



Putting Patients First: Lessons Learned for Patient-Oriented Research



VANCOUVER | October 4, 2018
@BCSUPPORTUnit
#PPF18



Marriott Vancouver Pinnacle Downtown
1128 West Hastings Street
8:00am - 6:00pm

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Territorial Acknowledgement

We acknowledge that our event takes place on the traditional, ancestral, and unceded Indigenous territories of the ʷməθkʷəyəm (Musqueam), sk̓wx̓wú7mesh (Squamish), and sel̓íwítlh (Tseil-Waututh) First Nations.

As guests to this beautiful land, we are thankful and consider it a privilege to be able to do our learning here.

A Welcome from Our Leaders

On behalf of the BC SUPPORT Unit, we welcome you to our second annual conference, *Putting Patients First: Lessons Learned for Patient-Oriented Research (or PPF18)*, and thank you for joining us today. We're pleased to welcome a diverse audience from across BC and beyond, from a variety of disciplines, to network and to learn from one another about patient-oriented research (POR). We're also pleased to announce that this year's conference has achieved Patients Included accreditation, after satisfying five criteria to ensure full patient engagement.

The BC SUPPORT Unit, including our Provincial Hub, regional centres and funding partners, implements Canada's national Strategy for Patient-Oriented Research (SPOR), led by the Canadian Institutes of Health Research (CIHR), in British Columbia. We're also a unit of the BC Academic Health Science Network (BC AHSN). To learn more about the Unit, SPOR and BC AHSN, please visit bcsupportunit.ca.

Our 2018 conference theme is "Lessons learned for POR," and we're very excited to hear about this topic from our plenary presenters, Bernadette Pauly and Simon Denegri, from the presenters of eight breakout sessions, as well as the 10 poster presenters. The conference program is designed to provide learnings and offer opportunities for sharing of experiences across our four stakeholder groups: patients, 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, our key demonstration projects, our partners and our funders.

You'll notice that we'll be livestreaming and recording portions of today's activities – this is to ensure that our conference is inclusive of those unable to attend in person. Thank you once again for being at PPF18 with us today. We wish you a rewarding conference experience and hope that you find new collaborative opportunities through your networking time today. Please find us and say hello!



Stirling Bryan
Scientific Director



Minnie Downey
Executive Director

A Note from the Conference Planning Team

Networking and making connections are two of the goals for this conference. This will include refreshment breaks, a Wine & Cheese poster session, live tweeting, and facilitated keynote discussions. To make the most of these opportunities we encourage you to sit next to someone new at each session, talk to one new person at each refreshment break, live tweet with **#PPF18**, and follow others tweeting to that hashtag. We wish you an excellent conference, meeting potential new patient-oriented research collaborators.

Conference Planning Team:

- **Alison Hoens**, Knowledge Translation Specialist, Methods Clusters, BC SUPPORT Unit
- **Anna Rychtera**, Patient Representative, Co-facilitator for POR workshop, member of the Patient Council, BC SUPPORT Unit; member of the Standing Committee on Health Services and Population Health, MoH (Ministry of Health); member of the Patient Advisory Council for ARNBC (Association of Registered Nurses of BC)
- **Annie Moore**, Research Education and Grant Facilitator, Island Health
- **Camille Viray**, Education and Communications Coordinator, Department of Evaluation and Research Services, Fraser Health Authority
- **Colleen McGavin**, Patient Engagement Lead, BC SUPPORT Unit
- **Dan Enjo**, Communications Specialist, BC SUPPORT Unit
- **Grace Park**, Regional Medical Director Home Health, Fraser Health Authority Division of Family Practice, White Rock/South Surrey
- **Jenny Cartwright**, Knowledge Broker, BC SUPPORT Unit Vancouver Island Centre; Island Health
- **John Ward**, Performance Measurement Lead, BC SUPPORT Unit
- **Katrina Plamondon**, Regional Practice Leader, Research and Knowledge Translation, Interior Health; Adjunct Professor, UBC Okanagan School of Nursing
- **Kent Cadogan Loftsgard**, Clinical Educator/Research Co-Investigator/Patient Partner, Vancouver Coastal Health & University of British Columbia; BC SUPPORT Unit; Providence Health Care
- **Lupin Battersby**, Knowledge Translation Specialist, BC SUPPORT Unit Fraser Centre; Simon Fraser University
- **Margot Wilson**, Director, Chronic Disease Management Strategy, Providence Health Care; Faculty/Coach, Canadian Foundation for Healthcare Improvement; Adjunct Faculty, UBC School of Nursing
- **Nicole Cook**, Clinical Nurse Specialist, Provincial Health Services Authority; Adjunct Associate Professor, University of Victoria School of Nursing
- **Noreen Frisch**, Professor, School of Nursing, University of Victoria
- **Pat Atherton***, Director, Training and Virtual Networking Platform, BC SUPPORT Unit
- **Rachael Wells**, Manager, Health Research Initiatives; Co-Lead, BC SUPPORT Unit Northern Centre; University of Northern British Columbia
- **Larry Mróz**, Research Navigator and Patient Engagement Coordinator, BC SUPPORT Unit Vancouver Centre

***Team Lead**

Frequently Asked Questions (FAQ)

Where is the conference located? The conference venue is the **Marriott Vancouver Pinnacle Downtown**, located at **1128 West Hastings Street, Vancouver**. The day starts with breakfast at 8:00am and finishes at the end of the Networking Wine & Cheese reception by 6:00pm.

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 #PPF18 and follow us on Twitter @BCSUPPORTUnit. Feel free to tag us using this handle.

Looking for the BC SUPPORT Unit YouTube channel for live streamed and recorded sessions? Please visit <https://bcsupportunit.ca> and click on the YouTube logo at the bottom of the page. You can also visit <https://www.youtube.com> and search for 'BC SUPPORT Unit'. Please follow our channel to view the stream.

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 Networking Wine & Cheese reception from 4:30 – 6:00pm. See pages 19-28 of this program for poster abstracts. Please explore the posters and learn about other POR projects. Vote for your favourite poster! The winner will be announced via social media, the BC SUPPORT Unit newsletter and website (<https://bcsupportunit.ca/conference>).

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 – drop your ballot in the box by 6:00pm.

How do the breakout sessions work? 8 breakout sessions have been programmed: 4 from 11am-12pm and 4 from 2:30pm-3:30pm. The sessions will not be repeated. See pages 13-17 of this program 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 7 for a site map.

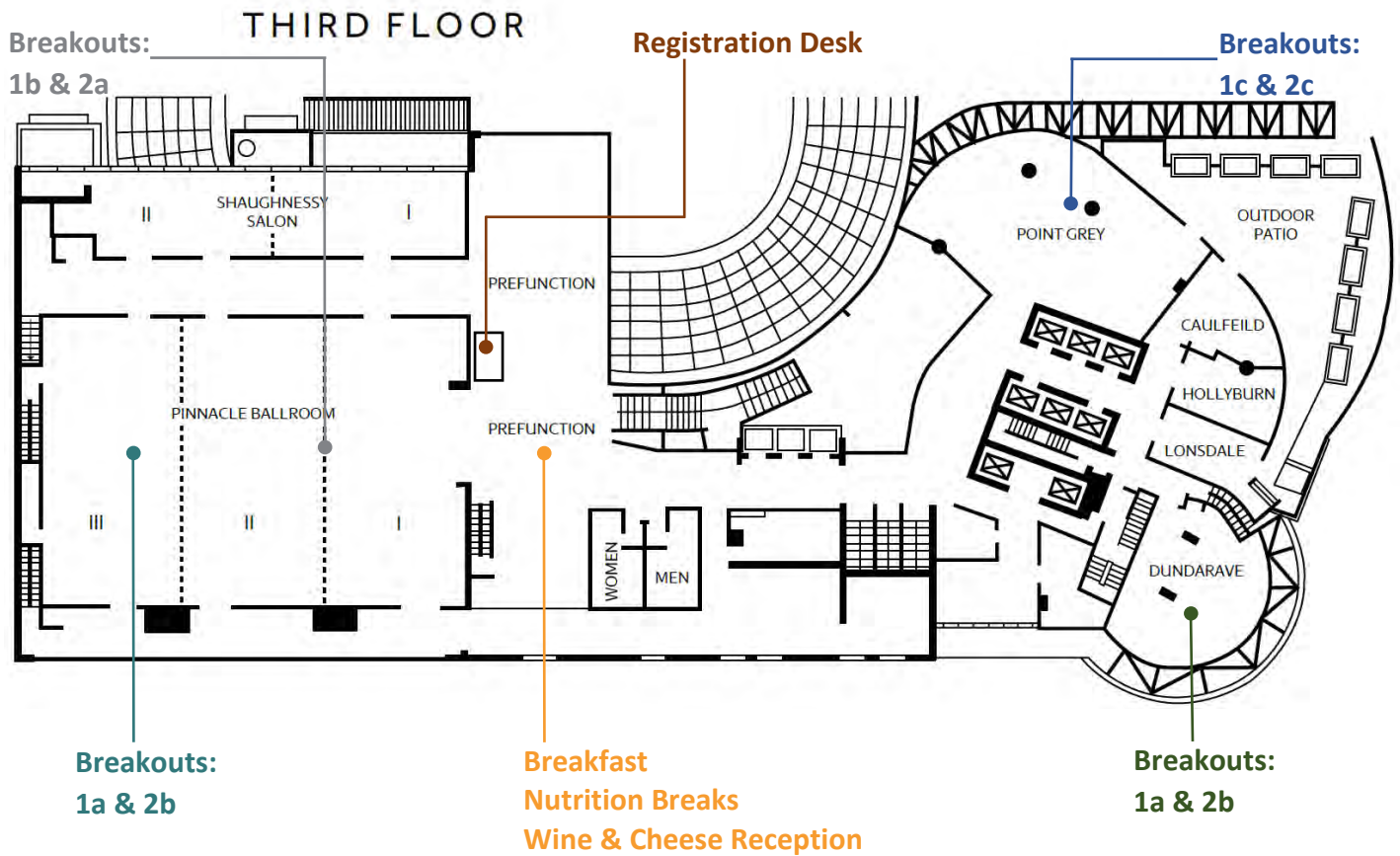
Is the hotel wheelchair accessible? Yes, all hotel elevators will take you to the third floor where meetings are held. All washroom facilities are wheelchair accessible. Washrooms are located on the third floor (beside the Pinnacle Ballroom) and additional washrooms are available on the lobby floor (beside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

Venue Map



Conference Agenda

Time	Event	Meeting Room
8:00-9:00	Registration and Networking Breakfast	Exhibits: Foyer
9:00-9:05	Moderators' Remarks Rachael Wells & Viva Swanson	Ballroom (Pinnacle I/II/III)
9:05-9:10	Opening Welcome/Prayer Elder Roberta Price	
9:10-9:20	Welcoming Remarks: BC Academic Health Science Network (AHSN) Tom Noseworthy, CEO	
9:20-9:30	Welcoming Remarks: BC SUPPORT Unit Leadership Minnie Downey & Stirling Bryan	
9:30-10:10 Keynote Session	When is Patient-Oriented Research Culturally Safe?+ Bernadette Pauly, Fred Cameron, Paige Phillips	
10:10-10:30	Questions & Answers Kimberlyn McGrail	
10:30-11:00	Break: Nutrition & Networking	Exhibits: Foyer
11:00-12:00 Breakout Session	#1a New Virtual Platforms to Support POR Presenters: Sarah Kesselring, Amanda Chisholm, Sharla Drebit, Alison Orth, Elodie Portales-Casamar, Noreen Frisch	Pinnacle III
	<ol style="list-style-type: none"> 1. BC Data Scout: Sarah Kesselring 2. BC Health Research Connection Project: Amanda Chisholm 3. BC Emergency Medicine Network: Sharla Drebit 4. Clinical Trials BC: BC Clinical Research Showcase: Alison Orth 5. REDCap: Elodie Portales-Casamar 6. BC SUPPORT Unit's Electronic Communities of Practice: Noreen Frisch <p>Host: Alison Hoens, BC SUPPORT Unit Provincial Hub</p>	
11:00-12:00 Breakout Session	#1b Patient Partner Compensation: Lessons Learned+ Panel: Minnie Downey, Colleen McGavin, and Sunny Loo	Pinnacle I & II
	Host: Larry Mróz, BC SUPPORT Unit Vancouver Centre	

Time	Event	Meeting Room
11:00-12:00 Breakout Session	<p data-bbox="363 174 769 203">#1c Lessons Learned: K* for P*</p> <p data-bbox="363 214 1138 243">Presenters: Marie Westby, Iva Cheung, Jennifer Baumbusch</p> <ol data-bbox="412 302 1195 873" style="list-style-type: none"> <li data-bbox="412 302 1166 485">1. Patients' and healthcare professionals' resource preferences for a knowledge translation toolkit for hip and knee replacement rehabilitation (10 minutes) Presenter: Marie Westby Q&A (5 minutes) <li data-bbox="412 495 1114 678">2. Improving Mental Health Act rights advice in BC: a patient-oriented integrated knowledge translation project (10 minutes) Presenter: Iva Cheung Q&A (5 minutes) <li data-bbox="412 688 1195 873">3. Fostering Support, Networking, Education and Sustained Engagement in Long-term Care: A Research Co-Creation Project with Families (10 minutes) Presenter: Jennifer Baumbusch Q&A (5 minutes) <p data-bbox="363 919 748 949">Open discussion (15 minutes)</p> <p data-bbox="363 995 1089 1024">Host: Brittney La Pietra, BC SUPPORT Unit Fraser Centre</p>	Point Grey
11:00-12:00 Breakout Session	<p data-bbox="363 1073 1122 1142">#1d Giving Voice to Our Patients: Using and Reporting on Patient-Centered Measures</p> <p data-bbox="363 1152 748 1182">Presenters: Richard Sawatzky</p> <p data-bbox="363 1228 1089 1257">Host: Wendy Petillion, BC SUPPORT Unit Interior Centre</p>	Dundarave
12:00-1:00	Networking Lunch	Exhibits: Foyer
1:00-2:00 Plenary Session	<p data-bbox="363 1461 1154 1530">Challenging cultures, changing systems - the UK's journey in public involvement in health research</p> <p data-bbox="363 1541 976 1570">Moderators: Erika Belanger & Tamara Reichert</p> <p data-bbox="363 1617 781 1646">Plenary Speaker: Simon Denegri</p>	Ballroom (Pinnacle I/II/III)
2:00-2:15	<p data-bbox="363 1696 651 1726">Questions & Answers</p> <p data-bbox="363 1736 607 1766">Kimberlyn McGrail</p>	
2:15-2:30	Break: Nutrition & Networking	Exhibits: Foyer

Time	Event	Meeting Room
2:30-3:30 Breakout Session	<p data-bbox="363 176 1097 243">#2a BC SUPPORT Unit Methods Clusters: A Living Lab of Learning</p> <p data-bbox="363 254 873 279">Presenters: Stirling Bryan, Alison Hoens</p> <p data-bbox="363 331 1175 436">Panel of Methods Cluster Leads: Nick Bansback, Leanne Currie, Linda Li, Erin Michalak, Rick Sawatzky, David Whitehurst, Hubert Wong</p> <p data-bbox="363 489 1029 514">Host: Kelly Moran, BC SUPPORT Unit Provincial Hub</p>	Pinnacle I & II
2:30-3:30 Breakout Session	<p data-bbox="363 564 1081 632">#2b Lessons Learned: Patient and Family Experiences⁺ (Oral Presentations)</p> <p data-bbox="363 684 1175 747">Presenters: Alexandra Warren, Nicole S.Y. Liang, Isabel Jordan, Kelsey Ohs, Mary De Vera, Clayon Hamilton</p> <ol data-bbox="412 800 1195 1604" style="list-style-type: none"> <li data-bbox="412 800 1195 978">1. The PREFeR (PRioritiEs For Research) Project: Results from a multistage patient priority setting project for primary care research in British Columbia⁺ (10 minutes) Presenter: Alexandra Warren Q&A (5 minutes) <li data-bbox="412 989 1195 1167">2. Participants as Partners in Research: Communicating a timeline to research participants for results with a 'fuzzy ending'⁺ (10 minutes) Presenter: Nicole S.Y. Liang, Isabel Jordan, Kelsey Ohs Q&A (5 minutes) <li data-bbox="412 1178 1195 1398">3. Exploring Strategies to Support Medication Adherence in Patients with Inflammatory Arthritis: A Patient-Oriented Qualitative Study Using an Interactive Focus Group Activity (10 minutes) Presenter: Mary De Vera Q&A (5 minutes) <li data-bbox="412 1409 1195 1604">4. Development and initial validation of a questionnaire to assess the quality of patient engagement in research (10 minutes) Presenter: Clayon Hamilton Q&A (5 minutes) <p data-bbox="363 1656 1062 1682">Host: Larry Mróz, BC SUPPORT Unit Vancouver Centre</p>	Pinnacle III
2:30-3:30 Breakout Session	<p data-bbox="363 1730 1188 1797">#2c Finding Patient-Oriented Research in PubMed and Beyond (Workshop)</p> <p data-bbox="363 1808 841 1833">Presenters: Ursula Ellis, Helen Brown</p> <p data-bbox="363 1885 1062 1911">Host: Michelle Duffy, BC SUPPORT Unit Provincial Hub</p>	Point Grey

Time	Event	Meeting Room
2:30-3:30 Breakout Session	#2d Don't Categorize Me or My Sexual Choices: Lessons Learned for Patient-Oriented Sexual Health Research By, With, and For Women Living with HIV (Panel) Presenters: Valerie Nicholson, Peggy Frank, Mary Kestler, Angela Kaida Host: Jenny Cartwright, BC SUPPORT Unit Vancouver Island Centre	Dundarave
3:30-3:35	Room shift	
3:35-4:25 Wrap Up Panel Discussion & Plenary Session	Wrap Up Panel Discussion Moderator: Davina Banner Panelists: Bernadette Pauly, Simon Denegri, Stirling Bryan, Fred Cameron, Paige Phillips	Ballroom (Pinnacle I/II/III)
4:25-4:30	Ceremonial Closing Elder Roberta Price	
4:30-6:00	Networking Wine & Cheese Reception (cash bar)	Foyer
4:30-6:00	Poster Presentations and Voting for Best Poster	Shaughnessy Salon

[†]These sessions will be livestreamed and recorded on our YouTube channel. Please follow our channel to view the stream.

Exhibits & Exhibitor Information

Exhibit times:

- 8:00-9:00am
- 10:30-11:00am
- 12:00-1:00pm
- 2:15-2:30pm

Be sure to take some time to check out the organizations that are providing exhibits at the conference:

- **BC Academic Health Science Network (BC AHSN)**, host institution of the BC SUPPORT Unit
- **BC Emergency Medicine Network**, a BC SUPPORT Unit demonstration project
- **BC Health Research Connection Project**, a BC SUPPORT Unit demonstration project
- **Canadian Institutes of Health Research***
- **Clinical Trials BC**, a unit of BC AHSN
- **Michael Smith Foundation for Health Research***
- **Research Ethics BC**, a unit of BC AHSN

And **BC SUPPORT Unit Regional Centres**: Regional Centres (<http://bcsupportunit.ca/locating-your-regional-centre>) are partnerships between a regional health authority and a corresponding university in that region. They are the first point of contact for stakeholders interested in patient-oriented research. Fraser, Interior, Island, Northern and Vancouver Regional Centres provide specialized expertise and supports in response to the particular needs and interests of people in their region. The Regional Centres support: navigation of patient engagement planning, training, and outreach; knowledge translation activities; data and methods-related questions; and help connect people so they can pursue meaningful patient-oriented research. Stop by our shared exhibit tables to learn more about initiatives unfolding at each Regional Centre and meet some of the leaders involved!

***BC SUPPORT Unit extends its thanks to these funders.**

Morning Breakout Session Information

11:00AM - 12:00PM

#1a New Virtual Platforms to Support POR



This session will demonstrate highlights of six new platforms that have been recently launched to support patient-oriented research in BC. Participants will be exposed to high level functionality of each platform to be better informed about how each can be used in a POR environment.

1. *BC Data Scout*: Sarah Kesselring
2. *BC Health Research Connection Project*: Amanda Chisholm
3. *BC Emergency Medicine Network*: Sharla Drebit
4. *Clinical Trials BC: BC Clinical Research Showcase*: Alison Orth
5. *REDCap*: Elodie Portales-Casamar
6. *BC SUPPORT Unit's Electronic Communities of Practice*: Noreen Frisch

Meeting Room: Pinnacle III

Presenters: Sarah Kesselring, Amanda Chisholm, Sharla Drebit, Alison Orth, Elodie Portales-Casamar, Noreen Frisch

Host: Alison Hoens, BC SUPPORT Unit Provincial Hub

#1b Patient Partner Compensation: Lessons Learned⁺



While showing appreciation for study participants through honoraria and gifts is common practice in health research, this is not routinely done in respect to patient partners, and there are varying opinions on the subject. As a progressive organization and leader in the BC health research landscape, the BC SUPPORT Unit has adopted the stance that it is important to show appreciation beyond reimbursement by offering compensation. In February 2018, after extensive consultation with stakeholders, the SUPPORT Unit implemented a Patient Partner Appreciation Policy. In this session, we will share our policy, describe how we went about developing it, and discuss what we learned and are still learning as the policy gets implemented. We intend to leave lots of time for discussion.

Meeting Room: Pinnacle I & II

Panel: Minnie Downey, Colleen McGavin, and Sunny Loo

Host: Larry Mróz, BC SUPPORT Unit Vancouver Centre

⁺These sessions will be livestreamed and recorded on our YouTube channel. Please follow our channel to view the stream.

#1c Lessons Learned: K* for P* (Oral Presentations)



K* is a term used to describe the many processes of getting research & evidence into policy/ practice which includes knowledge management/translation/exchange. These oral presentations focus on different aspects of K* within the different forms of research that include Patients.

1. Patients' and healthcare professionals' resource preferences for a knowledge translation toolkit for hip and knee replacement rehabilitation. (10 minutes)

Presenter: Marie Westby

Q&A (5 minutes)

2. Improving Mental Health Act Rights Advice in BC: A patient-oriented integrated knowledge translation project. (10 minutes)

Presenter: Iva Cheung

Q&A (5 minutes)

3. Fostering Support, Networking, Education and Sustained Engagement in Long-term Care: A Research Co-Creation Project with Families (10 minutes)

Presenter: Jennifer Baumbusch

Q&A (5 minutes)

Open discussion (15 minutes)

Meeting Room: **Point Grey**

Presenters: Marie Westby, Iva Cheung, Jennifer Baumbusch

Host: Brittney La Pietra, BC SUPPORT Unit Fraser Centre

#1d Giving Voice to Our Patients: Using and Reporting on Patient-Centred Measures



This interactive workshop will serve as an introduction to patient-reported experience and outcome measures (PREMS and PROMS) and will include innovative examples of how results are reported and used in British Columbia to engage frontline leaders, clinicians, policy makers and others to focus both care and program planning efforts on what is important to patients.

Meeting Room: **Dundarave**

Presenter: Richard Sawatzky

Host: Wendy Petillion, BC SUPPORT Unit Interior Centre

Afternoon Breakout Session Information

2:30 – 3:30PM

#2a BC SUPPORT Unit Methods Clusters: A Living Lab of Learning



This session will provide an opportunity for attendees to hear about key lessons learned from the launch and development of the BC SUPPORT Unit Methods Clusters. The mandate of the clusters is to advance the evidence base of scientific methods, within the context of patient-oriented research, by fostering communities of BC-based methodologists and other stakeholders to undertake methodology focused projects. Leads from each of the 6 clusters will share their ‘biggest wins’ and ‘biggest challenges’, followed by a panel discussion highlighting lessons learned. The session will conclude with an opportunity to address session participants’ questions.

Meeting Room:

Pinnacle I & II

Presenters:

Stirling Bryan; Alison Hoens

Panel of Methods Cluster Leads: Nick Bansback, Leanne Currie, Linda Li, Erin Michalak, Rick Sawatzky, David Whitehurst, Hubert Wong

Host:

Kelly Moran, BC SUPPORT Unit Provincial Hub

#2b Lessons Learned: Patient and Family Experiences+ (Oral Presentations)



How do patient and family caregiver health care and illness experiences help inform research? In this research-findings presentation session, you'll hear about how this happened in several research projects:

- How patient and family experiences of primary care help informed selection of research priorities;
- How parents experienced the timelines involved in genetic testing and diagnosing of their children and helped improve communication and reduced anxiety;
- How living with a chronic condition helped inform development of medication adherence guidelines;
- How measurement of patient experiences has engaged research partners.

1. The PREFeR (PRioritiEs For Research) Project: Results from a multistage patient priority setting project for primary care research in British Columbia⁺ (10 minutes)
Presenter: Alexandra Warren
Q&A (5 minutes)
2. Participants as Partners in Research: Communicating a timeline to research participants for results with a 'fuzzy ending'⁺ (10 minutes)
Presenter: Nicole S.Y. Liang, Isabel Jordan, Kelsey Ohs
Q&A (5 minutes)
3. Exploring Strategies to Support Medication Adherence in Patients with Inflammatory Arthritis: A Patient-Oriented Qualitative Study Using an Interactive Focus Group Activity (10 minutes)
Presenter: Mary De Vera
Q&A (5 minutes)
4. Development and initial validation of a questionnaire to assess the quality of patient engagement in research (10 minutes)
Presenter: Clayon Hamilton
Q&A (5 minutes)

Meeting Room: Pinnacle III

Presenters: Alexandra Warren, Nicole S.Y. Liang, Isabel Jordan, Kelsey Ohs, Mary De Vera, Clayon Hamilton

Host: Larry Mróz, BC SUPPORT Unit, Vancouver Centre

⁺*These sessions will be livestreamed and recorded on our YouTube channel. Please follow our channel to view the stream.*

#2c Finding Patient-Oriented Research in PubMed and Beyond (Workshop)



Two health librarians will demonstrate search techniques and tools for finding patient-oriented research, including: Search filters for PubMed PCORI's Engagement in Health Research Literature Explorer. The instructors will also discuss open access initiatives making articles freely available to the public, and the increasing use of lay summaries as a knowledge translation tool.

Meeting Room: Point Grey

Presenters: Ursula Ellis & Helen Brown

Host: Michelle Duffy, BC SUPPORT Unit Provincial Hub

#2d 'Don't categorize me or my sexual choices': Lessons learned for patient-oriented sexual health research by, with, and for women living with HIV (Panel)



Women comprise nearly one-quarter of people living with HIV in Canada, but their health and social priorities are under-represented in HIV research. This panel of diverse stakeholders will highlight lessons learned from engaging in patient-oriented research related to sexual health among women living with HIV (WLWH), from a sex-positive and critical feminist lens.

Stakeholders will discuss their engagement in research on the criminalization of HIV non-disclosure and 'Undetectable=Untransmittable' (U=U) as two opposing HIV prevention strategies. Visual representations depicting the results of patient-centred research will be displayed as a PowerPoint loop and an art gallery of life-sized Body Maps (visual narratives depicted through images and symbols).

Angela Kaida will discuss the feminization of HIV in Canada, including the under-emphasis of sex-positive research, and the rationale for patient-oriented research studies by, with, and for WLWH. Focusing on the gendered impacts on sexual health, she will discuss research on the criminalization of HIV non-disclosure in Canada and the global U=U campaign, which disseminates research evidence that with a suppressed viral load, people living with HIV have effectively no risk of transmitting HIV.

Peg Frank will emphasize the critical need for community-driven research approaches to investigate the impacts of HIV non-disclosure laws on the safety and health of WLWH, including risks of violence against women. She will share her experiences as a WLWH and peer researcher, whose sexual life is 'under surveillance'.

Valerie Nicholson will share experiences working in sexual health and HIV research; and how the U=U campaign is helping many people living with HIV reclaim their sexuality. She will highlight how being meaningfully involved in research has helped her to fight stigma and celebrate the sexuality of WLWH.

Mary Kestler will discuss experiences working as a physician to support women's healthy sexuality, and how the criminalization of HIV non-disclosure impacts her ability to support women.

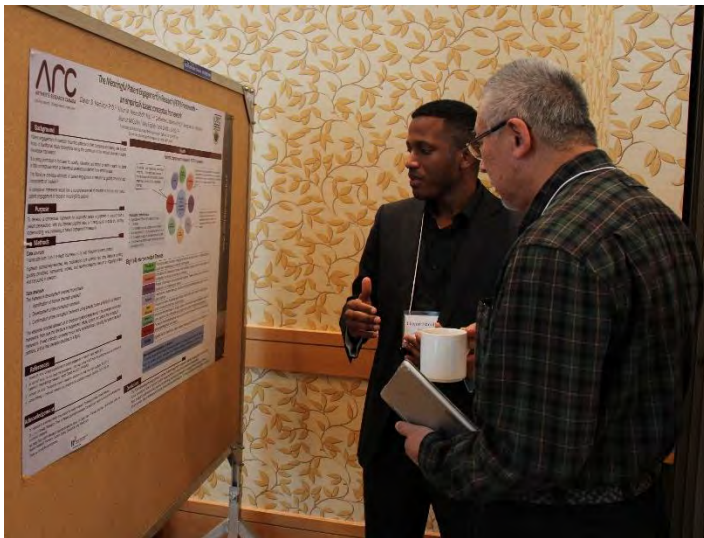
Meeting Room: Dundarave

Presenters: Valerie Nicholson, Peggy Frank, Mary Kestler, Angela Kaida

Host: Jenny Cartwright, BC SUPPORT Unit Vancouver Island Centre

Poster Presentations

Poster Number	First Author
1	Lauren Airth
2	Shazhan Amed
3	Dhwani Babla
4	Davina Banner
5	Barbara Croome
6	Chad Dickie
7	JL Maiorino
8	Jim Mann
9	Nelly Oelke
10	Catherine Turner



Poster session participants from PPF17

Poster Abstracts

Poster #1: Using Photovoice for Patient-Oriented Research: Understanding the Mental Health Experiences of Adults 50 years and Older Living in the Similkameen

Lauren Airth¹, Nelly D. Oelke², Carolyn Szostak³, Sharon Evans⁴, Karen Fulton⁵, Nola Mensch

¹ UBC, Okanagan, ²School of Nursing, UBC, Okanagan, ³ Department of Psychology, UBC, Okanagan, ⁴ South Okanagan Similkameen Mental Wellness Society, ⁵ Interior Health Authority

Introduction and Background:

This research aims to understand the experiences of adults 50 and over who have mental health concerns in rural Southern Interior BC.

Little research has focused on the experience of rural older adults with mental health concerns. Stigma is a significant issue in rural communities, particularly with older adults, impacting access to treatment despite proven benefits. Stigma is also perpetuated by clinicians prioritizing physical over mental health.

Methods:

Critical theory underpins this research focusing on power imbalances in society requiring reflection and action on knowledge created. Data collection includes: 1) Focus group to collectively identify what participants would like others to know about their experiences with mental health concerns in this community; 2) Participants to take photos related to the themes; 3) Individual interviews with participants to discuss photos' significance; 4) Focus group to discuss knowledge translation (KT) approaches; 5) Photovoice provides participants with the opportunity to tell their stories and acknowledges multiple realities; and 6) Ten adults 50 and over will participate in the study

Preliminary Results:

Preliminary results from the research will be shared.

Discussion:

This methodology is well aligned with patient-oriented research where community members are actively engaged in determining the direction of the research, collecting data, and sharing results. We use an integrated KT approach by including a community member and decision-maker as equitable team members and involving them in all aspects of the research. Furthermore, this study will give voice to a marginalized population. It will increase awareness and has the potential to reduce stigma in the community. Furthermore, it will contribute to healthcare providers' ability to make informed decisions regarding the care of rural older adults.

Dissemination and Knowledge Translation Approach:

KT will be determined by participants and may include a gallery showing or photobook. Results will also be shared via community and conference presentations, and publications.

Poster #2: Child-Sized Knowledge Translation

Shazhan Amed^{1,2}, Ian Pike³, Kishore Mulpuri⁴, Stephanie Glegg⁵, Julie Rolliard⁶, Elodie Portales-Casamar⁷, Louise Masse⁸, Mariana Brussoni^{9,10}, Janet Mah¹¹, John Jacob¹², Rosa Livingston¹³, Jenny Morgan¹⁴

¹ BC Children's Hospital, Department of Pediatrics, ² BC Children's Hospital Research Institute, ³ Department of Pediatrics, BC Children's Hospital Research Institute, ⁴ Department of Orthopaedics, BC Children's Hospital Research Institute, ⁵ Department of Occupational Science & Occupational Therapy, Knowledge Broker and Facilitator, Sunny Hill Centre for Children, ⁶ Faculty of Medicine, BC Children's Hospital Research Institute, ⁷ Department of Pediatrics, BC Children's Hospital Research Institute, ⁸ School of Population and Public Health, ⁹ BC Children's Hospital Research Institute, ¹⁰ Department of Pediatrics, School of Population and Public Health, ¹¹ Department of Psychiatry, BC Children Hospital Research Institute, ¹² Department of Pediatrics, Senior Director Digital Lab team BCCH & UBC Pediatrics, ¹³ Family/Community Partner, ¹⁴ BC Women's and Children's Hospital, Director, Indigenous Health

Objective:

The objective of this study is to engage patients, families and practitioners, healthy children and youth, in a participatory approach to enable meaningful and sustainable engagement for the design, development and evaluation of a robust, interactive knowledge translation platform called Child-Sized KT.

Methods:

Eight consultation meetings were held over the course of one year. Participants included clinicians, researchers, administrators and managers, high-level decision-makers and parents. During each consultation, stakeholders were asked about their views on patient engagement in research, specifically, barriers and facilitators to engagement; skills or resources needed to maximize engagement, strategies for engaging those that do not typically participate; potential platforms and their functionalities; and opportunities and obstacles to moving into the development phase. In addition to these consultations, over 500 parents across BC completed an online survey, including those who have accessed care at BC Children's Hospital (BCCH) through the diabetes clinic. The survey explored parent perspectives on engaging in research at BCCH and doing so through an online platform.

Results:

Both parents and practitioners felt they could contribute the most to identifying the problem, developing the research question and sharing the results. Stakeholder perspectives on barriers and facilitators to engagement fell into five categories: resources, value, interpersonal connection, opportunity and culture.

Conclusion and Knowledge Translation Approach:

There is strong interest from all stakeholders to facilitate patient engagement in research at BC Children's Hospital (BCCH). A platform that is accessible, personal and offers all opportunities to those who are interested will maximize entry points into research.

Poster #3: The PREFeR (PRioritiEs For Research) Project: Rapid Literature Reviews on the Top 10 Patient-Identified Topics for Primary Health Care Research in British Columbia

Dhwani Babla¹, Nathaniel Tok¹, Louisa Edwards^{1,2}, Ruth Lavergne^{1,3}

¹ Faculty of Health Sciences, Simon Fraser University, ² Centre for Clinical Epidemiology and Evaluation, Vancouver Coastal Health Research Institute, ³ UBC, Centre for Health Services & Policy Research

Introduction and Background:

Much of primary care research focuses on understanding patient needs and gaps in care, but patients are infrequently included in prioritizing research ideas. PREFeR (PRioritiEs For Research) conducted rapid literature reviews based on patient-identified priorities for primary care research in British Columbia. These will reveal under-researched topics for future studies.

Methods:

A Patient Advisory explored experiences of primary care, generating 10 key topics. Rapid literature reviews were carried out in MEDLINE for published research conducted within BC and Canada. Topic-specific search strategies were constructed for English language publications from 2008-2018. All searches included 'primary health care' and province/country terms. Two reviewers independently screened abstracts/titles for relevance to the topics. Number and proportion of included BC and Canadian papers were summarized.

Results:

The number of papers initially extracted for the 10 topics ranged from 1 to 56 (BC) and 13 to 442 (Canada). After abstract screening, the topics with the fewest papers were Improving continuity and coordination (BC: n=1; Canada: n=1) and Mental health resources (BC: n=1; Canada: n=34). Conversely, topics with the most research were Accessing care when/where needed (BC: n=56; Canada: n=702) and Care guided by patient needs, values, preferences, priorities (BC: n=39; Canada: n=442).

Discussion:

Findings showed wide variability in the extent of published research among the 10 topics within BC and Canada, but the relative proportion of hits was similar for BC and Canada. Improving continuity/coordination and mental health are under-researched areas, but important to patients. Prioritizing future primary care research with patients is feasible, fruitful and benefits the end-users.

Dissemination and Knowledge Translation Approach:

Patient partners 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 #4: Learning Together: Initiating an Integrated Knowledge Translation Process to Explore Patient Engagement in Canadian Circulatory and Respiratory Research Networks

Banner, D.¹, Bains, M.^{2,3}, Carroll, S.⁴, Aaron, S.^{5,6,7}, Healey, J.^{8,9,10}, Stewart, D.^{11,12,13}, Tang, A.^{14,15}, Runte, M.^{2,16}, McGavin, C.¹⁷, Wong, C.¹⁸, Kandola, D.¹⁹, Graham, I.D.^{20,21}

¹ Associate Professor, School of Nursing, University of Northern British Columbia (UNBC), ² Patient Partner, ³ Vice President of HeartLife Foundation, ⁴ Associate Professor, School of Nursing at McMaster University, ⁵ Director, Canadian Respiratory Research Network, ⁶ Senior Scientist, Ottawa Hospital Research Institute & Chief of Respiratory Medicine, ⁷ Professor, University of Ottawa, ⁸ Chair of the Canadian Stroke Prevention Intervention Network, ⁹ Director, Arrhythmia Services at Hamilton Health Sciences, ¹⁰ Associate Professor, McMaster University, ¹¹ Director of the Canadian Vascular Network, ¹² CEO and Scientific Director of the Ottawa Hospital Research Institute, ¹³ Professor, University of Ottawa, ¹⁴ CEO of the Canadian Arrhythmia Network, ¹⁵ Professor, Western University, ¹⁶ Associate Professor, University of Lethbridge, ¹⁷ Patient Engagement Lead at the BC SUPPORT Unit (SPOR), ¹⁸ Executive Manager, Centre of Excellence of Partnership with Patients and the Public, ¹⁹ Doctoral student and Research Associate, UNBC, ²⁰ Professor, School of Epidemiology, Public Health and Preventative Medicine at the University of Ottawa, ²¹ Senior Scientist at the Ottawa Hospital Research Institute

Introduction and Background:

Circulatory and respiratory diseases (CRDs) are a major cause of morbidity and mortality, accounting for significant healthcare expenditure in Canada and beyond. As rates of CRDs continue to rise, health care organizations are becoming challenged to develop and implement services that are evidence-based and improve outcomes. Despite this growing focus, variations in health care delivery continue to adversely impact patient care and outcomes. Patient engagement in health care and research has been hailed as an important mechanism to address these ongoing concerns. This poster will present the process of initiating an integrated Knowledge Translation (iKT) process to examine patient engagement in CRD research.

Methods:

To initiate this work, our team worked to foster team building and co-create a successful application for funding to support partnership development and patient engagement. Our team encompasses a broad range of knowledge users, patients and researchers interested in patient-oriented research.

Results:

Research that is underpinned by the iKT process requires early and sustained collaboration between researchers, stakeholders and national networks. In order for us to set up the conditions for ongoing collaboration, we first needed to secure funding to support early engagement activities, team development and priority setting. This poster will explore our journey to date, lessons learned, and will examine how we are working collaboratively to explore patient-oriented CRD research and to contribute to the science of iKT and patient engagement.

Discussion/Implications:

Collectively, these early partnerships and team building activities provided a foundation for ongoing collaboration and a means to catalyze further research. By fostering these early connections, our group was able to mobilize rapidly to facilitate a successful funding proposal and cement a commitment to further patient-oriented research. By exploring our planning and engagement activities, we hope to share ideas for others interested in developing research that reflects the needs, values and priorities of patients.

Poster #5: Stroke Through the Eyes of a Survivor: Lived Experience as an Opportunity for Improving Patient Experience

Barbara Croome¹, Davina Banner², Daman Kandola², Si Transken², Haidar Hadi³, Barbara Hennessy⁴, Tanya Barrett⁵, Pam Aikman⁶

¹ Patient Partner, ² University of Northern British Columbia (UNBC), ³ Cardiologist, Northern Health Authority, ⁴ Consultant, Cardiovascular Health and Stroke, ⁵ University Hospital of Northern British Columbia, ⁶ Provincial Director, Provincial Health Services Authority

Introduction and Background:

Stroke is an important public health concern in Canada. Those living in small urban, rural, and remote areas are particularly vulnerable to stroke and its consequences, particularly in light of the escalating levels of chronic disease and more limited access to specialized services and supports. To understand this further, we undertook an exploratory study aimed at gathering insights into the barriers and facilitators of stroke prevention and management in northern BC. A central aspect of this work was to provide an avenue for the patient voice through the sharing of personal stories of stroke.

Methods:

Patient journey mapping was conducted with patients who had recent experience of stroke and we then partnered with patients to create innovative knowledge translation outputs to share this journey with health care providers, decision-makers and researchers. This work was underpinned by a trauma-informed integrated knowledge translation approach and involved cycles of in-depth qualitative interviews and art sessions. In congruence with the principles of patient-oriented research, these activities have been co-created with patients and has involved meaningful collaboration across the research process.

Findings and Knowledge Translation Approach:

Significant gaps in stroke care exist in rural settings, including a lack of post-hospital supports and timely rehabilitation. This can leave many patients feeling abandoned as they recover from stroke. In this presentation, our patient partner will present her experience of navigating care and recovering from stroke in a rural community and will share a co-created interactive arts-based knowledge translation product. Our team will then present on our planned stroke care priority setting workshop. Through this, we have had the opportunity to share the patient voice with those developing and delivering services, as well as being a catalyst for wider community-based initiatives that foster the voice of stroke survivors, identify patient priorities, and inform initiatives to improve patient care.

Poster #6: Does SPOR mean MORE (Meaningful Opportunities for Research Engagement) for Patient Partners?

Chad Dickie¹, Lisa Ridgway¹, Taylor Hainstock²

¹ Patient Partner, BC SUPPORT Unit Vancouver Island Centre, Oversight Committee, ² Patient Liaison, BC SUPPORT Unit Vancouver Island Centre

Introduction and Background:

High-level patient engagement is key to ensuring the right patient receives the right intervention at the right time by including the patient voice on decision-making boards, committees and working groups. Identifying empowerment at this level of patient engagement is key to understanding and recognizing higher-level patient engagement that are meaningful.

Methods:

Using the IAP2 Spectrum as a guide, we measured patient engagement on review boards, governance and oversight committees, and other decision-making, empowered activities since the implementation of the BC SUPPORT Unit in 2016. We identified empowered engagements to qualify and recognize valuable contributions. Select patient-partners were interviewed to identify characteristics of the meaningful engagement environment, whether the engagement increased patient-partner capacity, and improved overall understanding of SPOR goals, strategies and challenges.

Results:

One patient-partner qualitative interview consisting of five questions was completed. Themes were identified for meaningful engagement, working with multi-disciplinary teams, and whether engagement improved policies and practices related to patients. We identified beneficial engagement environment and structure, invitations for meaningful contributions, equal voting rights, and patient healthcare system knowledge acquisition.

Discussion:

By building a framework usable by other SUPPORT Units and SPOR initiatives across Canada, this project can measure patient research knowledge acquisition, improved understanding of POR linkages to the broader healthcare system and identify opportunities by sharing of patient-partner experiences.

Dissemination and Knowledge Translation Approach:

Our data and information will be shared with photographs, charts and graphs that are easy to read, translatable to other languages, and visually appealing. Future iterations may include video. Our research will abide by all CIHR Responsible Conduct of Research guidelines and attained institutional and organizational ethics approvals as required. Participants will submit Informed Consent Forms including permission to share findings at sanctioned SPOR conferences and POR events. A framework model will be published and disseminated with SPOR across Canada.

Poster #7: From the Heart: Designing HeartHub.ca, a Cardiovascular Health Information Hub for Patients, by Patients

Maiorino JL¹, Miller KJ^{1,6}, Leese J², Mamdani A¹, Castelino C¹, Hardiman S³, Tyler M⁴, Shepherd J⁵, Whitehouse T⁵, Humphries K¹

¹ BC Centre for Improved Cardiovascular Health, ² Arthritis Research Canada & Department of Physical Therapy, University of British Columbia, Vancouver, BC, ³ Cardiac Services BC, Provincial Health Services Authority, BC, ⁴ Providence Health Care, Vancouver, BC, ⁵ Patient Voices Network, BC Patient Safety & Quality Council, Vancouver, BC, ⁶ Sunny Hill Health Centre for Children, Vancouver, BC

Introduction and Background:

Many patients told us in interviews/focus groups that when they had an angiography test to determine if they had coronary artery disease: 1) they were unaware a heart treatment decision might need to be made right away; and 2) they did not have the information they needed to support them in decision-making with their doctor. The aim of HeartHub.ca was to co-design web-based knowledge dissemination resources/tools with the intention of supporting patients to feel more confident and prepared to participate in evidence-informed heart treatment decisions.

Methods:

The HeartHub.ca resources/tools were planned in a workshop of patient partners, decision-makers, researchers, and clinicians using patient information needs and preferences identified in patient interviews/focus groups. The quality of the workshop engagement was evaluated using the Public and Patient Engagement Evaluation tool (PPEET). Seven patient partners and four clinicians committed to co-designing the final HeartHub.ca content post-workshop. Ongoing feedback was sought from patients and clinicians. Patients awaiting angiography at St. Paul's Hospital were invited to view HeartHub.ca and complete a survey evaluating the usefulness of the website.

Results:

All workshop participants (10/23) who completed the PPEET agreed/strongly agreed their views were heard and that the planned resources/tools would be useful. Of 30 patients who viewed HeartHub.ca as they awaited angiography, 76% agreed/agreed strongly they felt more confident and 74% agreed/agreed strongly they felt more prepared to make an informed treatment decision. Patients suggested they would have preferred to view HeartHub.ca before their hospital visit.

Discussion/Implications:

Most patients felt more confident and more prepared to participate in informed heart treatment decisions after viewing HeartHub.ca, a knowledge dissemination website including tools/resources co-designed for patients by patients.

Dissemination and Knowledge Translation Approach:

HeartHub.ca will be translated into three common languages. Our plan is for <http://hearhub.ca/> to be included with other information sent to patients prior to their angiography appointments.

Poster #8: Co-research with People with Dementia for Change

Jim Mann^{1,2}, Lillian Hung^{1,3}

¹ Vancouver Coastal Health, ² Patient Partner, ³ Alzheimer Society Post-Doctoral Fellow

Research about patients with dementia in acute care has been traditionally designed and carried out by researchers with little or no involvement of people with dementia. Moving away from the old way of conducting research 'on' people with dementia, this study involved people with dementia as experts of lived experiences to 'co-develop' knowledge for change. This animated poster presents our shared experiences (a person with dementia, Jim Mann and a researcher, Lillian Hung) gained from an action research conducted at Vancouver General Hospital.

Action research methodology was applied to the study, involving cycles of observations, plan, action, and evaluation. The study involved patients with dementia, families, and a team of interdisciplinary staff in a medical unit to inquire and take actions for improving dementia care in a medical unit. The research led to results of the co-creation of an education package, including an online game, staff training in dementia care, and integration of new clinical tools for better family communication.

Jim and Lillian have co-authored a peer-reviewed paper to call for attention to everyday ethics, which go beyond the traditional principles in University Research Ethics prescribes. Based on our lessons learned, we developed a useful framework, ASK ME to inspire and support others to co-research 'with' people with dementia.

ASK ME offers five practical tips for co-research with people with dementia:

1. Avoid assumption
2. Support the person to do the best
3. Knowledge needed to be put into action and acknowledged
4. Meet regularly and early
5. Ethical sensitivity and responsibility.

We provide specific examples to illustrate challenges, strategies and possibilities in co-researching dementia care to making real impacts on hospital care for patients with dementia. Our study demonstrated that the positive relationship, featured with collaborative, reflexive and respectful approaches, was vital to enhance the quality and rigor of the research.

Poster #9: Integrated Health Services Through Primary Health Care Teams: A Comparative Policy Analysis

Oelke, N.D.¹, Jagroop, B.², Ooms, S.³, Arsenault, D.⁴, Berg, S.⁵, Graham, P.⁶, Landry, G.⁷, Birdsell, J.⁸, Montesanti, S.⁹, Johnston, S.¹⁰, Breton, M.¹¹, Gaboury, I.¹¹, Green, L.⁹, Maiwald, K.⁴, Mallison, S.¹², Martin Misener, R.¹³

¹UBC Okanagan, ²BC Patient Partner, ³BC Ministry of Health, ⁴Interior Health, ⁵Alberta Health, ⁶Ontario Ministry of Health and Long-term Care, ⁷Ministère de la Santé et des Services Sociaux du Québec, ⁸Alberta Patient Partner, ⁹University of Alberta, ¹⁰University of Ottawa, ¹¹University of Sherbrooke, ¹²Alberta Health Services, ¹³Dalhousie University

Introduction and Background:

Improving health services integration for complex patients is challenging given the increasing complexity of patients and services they require. Team-based primary health care (PHC) models have been developed and implemented in diverse ways across Canada to improve patient experience and better coordinate care to improve population health and reduce costs. Evidence remains mixed regarding impact and determining which policies/structures facilitate, incentivize, or promote integration. The aim of this study is to examine policies/structures that support service integration for complex patients through PHC teams.

Methods:

This cross jurisdictional study (BC, AB, ON, QC) will use case study methodology. Phase 1: A document review of provincial and regional level policies/structures on PHC teams and integrated service delivery with individual (by province) and cross-case analysis will be completed. Phase 2: Interviews and deliberative dialogue (DD) will be conducted with patients/caregivers in each province to explore how they are and would like to be involved in policy development and implementation for PHC teams and integration. Phase 3: We will seek feedback on the research results from provincial and national stakeholders, including patients, through a series of online and virtual discussions. Recommendations and actions will be developed.

Results:

The protocol for the study will be presented.

Discussion/implications:

We will better understand policies/structures supporting integrated services delivery through PHC teams, how they do so, and when and how unintended consequences impede progress. Furthermore, we will understand how patients/caregivers wish to be involved in policy development and implementation. This study is timely and will allow provinces to learn from each other.

Dissemination and Knowledge Translation Approach:

We will use an integrated KT approach with the inclusion of knowledge-users, including patients, on our research team. Phases 2/3 use IKT approaches through DD and virtual discussions. One-page summaries, presentations and peer-reviewed publications will also be used.

Poster #10: Can-SOLVE CKD Network: Indigenous Peoples' Engagement and Research Council

Catherine Turner¹

¹ Can-SOLVE CKD Network

Introduction and Background:

Kidney disease has a strong impact on the health of Indigenous communities; therefore, strategies to improve kidney health must include culturally appropriate engagement of Indigenous peoples. The Can-SOLVE CKD Network is a patient-oriented initiative that is working to improve the kidney health of Canadians and bring Indigenous ways of knowing into health research.

Methods:

Can-SOLVE CKD has created an Indigenous Peoples' Engagement and Research Council (IPERC) to support collaboration grounded in traditional values and partnerships with Indigenous communities. Membership includes Indigenous patients, caregivers, researchers, and community leaders. Using an ethical framework that encompasses the principles of ownership, control, access and possession, IPERC guides Can-SOLVE CKD in respectful engagement of Indigenous peoples in research.

Results:

IPERC has created a culturally safe space for Indigenous individuals to participate in all aspects of patient-oriented kidney research. The council has instituted guidelines on ceremony and Elder participation that ensure recognition of traditional knowledge and territories. IPERC is also creating a cultural safety learning pathway, including a training module for health researchers and policy-makers.

Discussion/Implications:

Through IPERC, the Can-SOLVE CKD Network offers a model for respectful engagement of Indigenous communities in health research. By adopting Indigenous ways of knowing and fostering cultural competency, the network is working to close the gaps in kidney health outcomes between Indigenous and non-Indigenous communities.

Dissemination and Knowledge Translation Approach:

IPERC members have engaged in outreach to the broader research and educational communities through oral and poster presentations. A variety of resources are available online through the Can-SOLVE CKD website and social media, and members are also socializing with other SPOR networks and research entities to advocate for change in practice.

Plenary and Breakout Session

Presenter Biographies

Davina Banner is a cardiovascular and rural health researcher, nurse educator, and a palliative care practitioner. Davina currently works as an Associate Professor in the School of Nursing at the University of Northern British Columbia and leads an interdisciplinary program of research exploring cardiovascular care, patient and provider experiences and rural health service delivery. Dr. Banner has published and presented nationally and internationally and has a special interest in integrated knowledge translation and patient engagement.

Nick Bansback is seconded to the Unit from the School of Population and Public Health at the University of British Columbia (UBC), where he is an Assistant Professor. Among many affiliations, he is 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. Nick 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, Nick's research is focused on using decision science to maximize the value patients and the public gain from health care.

Erika Belanger is Research Associate at UNBC where she is a part of the BC SUPPORT Unit Northern Centre team. Erika is also a Master of Science Student in Health Sciences at UNBC. She works as a research associate contributing to both quantitative and qualitative research projects for the Rural Coordination Centre of BC. She also assists the furthering of multi-collaborative research and building capacity for patient-oriented research through the Health Research Institute at UNBC. Erika is experienced as a researcher, research liaison, and volunteer recruiter for research projects through UVic and UBC. She has first-hand experience of the health-related barriers northern community members face, which has served as further motivation to improve health care within northern BC.

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.

Fred Cameron is an outreach and peer support worker for people who use or have used substances. He is a community researcher with the Reducing Stigma and Creating Culturally Safe Primary Care Research Project and a member of the provincial patient advisory for the BC SUPPORT Unit.

Amanda Chisholm is the interim project manager for the BC Health Research Connection Project. Amanda completed her MSc and PhD at the University of Toronto in Rehabilitation Sciences. She moved to Vancouver to continue her training as a postdoctoral fellow at the International Collaboration on Repair Discoveries. Her work has involved designing and implementing research studies to develop clinical tools and test the impact of gait-training strategies for people living with neurological injuries.

Leanne Currie is seconded to the Unit from the University of British Columbia's School of Nursing. 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, Leanne 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 worth of grant funding in research projects from organizations such as the Canadian Institutes for Health Research (CIHR), the Michael Smith Foundation for Health Research 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.

Simon Denegri OBE is National Director for Patients, Carers and the Public in Research at the National Institute for Health Research (NIHR). He was Chair of INVOLVE – the national advisory group for the promotion and support of public involvement in research funded by NIHR – from 2011 until 2017. He was Chief Executive of the Association of Medical Research Charities (AMRC) from 2006 until 2011 and, prior to this, Director of Corporate Communications at the Royal College of Physicians from 2003. He also worked in corporate communications for Procter & Gamble in the United States from 1997 to 2000. He writes and speaks extensively about community and public involvement in health and social care and blogs at <http://simon.denegri.com/>. He also writes poetry which he publishes at <http://otherwiseknownasdotcom.wordpress.com/>. He was awarded the OBE in the Queen's Birthday Honours 2018.

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's 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. Also, she has 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.

Sharla Drebit is the Manager for the BC Emergency Medicine Network. With a MBA from the University of British Columbia and a MSc in Occupational Health and Safety from McGill University, Sharla has worked as a Project Manager in health care for the last ten years and has led several large international research studies and process improvement projects across BC. Her interests include the use of mobile technology to improve access to care in rural and remote settings, evaluative research, and knowledge translation. In her spare time, she enjoys traveling with her family, hiking and playing with her puppy 'Burger.'

Noreen Frisch is a professor at UVic's School of Nursing and was the Academic Co-Lead of InspireNet, BC's health services health research network, an MSFHR grant-funded project (2009-2016) that developed and optimized eCoPs for research teams in the province. That experience has been instrumental in developing a similar service for patient-oriented research teams through the BC SUPPORT Unit, where Noreen is seconded as Expert Advisor in capacity development areas

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 Unit 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.

Sarah Kesselring, MPH, is a Special Projects Coordinator with Population Data BC and Data Lead at the BC SUPPORT Unit. Her work involves assisting the BC SUPPORT Unit's Data Partners to organize and implement the different projects and services that are part of the Unit's [Data Plan](#). Prior to this, Sarah worked in health research and led studies at the BC Centre for Excellence in HIV/AIDS.

Lori Last is the Director of Marketing & Communications at the Michael Smith Foundation for Health Research. She oversees all communications activities for MSFHR, including branding and graphic identity, media relations, sponsorships, and internal communication.

Linda Li is a 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 Arthritis Research Canada. Linda earned a BSc in Physiotherapy at McGill University, a MSc at University of Western Ontario, and a PhD in Clinical Epidemiology at 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.

Sunny Loo is a volunteer with the Patients as Partners/Patient Voices Network. A pharmacist by training with a focus on technology and innovations, Sunny's 35 years in the profession included development of innovative patient support programs, implementation of medication management pilot programs in several provincial jurisdictions, and participation in the Ontario e-Health initiative as Director of e-Health for the Ontario Pharmacists Association. Currently, Sunny and his wife operate a consulting practice that strives to better understand physician practices. However, most importantly, Sunny is a patient living with a rare form of vasculitis (Wegener's Granulomatosis) for the past 7 years. Having been a part of the health care system as both a professional and as a patient, he looks forward to sharing his experience with others.

Colleen McGavin is the Patient Engagement Lead for the BC SUPPORT Unit. Her experiences as a cancer patient and as a caregiver for her aged parents prompted Colleen to become actively involved in efforts to improve the health care system. This eventually led her to become involved in health research. Currently, she is a patient member of several health research teams and she leads the BC SUPPORT Unit's efforts to advance the practice of patient engagement.

Kimberlyn McGrail is Data Director for the BC Academic Health Sciences Network, Scientific Director of Population Data BC, and an Associate Professor at UBC in the School of Population and Public Health and the Centre for Health Services and Policy Research. Her research interests are quantitative policy evaluation, aging and the use and cost of health care services, learning health systems and all aspects of population data science. She conducts research in partnership with clinicians, policy-makers and the public. Kim is a founding member of the International Population Data Linkage Network and founding Deputy Editor of the International Journal of Population Data Science. She was the 2009-10 Commonwealth Fund Harkness Associate in Health Care Policy and Practice, a 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.

Erin Michalak has a background in psychology, with a PhD awarded from the University of Wales College of Medicine in the UK. 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 brings valuable health research experience to the Unit. Her research has been well supported by organizations such as the Canadian Institutes of Health Research (CIHR) and the Michael Smith Foundation for Health Research. She is the founder and leader of the Collaborative REsearch Team for the study of psychosocial issues in Bipolar Disorder (CREST.BD, crestbd.ca), 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. Additionally, she has published more than 100 scientific articles and several books and book chapters.

Tom Noseworthy is CEO of the BC Academic Health Science Network. From 2012-2015, Tom served as Associate Chief Medical Officer for Strategic Clinical Networks of Alberta and held interim roles as Edmonton Zone Medical Director and Chief Operating Officer, North Sector. A critical care physician and graduate of the Harvard School of Public Health, Tom is a professor and the former head of the Department of Community Health Sciences, Faculty of Medicine, University of Calgary, and former professor and chair of Public Health Sciences, University of Alberta. Tom is highly-recognized for his numerous contributions to the field. He was appointed to the Order of Canada in 2007, has been named one of the “100 Physicians of the Century” in Alberta, and is a recipient of the Alberta Centennial Award. He received the Leadership Award while he was at the Royal Alexandra Hospital in Edmonton, where he was the CEO and President.

Alison Orth is a Consultant and Project Manager with Clinical Trials BC, a part of the BC Academic Health Science Network and Clinical Research Leader, Population and Public Health, Fraser Health. She is a Clinical Research Professional with over 20 years of experience managing health research studies at community and academic sites with a passion for quality, integrity and continuous improvement. Armed with a Bachelor of Business Administration from Simon Fraser University and Clinical Research Coordinator Certification from ACRP she has facilitated over 80 industries and grant funded clinical trials, outbreak investigations, attitudinal surveys and evaluation projects. Her past experience as an owner and manager of a large independent clinical research site and now working within a large health authority has provided Alison with diverse experiences that she draws upon to help others navigate their work more effectively. Currently, Alison is working with Clinical Trials BC to engage research participants about their experience with clinical research in order to enhance patient and public participation in trials and their overall experience as a participant. She also supports various research and evaluation projects within the Population Health Observatory at Fraser Health. Alison is dedicated to improving the clinical research environment within BC and Canada.

Bernadette Pauly is a Professor in the University of Victoria 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 severe 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.

Paige Phillips is a well-known community leader, public speaker, peer navigator and support worker with SOLID Outreach. She is a community researcher with the Reducing Stigma and Creating Culturally Safe Primary Care Research Project.

Elodie Portales-Casamar has a PhD in neuroscience and post-doctoral training in bioinformatics and genomics. She is a Clinical Assistant Professor in the UBC Department of Pediatrics and the Clinical Research Informatics Lead at BC Children's Hospital. In this role, she helps researchers access, collect, manage, integrate, and analyze data necessary for their clinical studies, with the goal to facilitate the translation of research into improved clinical practices. Her research interests lie at the interface between health sciences, bioinformatics, and clinical research informatics focusing on methodologies to integrate heterogeneous datasets and encourage and facilitate re-use of existing data while ensuring data privacy and security.

Roberta Price is from the Snuneymuxw and Cowichan Nations of the Coast Salish People, and is the mother of 4 children and grandmother to 8. Roberta has worked for many years as an Elder for the Richmond, Delta and Burnaby School Districts as well as in Elder Visiting Program for BC Women's and Children's Hospital. She has facilitated cultural teaching circles in lower mainland schools for 33 years and within communities and at St. Paul's Hospital, the UBC Learning Exchange and wherever she is called upon. She has also worked with the UBC School of Nursing as an Adviser/Research Partner and Elder and now for over 10-years providing Indigenous leadership and support in research projects such as women's intimate partner violence and mental health. Roberta is the Elder for Critical Research in Health and Health Care Inequities (CriHHCI) School of Nursing, University of British Columbia. Roberta has started her second year as Indigenous Co-Lead for the Postdoctoral Program at the UBC School of Family Medicine. She frequently responds to respectful requests to speak at local, national and international conferences.

Tamara Reichert is the Communications Advisor, Innovation and Development Commons at Northern Health. As part of her duties, Tamara provides communications support to the BC SUPPORT Unit Northern Centre and helps to ensure information pertaining to the Northern Centre reaches the desired audience. She has a Bachelor of Arts in Professional Communication from Royal Roads University and an Administrative Information Management diploma from the Southern Alberta Institute of Technology. Tamara resides in Prince George and has been working at Northern Health since January 2011.

Richard Sawatzky holds a Canada Research Chair in Person-Centred Outcomes at the Trinity Western University School of Nursing and is the Lead on Patient-Reported Outcomes at the University of British Columbia Centre for Health Evaluation and Outcome Sciences (CHEOS) and on Patient-Centred Measurement Methods with the BC SUPPORT Unit. He leads a program of research that focuses on the validation and use of person-centred health outcome measures and quality of life assessment instruments, with a particular emphasis on a person-centred palliative approach to care for people who have chronic life-limiting illnesses. His current research includes projects on: (a) the development and evaluation of statistical methods for patient-reported outcomes measurement in diverse populations; (b) the integration of electronic quality of life assessments in clinical practice for older adults who have life-limiting illnesses, and their family caregivers; and, (c) the selection and utilization of person-centred measures for healthcare decision making; the integration of a palliative approach. Rick's clinical background is in palliative care and medical nursing care. He teaches undergraduate courses on nursing research, medical and surgical nursing, nursing care of older adults, and health assessment and courses on knowledge synthesis and quantitative research methods in the Master of Science in Nursing program.

Viva Swanson is a wife and a mother, a sister and a daughter, a nurse and a friend. She is also a Breast Cancer "Thriver" seeking opportunity to apply both personal and professional experience in the health care system to influence positive change, activate quality care improvements and participate in the health care system transformation. Born, raised and educated in the North, she is able to provide a unique lens as it relates to the perspective of the patient, the nurse and the family member receiving and providing care in the North.

Rachael Wells is the BC SUPPORT Unit Northern Centre Co-Lead, and Manager of Health Research Initiatives at the University of Northern BC. For the past 10 years Rachael has been involved with supporting health research in Northern BC and fostering partnerships for research, mainly with Northern Health (NH) and more recently PHSA. As Manager of the UNBC Health Research Initiatives she focuses her daily efforts on promoting knowledge creation, synthesis and exchange, and fostering linkages among researchers, stakeholders, and partners to strengthen and enhance research capacity at the UNBC Health Research Institute (HRI). The BC SUPPORT Unit Northern Centre is positioned in the HRI and co-lead with NH to build upon the health research and partnerships in the region to develop a culture of Patient-Oriented Research. Rachael is a UNBC alumni graduating with a BA and MA from the Geography Program.

David Whitehurst is seconded to the Unit from the Faculty of Health Sciences at Simon Fraser University (SFU). He is 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.

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 **11 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 a unit of the **BC Academic Health Science Network (BC AHSN)**.

About the Conference

This conference is 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 emphasizes 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 helps 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 helps 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.



Attendees and panel members from PPF17

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

New this year!

Patients Included



This conference is a *Patients Included* accredited event, as it meets all five of the *Patients Included* conference charter clauses:

1. Patients or caregivers with experience relevant to the conference's central theme actively participate in the design and planning of the event, including the selection of themes, topics and speakers.
2. Patients or caregivers with experience of the issues addressed by the event participate in its delivery and appear in its physical audience.
3. Travel and accommodation expenses for patients or carers participating in the advertised programme are paid in full, in advance. Scholarships are provided by the conference organisers to allow patients or carers affected by the relevant issues to attend as delegates.
4. The disability requirements of participants are accommodated. All applicable sessions, breakouts, ancillary meetings, and other programme elements are open to patient delegates.
5. Access for virtual participants is facilitated, with free streaming video provided online wherever possible.

Details about *Patients Included* accreditation are available here: <https://patientsincluded.org/conferences/>



We're pleased to be offering livestreaming and archived recordings of some of our conference sessions, which are noted in the conference schedule. Archived recordings can be accessed after the conference on our YouTube channel. Visit YouTube.com and search for "BC SUPPORT Unit" to find our channel and subscribe. We're always adding new content related to patient-oriented research!

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