, and worked to ensure ongoing support for patient-oriented research in all parts of BC.

As we look to the future, we're excited about the possibilities presented as part of our new organization, Michael Smith Health Research BC. It will allow us to deepen an already strong collaborative relationship with the former Michael Smith Foundation for Health Research, an early proponent of the Unit and a funding partner.

As you listen to our speakers over the next two days, we ask you to reflect on lessons learned, and consider changes needed to realize a health system in BC that is truly evidence-informed and focused on the patient experience.



**Stirling Bryan**  
Chief Scientific Officer  
Michael Smith Health Research BC



**Bev Holmes**  
President & CEO  
Michael Smith Health Research BC



**Danielle Lavallee**  
Scientific Director, BC SUPPORT Unit  
Michael Smith Health Research BC

# Conference objectives

## Listening

- Accepting Indigenous knowledges and ways of knowing
- Soliciting patient participation in all aspects of research and care, including learning health systems

## Collaborating

- Building and expanding collaborations to advance patient-oriented research and learning health systems
- Building inclusiveness for all stakeholder groups

## Learning

- Building on our learnings from patient-oriented research as a foundation for future work
- Identifying and using data that is meaningful to patients, communities and populations

## Changing

- Incorporating responses to Truth and Reconciliation Calls to Action and In Plain Sight in our plans and behaviours
- Transforming health care in BC



# Why is this conference important

## For **patients:**

### Get engaged and be heard

Patient-oriented research emphasizes meaningful engagement with people who have lived experience throughout the research process. It seeks to address your needs and priorities by answering questions that matter to you, whether you have direct experience of a health condition or health system issue, or care for someone who does. This conference will help you learn more about patient-oriented research, including how you can get involved.

## For **researchers:**

### Get results with impact

Collaborating with patient partners ensures that your research questions, methods and results are relevant to their needs and preferences, so it's more likely that the evidence you generate will be implemented — making a real difference to patients, families, the health care system and communities. This conference will provide examples of successful engagement and collaboration with patient partners on patient-oriented research projects.

## For **health care providers:**

### Be a part of improving care

Patient-oriented research seeks to answer questions that are relevant to patients, and those answers can often have an impact on the delivery of care — which means that people who provide care play an essential role in the research process, too. This conference will help you learn how patient-oriented research works, and how you can contribute meaningfully to improved outcomes by helping to incorporate findings into care delivery.

## For **health system decision makers:**

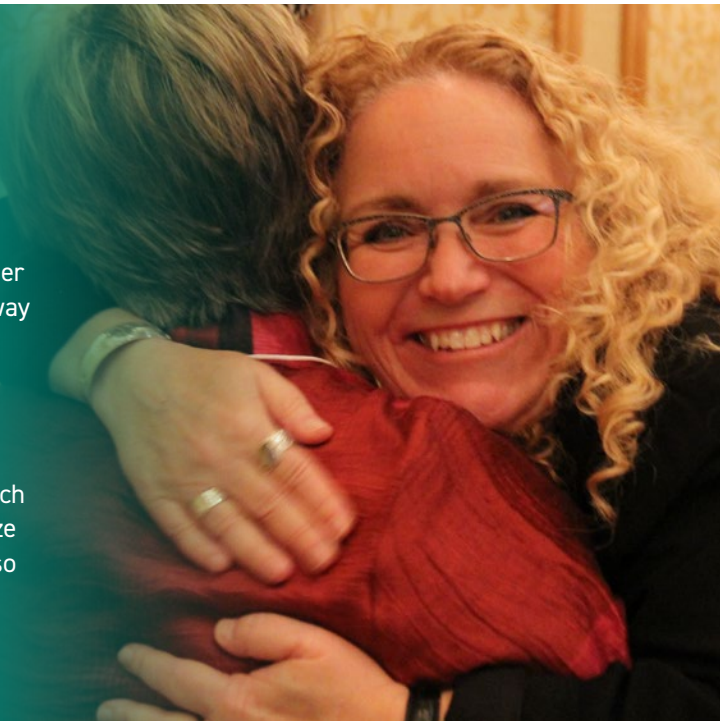
### Help to implement system change

The findings generated by patient-oriented research need system-level support to make a difference, and you can help research teams identify barriers and address issues that will aid implementation. This conference will showcase the impact of patient-oriented research, and how it can help you make system-level decisions to improve the quality of care for everyone in BC.

## In memory of Pat Atherton

The planning team would like to acknowledge the hard work and dedication of Pat Atherton who brought this team together to organize Putting Patients First 2022. Sadly, Pat passed away in August 2021.

Pat played a foundational role in shaping the work of the BC SUPPORT Unit. She leaves behind a legacy of work, both locally and nationally, that advanced training and capacity building to support the translation of patient-oriented research into practice. Those who knew and worked with Pat recognize that she will be missed, not only for the work she led, but also her warmth, energy, quick wit and friendship.



## Our planning team

Thank you to all the members of our planning team who devoted countless hours to making Putting Patients First 2022 a success.

### **Agnes Black**

Director Research and Knowledge Translation,  
Providence Health Care

### **Alia Januwalla**

Knowledge Translation Specialist, Regional Centre Staff,  
BC SUPPORT Unit Fraser Centre

### **Anne-Marie Visockas**

Decision-Maker, Interior Health (Retired)

### **Anni Rychtera**

Patient Partner, BC SUPPORT Unit

### **Belinda Jampoh**

Projects & Events Manager, Michael Smith Health Research BC

### **Charlotte Loppie**

Professor, School of Public Health and Social Policy; Associate  
Dean, Research, Faculty of Human and Social Development,  
University of Victoria

### **Danielle Lavallee**

Scientific Director, Michael Smith Health Research BC

### **Kent Cadogan Loftsgard**

Patient Partner, BC SUPPORT Unit

### **Kimberly Miller**

Senior Leader of Clinical Education and Special Projects;  
Manager, Child Development & Rehabilitation, Sunny Hill Health  
Centre at BC Children's Hospital

### **Martha MacLeod**

Professor, Health Sciences, Northern Health - UNBC Knowledge  
Mobilization Research Chair, Co-Leader, Health Research Institute,  
University of Northern BC

### **Noreen Frisch**

Professor Emerita, School of Nursing, University of Victoria

### **Paul Fogerty**

Director, Conference and Events, Malachite Management Inc.

### **Ron Lindstrom**

Health Systems Consultant, Island

### **Sunny Loo**

Patient Partner, BC SUPPORT Unit

### **Waqar Mughal**

Program Director - Data, BC SUPPORT Unit,  
Michael Smith Health Research BC

# Conference agenda

## Pre-conference day – Wednesday, March 9

**5:00-7:00**

### Pre-conference networking

Join the Michael Smith Health Research BC chief scientific officer and scientific director to learn more about what Health Research BC and the BC SUPPORT Unit have been up to and what's coming in the future. This will be an opportunity to have an early evening informal "chat" via Zoom's chat feature, hosted by Stirling Bryan and Danielle Lavallee.

## Day 1 – Thursday, March 10

**8:00-8:25**

### Networking

Please use the Video Networking module to join us for a morning coffee and catch-up.

**8:25-8:30**

### Moderator opening remarks

Danielle Lavallee, Scientific Director, Michael Smith Health Research BC

**8:30-8:45**

### Opening prayer

We are privileged to be joined by Elder Roberta Price and Elder Barb Hulme who will open our conference and welcome our participants.



### Elder Roberta Price

For over 30 years, Elder Roberta Price has actively shared her leadership, wisdom and teachings at UBC and throughout the Lower Mainland to assist both Indigenous and non-Indigenous community members to achieve improved outcomes in health care. A member of the Coast Salish Snuneymuxw and Cowichan Nations, she has been instrumental in helping to create shared spaces for both Indigenous and Western approaches to healing and health. Her ongoing involvement and leadership in research projects have been key to the continued work of decolonizing health care and creating cultural safety and equity for Indigenous patients.



### Elder Barb Hulme

Barb Hulme has deep connections to Métis communities in British Columbia and Manitoba. She was born in Selkirk, Manitoba in the heart of the Métis Nation's Red River Settlement and is an active member of the Victoria Métis community. After earning a diploma and a Bachelor of Science in nursing, Barb entered the Canadian Armed Forces where she rose to the rank of major. She is often called upon to represent Indigenous veterans at ceremonies and on committees. After retiring in Victoria, she became one of the founding members of Métis Nation Greater Victoria and has served in such roles as administrator, historian, citizenship coordinator and genealogy advisor. Barb has been involved in University of Victoria's Elders' Voices program for more than three years. When she's not spending time with students in the Elders Lounge at the First Peoples House, she can often be found leading beading, quilting and embroidery workshops. She's a strong advocate for cooking meals together because sharing stories and food is part of every Indigenous culture.

**8:45-8:50**

### Welcoming remarks

Bev Holmes, CEO, Michael Smith Health Research BC



8:50-9:45

Keynote

**Blurred lines: When patients design and provide the services they use**

Speaker: Fred Cameron

Moderator: Kent Cadogan Loftsgard

A few years back, Fred Cameron was unemployed and living in a supportive recovery facility at the mercy of the Ministry of Social Development. In the fall of 2016, he was invited to what he thought would be a one-time planning meeting for what would later be named the [Reducing Stigma in Primary Care](#) project. Looking back, that meeting was the beginning of a new career. Having developed a taste for patient-oriented research, Fred accepted a seat on the BC SUPPORT Unit's Patient Advisory Council and went on to join several other peer-led research projects. Now sitting as operations director of [SOLID Outreach Society](#), Fred is coordinator of six overdose prevention sites and collaborates with public health and policy-makers to help improve the lives of people who use substances. The session will include a narrative of how participating in patient-oriented research empowered one individual to use his own lived experience to help improve the health outcomes of hundreds of people in his community, and will identify some of the challenges and benefits of running a peer worker team.

**Fred Cameron**

After a lifelong battle with addiction, Fred Cameron entered the world of recovery in 2015. In his early struggles, he came to realize that if he embraced it, his experience could be used to help others. Fred is currently acting as operations director and harm reduction manager with SOLID Outreach Society in Victoria, BC. He has extensive experience as a community researcher with the Canadian Institute for Substance Use Research. He is in his fourth year as a member of the BC SUPPORT Unit Patient Council. Fred is an author and writer who has published on patient-oriented research and peer-led interventions, as well as other current issues, in local and regional magazines. In addition to working with SOLID, Fred is completing a degree in social work.

**Kent Cadogan Loftsgard (moderator)**

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.

9:45-10:00

Break



**10:00-10:50 Breakout session 1****Breakout session #1a: Panel****Reflecting on lessons learned: Studying consensus methods in integrated knowledge translation to promote patient-oriented research **\*

Team members: Miranda Cary, Katrina Plamondon, Davina Banner, Nelly Oelke, Heather Gainforth, Alison Hoens, Kathryn Sibley, Jennifer Baumbusch, Aline Silva, Kristy Baxter, Kiran Ghag, Ursula Wick, Ashmita Rai, Andrea Diebold, Kimberly Strain

**Breakout session #1b: Skills building workshop****Exploring drawing and arts-based methods in patient-oriented research**

Team members: Anita David, Maya Lefkowich, Jennica Nichols

**Breakout session #1c: Oral presentations (15 minutes each)****Patient engagement****Using the PEIRS-22 measure to improve meaningful patient engagement in research at the SPOR Evidence Alliance**

Team members: Clayton Hamilton, Aline Silveira Silva, Linda Li, Alison Hoens, Linda Wilhelm, Vikram Bubber, Elliot PausJenssen, Annette McKinnon, Jenny Leese, Thalia Otamendi, Wasifa Zarin, Andrea Tricco

**Partnering with patients on grant reviews: Strengthening practice-based research**

Team members: Agnes Black, Kristi Coldwell, Lynne Feehan, Larry Mroz

**The Patient-Oriented Research Database project: Learnings from a patient-initiated, collaborative journey**

Team members: Brittney Schichter, Stefanie Cheah, Swapnil Shah, Paul Burgener, Rhyann Fairbrother, Belinda Jampoh

**Breakout session #1d: Oral presentations (15 minutes each)****Issues in patient-oriented research****Raising awareness of conflict of interest in patient-oriented research**

Team members: Davina Banner, Marc Bains, Iva Cheung, Nassim Adhami, Shayna Dolan, Jennifer Brown, Stirling Bryan, Trina Fyfe, Alison Hoens, Daman Kandola, Erin Michalak, Michelle Mujoomdar, Haydn Molcak

**Collaboration across the nation: Lessons learned from pan-Canadian priority-setting partnership on multiple myeloma**

Team members: Lauren McLaughlin, Samantha Fowler, Sarah Bridges, William Paine, Barbara Ridgway, Lorelei Dalrymple, Robin Sully, Sharon Nason, Anthony Reiman

**Research ethics should not be an undue obstacle to the engagement of patients and citizens in research (and bioethicists are the ones saying this)**

Team members: Jean-Christophe Bélisle-Pipon, Vincent Couture, Marie-Christine Roy

**Breakout session #1e: Oral presentations (15 minutes each)****Pediatric patient-oriented research****Measuring what matters to children with lower limb differences: Development of a new patient-reported outcome measure**

Team members: Harpreet Chhina, Anne Klassen, Jacek Kopec, Anthony Cooper

**Guiding the development of a tool to help inform pediatric postsurgical pain management – a first glance at focus group data from family and patient partners**

Team members: Michael Wood, Rama Sreepada, Kim Correa, Kent Cadogan Loftsgard, Isabel Jordan, Simon Whyte, Gillian Lauder, Elodie Portales-Casamar, Matthias Görges

**A family-centered approach to understanding children's independent mobility in northern BC**

Team members: Katie Cornish, Caroline Sanders, Chelsea Pelletier

\*Presentations with this icon were funded by the BC SUPPORT Unit's Methods Clusters. For more info: <https://methodsclusters.ca>

10:50-11:00

Break



11:00-11:55

**Breakout session 2****Breakout session #2a: Panel****Engaging "prison patient partners" in research on the impact of COVID-19 on prisons**

Team members: Pam Young, Marnie Scow, Merv Thomas, Nicole Kief, Nadine Kronfli, Sofia Bartlett, Julia Santana Parrilla, Candice Wagner

**Breakout session #2b: Panel****Pressure injury in persons living with spinal cord injury: A patient-driven research project**

Team members: Spring Hawes, John Chernesky, Davina Banner-Lukaris, Nassim Adhami, Nicola Waters, Shayna Dolan, Penny Clarke-Richardson, Alana McFarlane, Shannon Rockall, John Cobb, Shannon Freeman, Nelly Oelke

**Breakout session #2c: Panel****Co-Developing the vaccine research agenda in BC**

Team members: Sabrina Gill, Manish Sadarangani, Alastair McAlpine, Monika Naus, Bonnie Henry

**Breakout session #2d: Oral presentations (15 minutes each)****Women's health****Partnering with patients! Oxytocin to start or advance labour: 5 questions to ask**

Speaker: Maryann Murray

**Experiences of endometriosis-associated dyspareunia: Piloting digital storytelling for knowledge translation**

Team members: Kiran Parmar, A. Fuchsia Howard, Heather Noga, Catherine Allaire, John Oliffe, Leanne Currie, Paul J. Yong

**Breakout session #2e: Oral presentations (15 minutes each)****Clinical trials and Secondary Data Analysis****What does this trial mean for me? Integrating patient values into clinical trials**

Team members: Rebecca Metcalfe, Mark Harrison, Joel Singer, Mary Lewisch, Terry Lee, Laura Magee, Nick Bansback

**How to present work productivity loss due to health problems in clinical trials**

Team members: Jacynthe L'Heureux, Lin Chen, Gary Johns, Helen McTaggart-Cowan, Theodore Steiner, Wei Zhang

**Patient Oriented Predictive Modelling of Healthcare Utilization (POPMHU)**

Team members: Piper Jackson, Shannon Freeman, Waqar Haque, Grace Kramer, Robin Teotia, Lucy Wu

11:55-1:00

Break



12:15-12:55

Lunch break/Poster session

Poster group #1

- Patient engagement (P1, 2, 7 and 9)
- Patient experiences/Patient involvement (P3-5, 8 and 10)

See pages 18 and 19 for a list of all posters and presenters.

**1:00-1:50 Breakout session 3****Breakout session #3b: Oral presentations (15 minutes each)****Engagement in community-focused research****The Rural Community Resilience Project (RCRP): Working with communities from across rural BC**

Team members: Soham Darji, Jude Kornelsen, Claire Styffe

**Communication in disaster to support families with children with medical complexity and special health care needs: A rapid scoping review** 

Team members: Neale Smith, Esther Lee, Meghan Donaldson, Mike Scott, Tayaba Khan, Craig Mitton

**Breakout session #3c: Oral presentations (15 minutes each)****Learnings and needs related to the COVID-19 pandemic****Unintended consequences of pandemic management strategies on residents and family in one long-term care home in British Columbia: A patient-supported qualitative study**

Speaker: Farinaz Havaei

**Patient partner and researcher perspectives within a study exploring COVID-19 and immunosuppression**

Team members: Shelby Marozoff, Jeremiah Tan, Bonnie Corradetti, Philippa Mennell, Peter Malone, Cheryl Koehn, Alison Hoens, Zahra Fazal, J. Antonio Avina-Zubieta

**Patient engagement in the development and application of a mental health promotion framework for COVID-19 pandemic recovery**

Team members: Marcie Dolce, Karen Davison, Vidhi Thakkar, Maura MacPhee, Simon Carroll

**Breakout session #3d: Oral presentations (15 minutes each)****Youth and young adults****A patient-led process for developing an Equine Assisted Psychotherapy (EAP) program for youth with eating disorders**

Team members: Maya Gislason, Angel Kennedy, Joan Fujiwara, Maya Khera, Kate Bennett, Katie Bauder, Elly Blake

**Theories, models and frameworks for supporting patient engagement in youth mental health and substance use research**

Speaker: Sherald Sanchez

**Partnering with young adults in the READY2Exit Study: A mixed methods doctoral project**

Team members: Brooke Allemang, Karina Pintson, Marcela Farias, Katelyn Greer, Megan Patton, Keighley Schofield, Susan Samuel, Andrew Mackie, Scott Patten, Kathleen Sitter, Gina Dimitropoulos

**Breakout session #3e: Oral presentations (15 minutes each)****Patient engagement, patient-oriented research, and policy****Engaging patients, family members and caregivers in policy for primary health care teams integration**

Team members: Ashmita Rai, Peter Hirschhorn, Shana Ooms, Judy Birdsell, Stephanie Montesanti, Sharon Johnston, Shannon Berg, Sara Mallinson, Karin Maiwald, Lee Green, Cailie Pritchard, Catherine Donnelly, Simone Parniak

**“It greatly affects me, and I would like to have a voice in there”: Engaging service users aged 50 years and over in mental health care and policy**

Team members: Ashmita Rai, Nelly Oelke, Laura Struik, Dennis Jasper

**Estimating for the costs that patients pay to manage major depressive disorder**

Team members: Sonya Cressman, Rohit Vijh, Shahzad Ghanbarian, Alison Hoens

**1:50-2:00**

Break 

**2:00-2:30****Closing session**

Moderator: Noreen Frisch, Professor Emerita, School of Nursing, UVic

- Celebration of Pat Atherton
- Pat Atherton Emerging Scholars Award for Patient-Oriented Research
- Closing remarks

## Day 2 – Friday, March 11

8:00-8:25

### Networking

- Please use the Video Networking module to join us for a morning coffee and catch-up.

8:30-8:45

### Moderator remarks, day 1 reflections and introduction of plenary speaker

Stirling Bryan, Chief Scientific Officer, Michael Smith Health Research BC

8:45-10:00

### Keynote and panel discussion

#### Learning health systems and CIHR: past, present, and future

Keynote speaker: Tammy Clifford Moderator: Stirling Bryan

Panelists: Margo Greenwood, Adeera Levin, Kim McGrail, Jaclyn Robinson

Dr. Tammy Clifford, CIHR's inaugural vice-president, Research – Learning Health Systems, will share her perspectives as to CIHR's past, current and planned initiatives that support learning health systems (LHS) across the country. In addition to describing the new portfolio, Tammy will provide insights as to its genesis and links to CIHR's Strategic Plan. She will also share her early thoughts as to how this new LHS team might work together with others engaged in LHS-related activities, all in support of better health for Canadians. It is hoped that the session will generate excitement, stimulate thought and encourage discussion as to the role of a national funder in LHS-related activities and, specifically, what additional activities or initiatives CIHR may wish to consider in order to better support LHS-related activities across the country. Following Tammy's presentation, a facilitated panel will discuss opportunities and challenges for LHS concepts in BC.



#### Dr. Tammy Clifford

In October 2018, Dr. Tammy J. Clifford joined CIHR as vice-president, Research Programs. In this role, Dr. Clifford has been responsible for the design, development and administration of the agency's funding programs and science policies. It has recently been announced that she will be assuming the role of CIHR's vice-president Research – Learning Health Systems. In this new role, Tammy will establish a team that will bring together existing and new initiatives related to clinical trials, patient-oriented research, knowledge mobilization, ethics, research excellence, EDI and capacity building, as well as CIHR's Centre for Research in Pandemic Preparedness and Health Emergencies.

Prior to joining CIHR, Tammy served as a member of the executive team at the Canadian Agency for Drugs and Technologies in Health (CADTH), most recently as chief scientist and vice-president, Evidence Standards. At the beginning of her career, she worked on a number of maternal and child health research projects at CHEO's Research Institute, where she also served as a member of the Research Ethics Board. She continues to hold an adjunct faculty appointment with the University of Ottawa's School of Epidemiology and Public Health.

Tammy is an authentic leader and is recognized for her passion and commitment to mentoring, as well as to training the next generation of health researchers. She received her PhD in Epidemiology and Biostatistics from the University of Western Ontario (now Western University), and her BSc and MSc from McGill.



#### Dr. Stirling Bryan (moderator)

Dr. Stirling Bryan, chief scientific officer, Michael Smith Health Research BC, is a university-based health economist with extensive experience of engagement with the policy and decision-making world. He began his career in the UK with appointments at St. Thomas' Hospital Medical School and then Brunel University, before moving to the University of Birmingham. His research track record reveals a long-standing goal of informing policy and practice, demonstrated, in part, through extensive engagement with the National Institute for Health & Care Excellence (NICE). For many years he led the University of Birmingham team that conducted economic analyses for NICE, and subsequently served for three years as a member of the NICE technology appraisals committee. In 2005, he was awarded a Commonwealth Fund Harkness Fellowship and spent one year at Stanford University, researching technology coverage decision-making in a U.S. health care organizations. He immigrated to Canada in 2008, taking on the roles of professor in UBC's School of Population & Public Health, and director of the Centre for Clinical Epidemiology & Evaluation. Over recent years, Stirling has become a strong advocate for, and practitioner of, patient-oriented research, and now partners with patients in all of his research activities. In 2016, he was appointed scientific director for the BC SUPPORT Unit, an operational unit of the BC Academic Health Science Network (BC AHSN), focused on promoting patient-oriented research. In 2020, Stirling became the president of BC AHSN which includes oversight of its operational units: the BC SUPPORT Unit, Clinical Trials BC and Research Ethics BC. He was in this role until September 2021, helping to navigate the consolidation of BC AHSN with the Michael Smith Foundation for Health Research.



#### Dr. Margo Greenwood (panelist)

Dr. Margo Greenwood, academic leader of the National Collaborating Centre for Indigenous Health, is an Indigenous scholar of Cree ancestry with years of experience focused on the health and well-being of Indigenous children, families and communities. She is also vice-president of Indigenous Health, Northern Health, and professor in both the First Nations Studies and Education programs at the University of Northern British Columbia. Margo has received numerous awards for her achievements in early childhood education and health policy, including the Queen's Jubilee medal (2002), BC Academic of the Year (2010), National Aboriginal Achievement Award for Education (2011), and, most recently, she was honoured to be appointed as an Officer of the Order of Canada (2021).



#### Dr. Adeera Levin (panelist)

Dr. Adeera Levin is a professor of medicine, Head Division of Nephrology at the University of British Columbia, and consultant nephrologist at Providence Health Care/St. Paul's Hospital, in Vancouver Canada. She is also senior medical lead, Integration Clinical and Academic Networks at PHC.

Further, Adeera is the executive director of BC Renal, which oversees the care, planning and budgets for kidney services in the province of British Columbia. She has recently established and led a province-wide Post COVID-19 Interdisciplinary Clinical Network (PC-ICCN), embedding research and clinical care in a learning health care network, and is lead of the PC ICCN, housed at Provincial Health Services Authority. She is a founding member of the KRESCENT program (Kidney Research Scientist Education National Training program), and continues as a senior advisor.

Adeera is active in international activities across the spectrum of kidney education, research and administrative activities, and was past president of the International Society of Nephrology (ISN) from 2015-17), and a founding member of the Declaration of Istanbul Custodian Group (DICG). She advocates for patient rights to equitable access to care and for the prevention of exploitation of vulnerable populations. Her major research interests include cardiovascular disease and comorbidities in CKD patients, variability in the progression of CKD and optimal models of care. With an H-index of 102, Adeera has over 600 peer-reviewed publications and numerous book chapters. She is the principal investigator on a CIHR SPOR network grant CAN SOLVE CKD, worth \$40 million — the first pan-Canadian grant of this size ever awarded to study kidney disease.



#### Dr. Kimberlyn McGrail (panelist)

Dr. Kimberlyn McGrail is a professor in the UBC School of Population and Public Health and Centre for Health Services and Policy Research, director of Research for UBC Health, and scientific director of Population Data BC and Health Data Research Network Canada. Her research interests are quantitative policy evaluation and all aspects of population data science. Kim is deputy editor of the International Journal of Population Data Science, the 2009-10 Commonwealth Fund Harkness Associate in Health Care Policy and Practice, 2016 recipient of the Cortlandt JG Mackenzie Prize for Excellence in Teaching, and 2017 recipient of a UBC award for Excellence in Clinical or Applied Research. She is currently a member of the Global Partnership for AI as part of the Data Governance Working Group. She is also part of the Expert Advisory Group for the pan-Canadian Health Data Strategy.



#### Jaclyn Robinson (panelist)

Jaclyn Robinson is the clinical nurse specialist for the Provincial Post Covid-19 Interdisciplinary Clinical Care Network (PC-ICCN). Given that she is a COVID-19 survivor and an experienced public health nurse, she is passionate to help support patients, families and staff during this pandemic. Jaclyn is involved in many COVID-19 plans and initiatives and strives to ensure they are informed by patient and family voices. Now working to support regional health authorities, patients and research organizations across BC, PHSA's PC-ICCN aims to support the best possible outcomes for people who have experienced serious cases of COVID-19, through best practices, education and research.



## 10:05-10:55 Breakout session 4

**Breakout session #4a: Panel****Dementia & design: Co-designs' role in improving POR practices**

Team members: Caylee Raber, Morgan Martino, Garima Sood

**Breakout session #4b: Interactive workshop****Fostering diversity of partners in perinatal patient-oriented research**

Team members: Marianne Vidler, Kendra Liberata Navaroli, Justine Dol, Janny Ke

**Breakout session #4c: Oral presentations (15 minutes each)****Patient Initiated research****Building a Patient-Initiated Research (PIR) Assistance Program in BC: Phase 1, environmental scan and consulting key informants about best PIR support practices**

Team members: Sunny Loo, Laurel Radley, Colleen McGavin, Rhyann Fairbrother, Lawrence Mroz

**Developing an educational pamphlet on post-sepsis syndrome to improve care for sepsis survivors**

Team members: Susan Korstad, Marie-Maxime Bergeron, Kristine Russell, Kristin MacDonald, Sela Grays, Sarah Carriere, Colin O'Neill, Stefanie Novakowski

**Brainstem abnormalities in myalgic encephalomyelitis/chronic fatigue syndrome: A scoping review and evaluation of magnetic resonance imaging findings**

Team members: Todd Nelson, Lan Xin (Nancy) Zhang, Kati Debelic, Hilary Robertson, Luis Nacul, Xiaowei Song

**Breakout session #4d: Oral presentations (15 minutes each)****Patient engagement and program development****Collaborating with patient partners to shape an evaluation of pharmacogenomic testing for depression**

Team members: Jehannine Austin, Linda Riches, Shahzad Ghanbarian, Sonya Cressman

**Understanding patient- and caregiver-identified health service priorities for stroke in northern BC on the quest to develop more responsive health care services**

Team members: Damanpreet (Daman) Kandola, Barbara Croome, David Snadden, Chelsea Pelletier, Shannon Freeman, Pam Ramsay, Davina Banner

**"People don't live in a vacuum": Co-developing a brain health pilot program in the community through citizen science**

Team members: Daniel R. Y. Gan, Eireann O'Dea, Claire Wang, Habib Chaudhury, John Best, Shelley Jorde, Seniors Council

**Breakout session #4e: Oral presentations (15 minutes each)****Participatory design****Leading a participatory design journey mapping process to understanding the patient experience at Heartwood Centre for Women**

Team members: Katie Mai, Kathryn Proudfoot, Victoria Maxwell, Caylee Raber

**Co-constructing patient-oriented research capacity in the BC Cancer Practice-Based Research Challenge**

Team members: Maria Torrejon, Peter Malone, Kristi Coldwell

**An infographic on abstracts crowd-sourced and co-created with patient partners**

Speaker: Dawn Richards

10:55-11:00

Break



**11:00-11:55 Breakout session 5****Breakout session #5a: Oral presentations (15 minutes each)****Knowledge translation****Co-creating knowledge translation outputs in patient- and family-partnered research**

Team members: Jennifer Baumbusch, Shawna Lamden-Bennett

**“We’ve dealt with so much. There’s more coming?”: Learning from adults with congenital heart disease to inform knowledge translation initiatives about brain health**

Team members: Vanessa Dizonno, Ismalia De Sousa, Thalia Field

**Engaging with patients in research on knowledge translation and implementation science methods:****A self study **

Team members: Martha MacLeod, Jenny Leese, Leana Garraway, Nelly Oelke, Sarah Munro, Sacha Bailey, Alison Hoens, Sunny Loo, Ursula Wick, Peter Zimmer, Linda Li

**Breakout session #5b: Oral presentations (15 minutes each)****Indigenous health research****BC network environment for Indigenous health research: Building bridges between research and community**

Team members: Tara Erb, Laura McNab-Coombs, Atlanta Grant, Zoe Verlaan

**Kwiis-hen-niip (change): Studying community-driven interventions to support emergency care in remote Indigenous communities**

Speaker: Megan Muller da Silva

**Engaging with First Nations women with experiences of breast cancer: A Debwewin journey through digital storytelling**

Team members: Kendra Rieger, Marlyn Bennett, Donna Martin, Thomas Hack

**Breakout session #5c: Oral presentations (15 minutes each)****Connecting evidence with community****From their experience: Developing a podcast to support families affected by stillbirth**

Team members: Erin Bohn, Lana Sullivan

**The GOSH podcast: Reflections on storytelling and knowledge translation**

Team members: Stephanie Lam, Nicole Keay

**Knowledge translation in gynecologic cancer research: patient-led, patient-inspired**

Team members: Stephanie Lam, Nicole Keay, Debra Walker, Nancy Cleveland, Rose Lee

**Breakout session #5d: Oral presentations (15 minutes each)****Clinical topics****Where to next? Engaging patients in charting the future of psilocybin-assisted therapy research**

Team members: Taylor Hainstock, Uta Sbotto-Franskenstein, Christian Wiens, Fraser Black, Julia Joyes, Anke Krey, Eshu Martin

**Trans community-determined surgical outcome research: Ideas and ideals**

Speaker: Leo Rutherford

**A patient-oriented research approach to studying sex and gender differences in the prosthetic needs and priorities of lower limb amputees**

Team members: Tess Carswell, Helen Monkman, Diane Reid, Julia Chisholm, Josh Giles




**11:00-11:55 Breakout session 5 (cont'd)**

Breakout session #5e: Oral presentations (15 minutes each)

**Patient-oriented research and vulnerable populations**

**Planning and developing a culturally safe framework for engaging immigrant, refugee, ethnocultural patients in mental health research**

Team members: Anita David, Cindy Quan, Nancy Clark, Fred Chou, Cathy Costigan

**Diverse communities facing multiple barriers to engagement in patient-oriented research: Early insights from immigrant and refugee participants** 

Team members: Nancy Clark, Davina Banner, Sue Mills, Barbara Croome, Shayna Dolan, Daisy Au, Russ Maynard, Daman Kandola, Kiran Ghag, Joyce Griffith

**Improving the infrastructure for facilitating sexual assault disclosure in health care settings: Findings from a qualitative research study in BC**

Team members: Jila Mirlashari, Misha Dhillon, Ann Pederson, Chandra Berkan-Hozempa, Kate Rossiter

**11:55-1:00** Break

**12:15-12:55** Lunch break/Poster session

Poster Group #2

- Technology in patient-oriented research (P11-P15)
- KT/Implementation (P16-P19)
- Mental health and addictions (P20-22)

See pages 18 and 19 for a list of all posters and presenters.

**1:00-2:00** Closing panel

**From research to re-search: Cultivating a hopeful skepticism at decolonial intersections**

Presenters: Len Pierre, Jordan White

**2:00-2:10** Moderator closing remarks

Danielle Lavalley, Scientific Director, Michael Smith Health Research BC


**2:10-2:30** Closing ceremony

Elder Roberta Price and Elder Barb Hulme

# Poster presentations

## Day 1 - March 10

### Patient engagement

- P1 Pathways for developing patient-reported outcome (PROMs) and experience measures (PREMs) for Indigenous peoples**   
Presenters: Lori d'Agincourt-Canning, Jenny Morgan, Shabnam Ziabakhsh
- 
- P2 Simulating COVID-19 in a long-term care setting using patient partner engagement**  
Presenters: Piper Jackson, Arafath Khan Mohammad, Shannon Freeman
- 
- P7 Development and operation of a provincial youth advisory council: Insights from our first six months**  
Presenters: Brooke Allemang, Zoya Punjwani, Megan Patton, Sarah Mooney, Daniella San Martin-Feeney, Laurel Ryan, Andrew Mackie, Susan Samuel, Gina Dimitropoulos
- 
- P9 Patients on patient experiences in the emergency department (PoPE-ED): An intersection of patient-oriented research and equity, diversity and inclusion**  
Presenters: Ross Duncan, Ed Martin, John Grogan, Louise Yeoh, Riyad Abu-Laban

### Patient experiences/Patient involvement


- P3 Longitudinal encounter histories as text: Using natural language processing and graph machine learning methods to locate patient voices within constituencies**  
Presenters: Kenneth Moselle, Jonas Bambi, Ernie Chang, Stanley Robertson, Yudi Santoso, Mahdi Hajiabadi, Ashlin Richardson, Joseph Howie, Abraham Rudnick, Andriy Koval
- 
- P4 Behavioural support transition neighbourhoods: Using deliberative dialogue to build consensus on outcomes**   
Presenters: Aline Silveira Silva, Nelly Oelke, Anita Wahl
- 
- P5 Home and Community Care needs of older adult living with HIV in BC's Fraser Health region: findings from a patient-oriented, community-based research initiative**  
Presenters: Hesham Ali, Gary Lising, Antonio Marante, Claudette Cardinal, Patience Magagula, Sharyle Lyndon, Surita Parashar
- 
- P6 Patient perspective on interdisciplinary peripheral nerve trauma care**  
Presenter: Aidan Pye
- 
- P8 Evaluating the impact of syncope and presyncope on quality of life: A systematic review and meta-analysis**  
Presenters: Brooke Hockin, Natalie Heeney, David Whitehurst, Victoria Claydon
- 
- P10 The Independence Model (TIM): Function from day one**  
Presenters: Sandra Squire, Indershini Pillay

## Day 2 – March 11

### Technology in patient-oriented research

- P11** Provincial pilot study using virtual and online mixed methods to access marginalized disease groups (ME) in exploration of unmet needs of British Columbians living with myalgic encephalomyelitis  
Presenters: Lana LeBlanc, Hilary Robertson
- P12** Patient-reported benefits and limitations of mobile health technologies for diabetes in pregnancy: A scoping review  
Presenters: Katelyn Sushko, Holly Tschirhart Menezes, Qi Rui Wang, Donna Fitzpatrick-Lewis, Diana Sherifali
- P13** A social media campaign to raise awareness of sex, pain and endometriosis  
Presenters: Heather Noga, Sarah Lett, Kiran Parmar, Jessica Sutherland, Natasha Orr, Rebecca Coxson, Catherine Allaire, Fuchsia Howard, Paul Yong
- P14** The Kid-League: Patient-centered development of social robotics for children and youth living with anxiety  
Presenters: Jill Dosso, Jaya Kailley, Julie Robillard
- P15** Train your brain: Can three-dimensional multiple-object tracking improve cognition and daily-life functions in individuals with moderate to severe brain injury? A patient-partnered study  
Presenters: Taylor Snowden, Lisa Ohlhauser, Briar Mayoh, Jamie Morrison, Sydney Waddington, Andrew Varghese, Jodie Gawryluk, Brian Christie

### KT/Implementation

- P16** Planning for knowledge translation as an ethical imperative: Validating the Knowledge Dissemination in Patient- and Community-Oriented Research Ethics Assessment Tool (KD-PCOREAT) with research ethics boards in BC using a modified Delphi approach  
Presenters: Alia Januwalla, Brittney Schichter, Sarah Flann, Nikita Aistov, Kristie Nicol
- P17** Exploring the intersection of hermeneutics and implementation: A scoping review   
Presenters: Martha MacLeod, Steinunn Jonatansdottir, Lela Zimmer, Erin Wilson, Graham McCaffrey, Ian Graham, David Snadden, Peter Zimmer, Erica Koopmans, Trina Fyfe, Cathy Ulrich
- P18** IMPART (Improving Psychology Awareness through Research Translation): A UBC BRAIN Lab patient-oriented research podcast  
Presenters: Sydney Penner, Anurada Amarasekera, Alyx Hewlett, Luce Calderon, Myriam Juda, Christian Schütz
- P19** Encouraging diversity in family engagement in research: Reflections on the development of knowledge translation tools  
Presenters: Janet Mah, Katie Nickerson, Mahdiah Yousef, Peter Welsh

### Mental health and addictions

- P20** Collaborating with patient partners to model clinical care pathways for major depressive disorder: Mixing evidence and experience  
Presenters: Mary Bunka, Shahzad Ghanbarian, Linda Riches, Louisa Edwards, Alison Hoens, Stirling Bryan, anonymous patient partner
- P21** Pharmacogenomic testing for depression in BC: A qualitative, patient-partnered collaborative study of the perceptions of health care providers, policy makers and people with lived experience  
Presenters: Caitlin Slomp, Emily Morris, Louisa Edwards, Alison Hoens, Linda Riches, Lisa Ridgway, Stirling Bryan, Jehannine Austin, anonymous patient partner
- P22** Introduction of patient-oriented research to The Redfish Healing Center for Mental Health and Addiction  
Presenters: Tannis Teale, Suzanne Paddinge, Priya Johal, Anisha Lehal, Mark Ng Shun, Noor Ramadhan, Myriam Juda, Christian Schutz



# Putting Patients First **2022**



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