



Putting Patients First 2019

November 20 | Vancouver, BC | #PPF19

Conference Program



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

**Working Together
Across the Research
Life Cycle**

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We acknowledge that our event takes place on the traditional, ancestral, and unceded Indigenous territories of the w̱məθkʷəy̱əm (Musqueam), s̱kwx̱wú7mesh (Squamish), and seḻwítulh (Tsleil-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.



The BC SUPPORT Unit would like to thank:



Canadian Institutes of Health Research

British Columbia Ministry of Health

Michael Smith Foundation for Health Research

A Welcome from Our Leaders

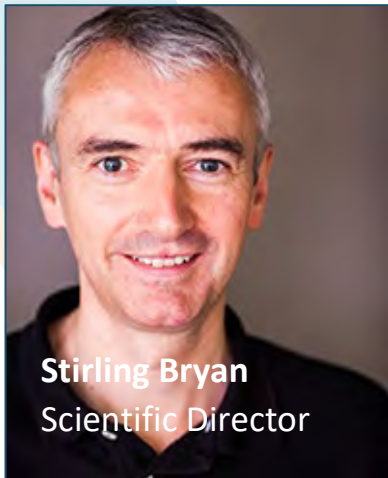
On behalf of the BC SUPPORT Unit, we welcome you to our third annual conference, *Putting Patients First (or PPF19)*, and thank you for joining us today. We're pleased to welcome a diverse audience from across BC and beyond, from a variety of disciplines, to network and to learn from one another about patient-oriented research (POR).

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.

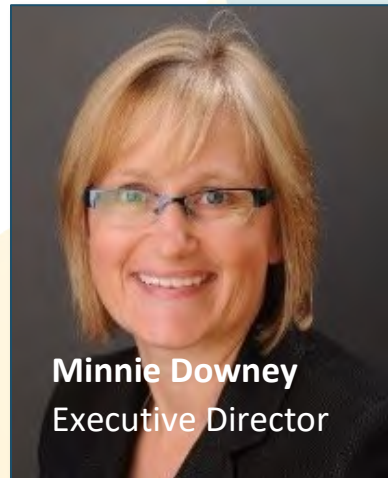
Our 2019 conference theme is "Working Together Across the Research Life Cycle," and we're very excited to hear about this topic from our plenary presenters, Evan Adams and Jennifer Johannesen, from the presenters of eight breakout sessions, as well as the 20 poster presenters. The conference program 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 PPF19 with us today. We wish you a rewarding conference experience and hope that you find new collaborative opportunities through your networking time. Please find us and say hello!



Stirling Bryan
Scientific Director



Minnie Downey
Executive Director

Why is this conference important to patients?

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

Why is this conference important to researchers?

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

Why is this conference important to health care providers?

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

Why is this conference important to health system decision-makers?

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

Conference Goals:

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

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.

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



A Note from the Conference Planning Team

Networking and making connections are two of the goals for this conference. We've tried to create time and space for this with the networking breakfast discussion, refreshment breaks, Wine & Cheese poster session, live tweeting, facilitated keynote discussions, and the use of CrowdCompass, the conference app.

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 break. Keep the conversation going using [Twitter handles](#) and hash tag [#PPF19](#), or download the **Putting Patients First 2019 conference app**. Be sure to follow [@BCSUPPORTUnit](#) on Twitter.

We wish you an excellent conference, meeting potential new patient-oriented research collaborators.

Conference Planning Team:

- **Anna Rychtera**, Patient Partner, BC SUPPORT Unit Provincial Hub; member of the Standing Committee on Health Services and Population Health, BC Ministry of Health; member of the PAC for Association of Registered Nurses of BC
- **Annie Moore**, Research Education and Grant Facilitator, Island Health
- **Belinda Jampoh**, Project Coordinator, BC SUPPORT Unit Provincial Hub
- **Jenny Cartwright**, Knowledge Broker, BC SUPPORT Unit Vancouver Island Centre
- **Kent Cadogan Loftsgard**, Patient Partner, BC SUPPORT Unit Provincial Hub; Clinical Educator/Research Co-Investigator, Providence Health Care, Vancouver Coastal Health & University of British Columbia
Twitter: [@Kentertainer](#)
- **Kim Peake**, Research Navigation and Community Facilitation Lead, Interior Health Research Department
Twitter: [@KimBarnesPeake](#)
- **Larry Mroz**, Research Navigator and Patient Engagement Coordinator, BC SUPPORT Unit Provincial Hub
Twitter: [@DrMroz](#)
- **Magdalena Newman**, Regional Centre Lead/Manager, BC SUPPORT Unit Fraser Centre
- **Margot Wilson**, Director, Chronic Disease Management Strategy, Providence Health Care; Faculty/Coach, Canadian Foundation for Healthcare Improvement; Adjunct Faculty, UBC School of Nursing
- **Noreen Frisch**, Professor Emerita, School of Nursing, University of Victoria
- **Pat Atherton**, Team lead; Director, Training & Virtual Networking Platform, BC SUPPORT Unit Provincial Hub
Twitter: [@PehMPA](#)
- **Tamara Reichert**, Communications Advisor, Innovation and Development Commons, Northern Health



Go Paperless



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Conference App Installation

1. Download

Download the Putting Patients First 2019 application from your phone's app store by searching "Putting Patients First 2019" or following one of the below links.

Apple:

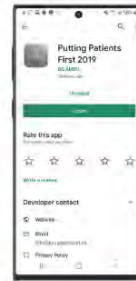


bit.ly/PPF19Apple

Android:



bit.ly/PPF19Google



2. Set Up

Open the app, select the event from the list, and verify your account by entering your email address. Enter the verification code that comes to your email inbox on the next page.



1. Select the Putting Patients First 2019 event from the event listing



2. Press Log In



3. Enter your first and last name



4. Enter your email. You will receive a verification code at this address.



5. Enter the verification code to start using the app!

3. Get going!

Begin using the app like you would the conference booklet and connect with other participants and discussions!!

- View the conference agenda
- Save sessions you are interested in
- Read about the speakers
- View a map of the conference venue
- Participate in question & answer sessions (See sheet #2)
- Participate in social media

Follow along on the activity feed

Learn about the exhibitors

View the schedule & add sessions to your personalized agenda



Meet the speakers and read their bios

View the interactive venue map

View frequently asked questions

Need more information? Find someone with an "Ask Me" Button






Frequently Asked Questions (FAQ)

What are the Ask Me badges?

BC SUPPORT Unit personnel who are able to answer your questions are wearing these badges. Feel free to ask them if you have any questions.

What are the coloured dots about?

PPF19 has been designed to be a learning and networking event, helping you to find other people to work with in a patient-oriented research approach. Coloured dots are available at the registration desk area to show others how you most closely identify with the four stakeholder groups (and supporters of those groups). Look for name badge dots to locate others you might collaborate with, or to strike up a conversation.

-  Green: Patient
-  Red: Researcher
-  Blue: Health care provider
-  Yellow: Health system decision-maker
-  Other: POR supporter (staff who work in a SUPPORT unit/network, or with research teams)

What hashtag should I use?

#PPF19; follow us on Twitter @BCSUPPORTUnit.

How do the breakout sessions work?

8 breakout sessions have been programmed: four from 11am-12pm and four from 2:30pm-3:30pm. The sessions will not be repeated. See pages 22-37 of this program for details on these sessions.

Why are there dice on our breakfast tables?

PPF19 Networking Breakfast Conversation Starters: Get to know your neighbours! On your table are six cards and one dice. On one side of each card is a broad conversation topic and on the flip side are questions. Roll the dice to select one of the six topics, and use the questions as a discussion guide. Have fun!



How do the ePosters work?

Congratulations to the 20 ePosters' presenters! These are being displayed on 5 kiosks in the **Foyer, Caulfield** and **Hollyburn** rooms – all 20 can be viewed at any time on any kiosk throughout the day using the tablet at the kiosks to navigate through the poster. ePoster presenters will be presenting their work during the ePoster session during the wine and cheese reception (see page 38 for times and kiosk numbers). **Remember to use your ballot to vote for your favourite before 6pm!** Just colour in the number of poster that gets your vote. Your ballot is located at the back of your name badge. The ballot box is located at the registration desk. The winner will be announced in our newsletter.

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.

Is there wi-fi available?

Wi-fi is available throughout the hotel. The code is **supportunit**.

Where are the washrooms?

Washrooms are located on the third floor (beside the Pinnacle Ballroom) and additional washrooms are available on the lobby floor (beside the gift shop).

Are there coat racks?

Coat racks are located at registration – please keep valuables with you.

With so many people here, how do I get some quiet?

Visit the Quiet Room. Your well-being is important. We've arranged for a quiet space in the far end of the **Shaughnessy Salon**, across the hall from **Pinnacle III**. If you're looking for a place to have a break or a quiet moment, please feel free to stop in and use this space for a breather.

What's the background with these gorgeous conference bags?

We'd like to thank our beautiful conference bags' supplier, Common Thread (<https://www.commonthreadcoop.ca>). Common Thread is a social enterprise: a business with a primary social purpose. Their main purpose is creating employment, providing sewing training and production coaching for newcomers to Canada, people living with mental illness and others who thrive in a flexible work environment. Their secondary purpose is environmental, reclaiming street banner material that would otherwise go to the landfill.

What's with the lights/cameras/action in the ballroom?

Plenary sessions held in the main ballroom will be livestreamed so those individuals unable to join us today can watch in real time or view a recording later.

Recordings will be available on the Unit's YouTube channel. Go to our website and follow the link on the home page to easily subscribe to our channel. Tell your colleagues to tune in today to watch the proceedings: <https://webcast.fmav.ca/PPF2019/>

What do I need to learn to be involved in or advance in patient-oriented research?

Learn about the *POR Pathways* Project! Are you curious about what **attitudes, knowledge and skills** you need to participate in patient-oriented research as a **patient partner or researcher**? The Unit has compiled the "POR Pathways" tools to help you develop these competencies. Visit the Unit's exhibit table in the foyer to see the self-assessment tool and to speak to someone about how to use it.

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.



Patient partner initiative: SPORCast

SPORCast: Canada's first Patient Oriented Research podcast! Bev Pomeroy and Lisa Ridgway are patient partners, and we are your SPORcast hosts. We aim to inspire patients to get involved and create their own impact through patient engagement in patient-oriented research - in order to help health care research be more relevant and meaningful! We partner with health care decision makers, researchers, clinicians and most importantly, patients and their families to bring patient-oriented research to all stakeholders. SPORcast is a new form of knowledge translation and can be enjoyed anytime and anywhere.



Bev Pomeroy and Lisa Ridgway bring patient-oriented research right to you - visit with the SPORcast podcast team in the **Shaughnessy Salon** - join us throughout the conference!

Have you been SPORcast?

SPORCast website: <https://sporcast.weebly.com/>

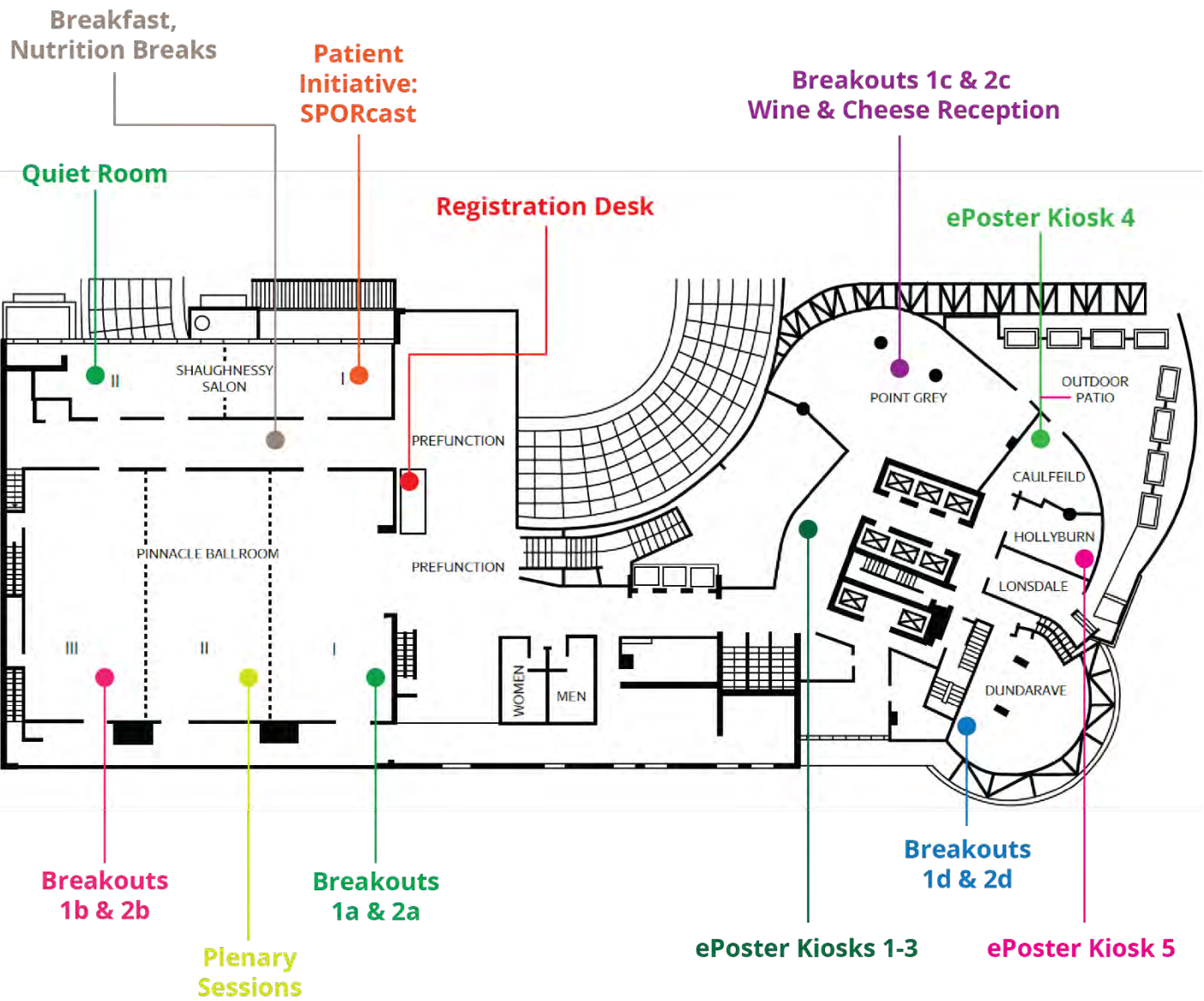
Beverley Pomeroy is a patient partner, health care educator and author of *Living Grief; the Profound Journey of Ongoing Loss*. Bev is co-lead on several research projects partnering with UBC and BC Children's Hospital as well as collaborates with BC Patient Safety Quality Council, Accreditation Canada, BC SUPPORT Unit, SPOR Evidence Alliance and Patient Voices Network (PVN). Bev fell into patient-oriented research after her daughter, Sophia, passed away from a rare, complex, chronic disease at the age of 16. She can be found on the golf course, or searching for the best burger and lager in town.

Twitter: [@BeverleyPomeroy](https://twitter.com/BeverleyPomeroy)

Lisa Ridgway is a patient partner and a lawyer. After UBC Law and 15 years of wearing a suit and heels, she became an advocate for patient oriented research and mental health issues. Lisa leads a research project as a patient, and also collaborates with UVIC, UBC, Island Health, the BC SUPPORT Unit and PVN. She has a black Labrador called "Dazzle" and credits her dog with much of her recovery from mental health challenges.

Twitter: [@LisaRidgway8](https://twitter.com/LisaRidgway8)

Venue Map



Morning Agenda

Time	Event	Meeting Room
8:00-8:25	Networking Breakfast with table discussions	Exhibits: Foyer
8:25-8:30	Moderator's Remarks PPF19 Host: BC SUPPORT Unit, Fraser Centre	Ballroom (Pinnacle I/II/II)* e-Posters available at kiosks throughout the day: Foyer, Caulfield and Hollyburn
8:30-8:40	Opening Prayer Elder Roberta Price	
8:40-8:45	Welcoming Remarks from the BC Academic Health Science Network Tom Noseworthy	
8:45-8:50	Welcoming Remarks from the BC SUPPORT Unit Minnie Downey, Stirling Bryan	
8:50-9:45	Keynote: <i>Nothing For Us, Without Us: Advancing Cultural Safety in Patient-Oriented Research with Indigenous Communities</i> Plenary speaker: Evan Adams; Q&A Led by Kim McGrail	
9:45-10:45	Panel: <i>Talking with Health care Leaders: How is Patient Oriented Research positively impacting the health system and how can this be amplified?</i> Panelists: Linda Dempster, Denise Jaworsky, Anne-Marie Visockas, Mark Blandford; Moderator: Chad Dickie. Introductions by Elinor Wilson, Board Chair of the Michael Smith Foundation for Health Research	
10:45-11:00	Break: Nutrition & Networking	Exhibits: Foyer
Breakout Sessions 1 (not repeated) CHOOSE ONE OF FOUR		
11:00-12:00	Breakout session #1a: Panel <i>BC SUPPORT Unit Methods Clusters: What progress? What successes?</i> Nick Bansback, Kim McGrail, Linda Li, Erin Michalak, Rick Sawatzky, Hubert Wong; Chair: Stirling Bryan Host: Amber Hui	Pinnacle I & II
	Breakout session #1b: Skills Building Workshop <i>Patients Score the POR: Working Together to Review Grants</i> Christine Andrews Stobart & Kate Dunn Host: Rachael Wells	Pinnacle III
	Breakout session #1c: Panel <i>Creating Culturally Safe Primary Care</i> Bernie Pauly, Paige Phillips, Fred Cameron, Conor Rosen, Troy Haddad, Hailly Wagner, Bill Bullock, Cindy Trytten, Karen Urbanoski Host: Ken Biron	Point Grey
	Breakout session #1d: Oral Presentations (15 minutes each) Working Together Across the Research Life Cycle #1 <ul style="list-style-type: none"> <i>Kidney Check: Identifying kidney disease and diabetes in BC First Nations communities</i>, Catherine Turner <i>Digital Storytelling: The power of the patient voice to achieve research impact</i>, Hannah Roy <i>Prioritizing patient perspectives in the development and design of an intervention study to examine the effectiveness of medical respite</i>, Sarah Canham <i>Social, ethical, and other value judgments in Health Economics and Simulation Modelling studies</i>, Stephanie Harvard Host: Rich Sobel	Dundarave

* Plenary sessions will be livestreamed and recorded; available after the conference on the Unit website

Afternoon Agenda

Time	Event	Meeting Room
12:00-1:00	Networking Lunch	Exhibits: Foyer
1:00-2:00	Keynote: <i>Ethical Implications of Engaging Patients in Research</i> Jennifer Johannesen; Discussant: Erin Michalak; Moderator: Kim McGrail	Ballroom*
2:00-2:30	Break: Nutrition & Networking	Exhibits: Foyer
Breakout Sessions 2 (not repeated) CHOOSE ONE OF FOUR		
2:30-3:30	Breakout session #2a: Panel <i>Using Film and Video to Share Knowledge with the Public: Lessons Learned</i> Sarah Munro, Stephanie Harvard; Moderator: Erin Michalak Host: Amber Hui	Pinnacle I & II
	Breakout session #2b: Panel <i>Creating the Dream Team: Success in engaging a diverse stakeholder research team</i> Rebekah Sandhu, John Engbers, Treeva Elliott Host: Colleen McGavin	Pinnacle III
	Breakout session #2c: Panel <i>"Reach out, and never stop speaking out" - Women living with HIV mobilizing knowledge to action to fight the criminalization of HIV non-disclosure in Canada</i> Angela Kaida, Valerie Nicholson, Peggy Frank, Mary Kestler, Claudette Cardinal, Kath Webster, Melanie Lee, Margarite Sanchez, Rebeccah Parry, Rebecca Gormley, Sarah Spencer Host: Ken Biron	Point Grey
	Breakout session #2d: Oral Presentations (15 minutes each) Working Together Across the Research Life Cycle #2 <ul style="list-style-type: none"> <i>A Two-Eyed Seeing Approach to Wholistic Healing and Wellness for People with Drug Use Experience</i>, Matthew Fischer, Candice Norris & Alexandra King <i>Patient informed feasibility testing of two approaches to assess quality of rehabilitation care after total joint replacement surgery</i>, Marie Westby <i>Patient Engagement in Developing Core Outcome Sets for Rare Pediatric Diseases</i>, Nicole Pallone <i>Creating and Evaluating a Parent Co-developed Tool for Families Receiving Genomic Test Results</i>, Julia Handra Host: Larry Mroz	Dundarave
3:30-3:35	Room shift	
3:35-4:30	Panel: <i>Ethical Considerations in Patient-Oriented Research</i>** Panel: Lillian Hung, Jim Mann, Jennifer Johannesen, Holly Longstaff; Moderator: Stirling Bryan	Ballroom*
4:30-4:40	Closing ceremony Elder Roberta Price	Ballroom
4:45-6:00	Networking wine & cheese reception ePosters session (see page 38 for details) and ePosters voting	Foyer

* Plenary sessions will be livestreamed and recorded; available after the conference on the Unit website

** Continue the conversation at a **post-conference Tweetchat #PPF19 Tuesday, November 26 @ 12-1pm**. Join the Unit's Scientific Director, Stirling Bryan, in exploring questions from the conference panel session. Follow **#PPF19**.

Plenary Sessions: Speaker Biographies

Keep the conversation going using [Twitter handles](#) and hash tag [#PPF19](#), or download the **Putting Patients First 2019** conference app.

Evan Tesla II Adams is a Coast Salish actor & physician from the Tla'amin First Nation near Powell River. Evan stars as Thomas Builds-The-Fire in Miramax's *SMOKE SIGNALS*, written by Sherman Alexie and directed by Chris Eyre. He also won Best Actor awards from the American Indian Film Festival, and from First Americans in the Arts, and a 1999 Independent Spirit Award for 'Best Debut Performance'. He won a 2011 Gemini Award for co-hosting the National Aboriginal Achievement Awards along with Adam Beach. Aside from his career in the arts, Evan has completed a Medical Doctorate from the University of Calgary in 2002, and a residency in the Aboriginal Family Practice program at St. Paul's Hospital in Vancouver, BC. Dr. Adams has a Masters of Public Health (2009) from Johns Hopkins University in Baltimore, MD. He was the first-ever Aboriginal Health Physician Advisor in the Office of the Provincial Health Officer, BC Ministry of Health (2007-2012). He was the Deputy Provincial Health Officer for the province of BC from 2012 to 2014. He is currently the Chief Medical Officer of the First Nations Health Authority.

Twitter: [@doctoreonline](#)

Mark Blandford began his working life as a British Police Officer with the Hampshire Constabulary. Mark left the Police Service and moved into healthcare in his late twenties and graduated as an Occupational Therapist in 1986 from the University Hospital of Wales, Cardiff, UK moving shortly afterward to North Sidney, Nova Scotia to begin his healthcare career in earnest. After moving to Victoria British Columbia in 1991 Mark worked in a variety of clinical roles until 2002 when he joined the team developing Island Health's Assisted Living program becoming its manager in 2006. After completing a Master's Degree in Leadership at Royal Roads University Mark's subsequent leadership roles have included Director of Development at the non-profit Beacon Community Services as well as senior management roles in Island Health's Residential Care, Seniors Health and Home & Community Care programs. In early 2014, Mark was appointed as Deputy Seniors Advocate with the newly created provincial Office of the Seniors Advocate for British Columbia. In January 2016, he returned to Island Health as the Director of Clinical Operations at the Victoria General Hospital. In January 2019, Mark became Island Health's new Executive Director for Primary Care and Seniors Health. He holds a critical role in leading the transformation of health care services in Primary Care and community based services for seniors and those with complex medical conditions.

Stirling Bryan is the Scientific Director, BC SUPPORT Unit, BC Academic Health Science Network and Professor, UBC School of Population & Public Health, and Senior Scientist, Centre for Clinical Epidemiology & Evaluation Vancouver Coastal Health Professor (part-time), and Health Economics Research Unit, University of Aberdeen. Stirling 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 an 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 US 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 component part of BC's Academic Health Sciences Network, focused on promoting patient-oriented research.

Twitter: [@StirlingBryan](#)

Linda Dempster, Vice President, Patient Experience, Fraser Health. Linda Dempster provides strategic leadership for the Patient Experience portfolio, ensuring the health care journey is both high quality and seamless for patients, clients, residents and their families. The portfolio includes Quality and Patient Safety, including the Patient Care Quality Office, Accreditation and the National Surgical Quality Improvement Program, Professional Practice, Infection Prevention and Control, and Innovation, Planning, Research and Evaluation. Linda has over 30 years of experience in a variety of health care settings. She was the winner of the CRNBC Award of Distinction in Nursing in 2014. Most recently she led the Professional Practice Department within Alberta Health Services, with responsibility for provincial staffing services as well as all aspects of professional practice such as specialty education, student placement, new graduate transition, collaborative practice to name a few. Prior to that Linda led the Quality and Patient Safety portfolio for Vancouver Coastal Health which included leading the accreditation, infection prevention and control, community engagement, performance improvement and human factors engineering processes across the organization.

Chad Dickie is Dene from the Fort Nelson First Nation in northeast BC. He is the Board Chair of A.V.I. Health & Community Services, formerly AIDS Vancouver Island, in Victoria, BC and contributes his patient voice on the BC Ministry of Health (MoH) Primary & Community Care Research Advisory Committee and the MoH Patient Survey Consultation Group. Chad also contribute his patient perspective to the Western Communities Primary Care Network Steering Committee, the Westshore Urgent Primary Care Centre Communications Working Group, and the Canadian Medical Association (CMA) Patient Voice Committee. He also coordinated panel presentations for the Canadian Conference on Global Health (with the Canadian Society for International Health) and the Community Based Research Network's Summit Conference, formerly the Gay Men's Health Summit. Chad is also Principal Knowledge User for a \$2-million, 5-year CIHR (Canadian Institute of Health Research) HIV Cure grant working with researchers from Simon Fraser University, the University of Toronto and the BC Centre for Excellence in HIV/AIDS. Chad, a proud graduate of the Pacific AIDS Network Positive Leadership Development Institute (PLDI, 2014-15), contributes his HIV lived experience with community-based research projects and public speaking engagements. For his work, Chad was awarded the 2019 BC Patient Safety & Quality Council Quality Award for "Leadership in Advancing the Patient Voice". Chad believes real change requires concerted effort to address stigma and discrimination within care provision and that person- and patient-centred must include addressing the social and structural determinants of health.

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

Twitter: [@Mpikedowney](https://twitter.com/Mpikedowney)

Lillian Hung is a clinical assistant professor at the UBC School of Nursing. Her research mainly focuses on examining how technology and environment impact the care experiences of persons with dementia. Her research is practice-based and patient-oriented. She is committed to facilitating connectivity between academia and practice, working collaboratively with interprofessional practitioners to find practical solutions to address pressing problems in care settings.

Twitter: [@nurselillian](https://twitter.com/nurselillian)

Jennifer Johannesen's son, Owen, had multiple severe disabilities all his life. He died in 2010 at the age of 12. Jennifer's experiences as Owen's caregiver and advocate led her to ask broader questions about disability and society, special education and clinical health care practice. Specifically: why do we do what we do, and whom does it serve? Jennifer now writes, lectures and consults on health care practice and policy related to patient-centred care, patient engagement, and critical thinking in clinical practice. Jennifer recently earned a Master of Science in Bioethics from Clarkson University (Schenectady NY), and is based in Toronto, Canada.

Twitter: [@jenjohannesen](https://twitter.com/jenjohannesen)

Denise Jaworsky is a general internal medicine physician in Terrace, BC, where she is also the co-site director for the Integrated Community Clerkship program for third year medical students. As a specialist, she works closely with primary care providers and Northern Health authority services to support people living with chronic disease. She is pursuing a PhD in Clinical Epidemiology through the University of Toronto and her research interest focuses around community engagement in epidemiology research. She works closely with patient partners on many research projects and is very interested in exploring new ways to engage patient partners as team members. She is also the proud mom of a 9-month who will also be attending #PPF19.

Holly Longstaff is responsible for guiding the development, recommendation and implementation of innovative approaches to privacy policy and practice to build accountable information stewardship and privacy conscious practices that enable the execution of PHSA's expanded mandate and the conduct of health research. She advises on the privacy requirements relating to new and expanded provincial initiatives working closely with PHSA's Information, Access and Privacy, and Legal Services teams. She also provides leadership in developing and implementing governance mechanisms to enable nimble, multidisciplinary review of privacy and security requirements for new and expanded initiatives and research, including province-wide platforms and systems, digital and information technologies, and data access/sharing. Holly is a PhD level trained ethicist and research consultant. She serves as the ethicist on the BC Cancer Research Ethics Board and a US-based IRB. She has worked as a consultant for Health Canada, the Public Health Agency of Canada, and the CIHR Ethics Office and her work has been published in a variety of journals including CMAJ, Trends in Neurosciences and Cell Stem Cell.

Jim Mann was diagnosed with Alzheimer's disease in 2007 and has since become an advocate and speaker in an effort to reduce stigma and shatter stereotypes around Alzheimer's and other dementias. He is an active community volunteer and advisor or co-investigator with various research projects. In line with Jim's focus on ethics and the ethics board approval process, Jim is an Advisory Council member of Research Ethics BC and was honoured to be invited by the W. Maurice Young School of Applied Ethics, UBC, to be a Visiting-Community Scholar in July of this year.

Twitter: [@JimMann83105425](https://twitter.com/JimMann83105425)

Kimberlyn McGrail is Data Director for the BC Academic Health Sciences Network. She is also a Professor at UBC in the School of Population and Public Health and the Centre for Health Services and Policy Research, Scientific Director of Population Data BC, and the PI for the SPOR Canadian Data Platform. 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.

Twitter: [@kimchspr](https://twitter.com/kimchspr)

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. Dr. Michalak 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.

Twitter: [@erin_michalak](https://twitter.com/erin_michalak)

Tom Noseworthy has been the BC Academic Health Science Network's CEO since June 2018. A critical care physician and graduate of the Harvard School of Public Health, his record of leadership spans numerous health innovation, academic and health care delivery settings. He previously served as Associate Chief Medical Officer for Alberta's Strategic Clinical Networks, head of the Department of Community Health Sciences in the University of Calgary's Faculty of Medicine, chair of Public Health Sciences at the University of Alberta, and CEO & President of the Royal Alexandra Hospital in Edmonton. 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 also received the Leadership Award while at the Royal Alexandra Hospital.

Elder Roberta Price from the Snuneymuxw and Cowichan First Nations has worked tirelessly over the past three decades to educate and raise awareness about issues affecting First Nations people in a positive, informative, and productive manner. She does this by working as a First Nations educator, sharing her traditional knowledge in schools, within the community, and with First Nations people. Healing is something Roberta is familiar with as she recalls a very painful childhood survived in foster care. Feeling isolated and separated from her culture took a toll on her. Today, she has "risen up" and is completely devoted to being an agent of positive change. The mother of four and grandmother of eight shared for the longest time, she thought she was doing the work for her children, but now realizes it's for her grandchildren.

Anne-Marie Visockas joined Interior Health in February 2017 as Vice President – Health Systems Planning, Mental Health & Substance Use (MHSU), and Residential Services. In January 2019, her portfolio changed to VP, Planning and Research. Her current portfolio includes Health System Planning, Strategic Information Management / Analytics, Health System Evaluation, Research, and Primary and Community Care Planning. In this role, Anne-Marie provides operational leadership and oversight for IH-wide planning, including the Health Authority service plan and alignment with Ministry of Health priorities, detailed operating plans to achieve Ministry operating expectations, and monitoring and reporting on strategic priority results. The portfolio is also responsible for research, information, analytics and evaluation support for Interior Health. Further, the portfolio provides leadership for Primary & Community Care Transformation planning. Previously, Anne-Marie was the Senior Program Officer for Financial Planning with Alberta Health Services (AHS) where she was responsible for leading the Financial Planning team, including development of the AHS \$14 billion budget and alignment with organizational strategic planning and directions. She also worked for Interior Health from 2003 – 2011 serving in leadership roles in our information support, information management, and research departments. Anne-Marie specializes in health services research and has extensive experience using linked health administrative databases for research into chronic health conditions and service utilization, along with use of health authority data to support analytics and performance management and reporting. She completed a PhD in Management and Policy Sciences specializing in Health Economics at the University of Texas Health Sciences Centre and has completed a post-doctoral fellowship at CHSPR in Vancouver. Anne-Marie has significant experience translating her academic background into practical application, combined with doctoral and post-doctoral work on primary and community care.

Non-plenary Sessions: Speaker Biographies

Biographies are included here as submitted.

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. Dr. Bansback 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, Dr. Bansback's research is focused on using decision science to maximize the value patients and the public gain from health care.

Kate Dunn is the Knowledge Translation Specialist at the Saskatchewan Center for Patient-Oriented Research (SCPOR). Kate works closely with the Saskatchewan Health Research Foundation (SHRF), a SCPOR partner, to administer the Patient-Oriented Research grants. Kate is proud that together, SCPOR and SHRF have committed to have a patient and family advisors review committee review all grant applications. Kate has been involved in creating the PORLET from inception and is proud to be sharing the product with interested individuals.

Twitter: [@KateLearnsKT](https://twitter.com/KateLearnsKT)

Matthew Fischer is a proud Two-Spirited Mi'kmaq member of the Qualipu First Nation in Newfoundland. He has traveled extensively within Canada and around the world. He has spent time in most of the provinces and two territories before finally making Vancouver his home and has for the past 25 years.

Matthew has a very responsible, expressive, inspirational and friendly personality. Expression comes to him naturally and he is rarely at a loss for words. In fact, he has to put forth effort at times to curb an over-active tongue! Matthew has been active in unionism using his voice and skills for those who face injustices at the workplace. Matthew now works as a Community Research Associate in health research involving Indigenous communities, people living with HIV and substance use, as well as a Peer Navigator at a local hospital's Rapid Access Addiction Clinic. He spends time learning about his culture that he was denied for 40 years. He enjoys gardening, biking, games and, yes, long walks on the beach wishing for world peace!

Peggy Frank, a community artist/facilitator/researcher, has always been concerned about the deep red stigma and purple isolation associated with HIV in rural communities. It colours her world and the world of too many other positive women. Locally, she co-founded the Southern Gulf Islands (HIV) Support Society and, focusing on the pandemic in sub-Saharan Africa - positively AFRICA. She is happiest with a mitt full of colored markers, or a brush, pen or meditation in hand. Peggy teaches Body-Mapping and Energy healing (Therapeutic Touch), and has traveled extensively in Canada, the US and Sub-Saharan Africa, and a wee bit in India, Mexico, South America and Nepal. Learning from and sharing with the locals is always relevant to her experiences.

Becky Gormley is a research coordinator for two national, community-based studies focused on the sexual and reproductive health and rights of women living with HIV in Canada. She is privileged to work and learn beside women living with HIV and is constantly working to practice allyship in a good way.

Janet Gunderson is a patient and family advisor at the Saskatchewan Center for Patient-Oriented Research (SCPOR). Janet sits on the Patient and Family Advisor Council with SCPOR and has been involved in a wide variety of patient engagement activities across Saskatchewan and Canada including presenting at the National SPOR Summit in Ottawa and Shared Decision Making Conference in Quebec City. Janet is also a patient with the SPOR Chronic Pain Network, a steering committee member with the Canadian Arthritis Patient Alliance (CAPA) and a volunteer with Cochrane Collaboration. Janet has reviewed grants for the Saskatchewan Health Research Foundation (SHRF) and the Canadian Institutes for Health Research (CIHR). Janet was instrumental in developing the PORLET and is excited to share with other SPOR SUPPORT Units how to utilize the tool.

Twitter: [@JanetGunderson](https://twitter.com/JanetGunderson)

Angela Kaida is an epidemiologist and Canada Research Chair at Simon Fraser University whose global research program centers on a rights-based, evidence-informed, and community-driven approach to sexual and reproductive health among women and youth affected by HIV. She is the co-Principal Investigator of the Canadian HIV Women's Sexual and Reproductive Health Study (CHIWOS) and the Women, ART, and The Criminalization of HIV (WATCH) study. Angela practices active allyship with women living with HIV throughout her work.

Mary Kestler is a Clinical Assistant Professor of Medicine at UBC. She is an Infectious Diseases specialist with particular expertise in HIV, TB, and Global Health. Today she works in Vancouver at St. Paul's Hospital, the BC Centre for Disease Control TB Clinic and the Oak Tree Clinic, a provincial referral centre for women and children living with HIV at BC Women's Health Centre. She is involved in two large community-based research cohorts of women living with HIV – the Canadian HIV Women's Sexual and Reproductive Health Study (CHIWOS) and the Sexual Health and HIV/AIDS: Women's Longitudinal Needs Assessment (SHAWNA). She is currently leading the Infectious Diseases curriculum for the UBC Medical School.

Alexandra King, MD, FRCPC, is an Internal Medicine Specialist with a focus on HIV/AIDS, Hepatitis C (HCV) and HIV/HCV co-infections. Alexandra is a citizen of Nipissing First Nation (Ontario, Canada). Alexandra is the inaugural Cameco Chair in Indigenous Health and Wellness at the University of Saskatchewan (Saskatchewan, Canada). She works with Indigenous communities and relevant stakeholders to understand the health and wellness needs of First Nations and Métis peoples in Canada and the structural changes required for improved Indigenous health outcomes. She holds several Canadian Institutes of Health Research (CIHR) grants to undertake Indigenous interventional wellness research in different contexts. In addition, she leads work to enhance Indigenous health education; advocate for improvements and funding; ensure sustainability of effective services and supports; and facilitate knowledge and resource mobilization to support improved Indigenous health and wellness. She is also the Co-Chair of International Group on Indigenous Health Measurement (IGIHM)'s working group on Indigenous wellness.

Linda Li is Professor, Harold Robinson/Arthritis Society Chair in Arthritic Diseases, and Canada Research Chair in Patient-Oriented Knowledge Translation at the Department of Physical Therapy, University of British Columbia. She is also a Senior Scientist at the Arthritis Research Canada. Linda earned a BSc in Physiotherapy at McGill University, 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.

Valerie Nicholson, honouring her given names The One the Eagles watch over, NoDe WenDa {wolf eyes} and Auntie from the Torres Straight Islanders, Valerie is Mi'kmaq, Haida, and gypsy. She is a mother of 4 boys and grandmother of 4 grandsons and 1 grand daughter. Living with HIV for 15 years, Valerie currently works at the British Columbia Centre for Excellence in HIV/AIDS as a Peer Researcher and co investigator and is the recipient of the 2018 CAHR Red Ribbon Research Award. Valerie is the board Chair of Canadian Aboriginal AIDS Network and an Indigenous Peer Navigator with Positive Living Society of BC. She is an Elder for Camp Moomba, YouthCo, First directions, and Yuusnewas. Her new adventure is in Artivism.

Candice Norris says "My name is Kihew Atayookan Iskew also known as Candice Norris – my colonial name." Candice was a Peer Research Associate with the Indigenous Wellness Research Group for approximately the last year and a half. When invited on the team, she was involved in community-based research in the Vancouver DTES, a place that she currently lives, works and plays. Her place of origins are Dene from NWT and Cree from Alberta. She is also of Irish and Scottish descent. She is committed to making her home, family and community a better place to live. Participating in cultural activities has helped in her healing from a 20-year period of addiction that landed her on the streets of homelessness,

incarceration as well as having HIV/HCV. Having lived experiences is her motivation, courage and determination to keep giving back to the community and ensuring the communities' voices are heard in exactly the way they express. Candice is also the mother of three beautiful children that propel her forward to stay the course. Her dreams of a fair healthcare system and a post-racial justice system are because of them. She sees hope in the future working alongside this team. Bringing culture to our community and loved ones is key to healing. Candice closes with All My Relations.

Hannah Roy is grateful for being born and raised on beautiful Vancouver Island, Victoria. She completed her undergraduate degree at the University of Victoria, obtaining a Bachelors of Art degree in Geography with a concentration in Medical Geography. Because of her life experiences, Hannah possesses a thriving passion to care for others within the health care system. Currently, she is completing an Advanced Entry Bachelors of Science in Nursing degree. Hannah would like to pursue a nursing career working with marginalized and vulnerable populations. She is Volunteer Coordinator at Foundry Victoria and is an active patient partner in health research. When Hannah is not studying or working she enjoys spending time in nature with her yellow lab.

Rick Sawatzky holds a Canada Research Chair in Person-Centred Outcomes at Trinity Western University (TWU) and is a professor in TWU's School of Nursing. He is also Patient-Reported Outcomes (PRO) Lead at the UBC Centre for Health Evaluation and Outcome Sciences (CHEOS). His extensive research program focuses on the validation and use of person-centred health outcomes measures and quality of life assessment instruments. Dr. Sawatzky's work has a strong emphasis on integrating a palliative approach to care for people who have chronic life-limiting illnesses, and he is currently developing and evaluating statistical methods for patient-reported outcomes measurement in diverse populations.

Christine Andrews Stobart is the Knowledge Translation and Capacity Development Platform Lead, Saskatchewan Center for Patient Oriented Research. Christine is an educator with a background in instructional leadership and mentorship, and currently develops and facilitates training opportunities for patients, researchers and trainees pursuing Patient-Oriented Research.

Hubert Wong is seconded to the Unit from the University of British Columbia (UBC), where he is an Associate Professor at the School of Population and Public Health, Program Head of Biostatistics at the Centre for Health Evaluation and Outcome Sciences (CHEOS), 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.

Morning Breakout Sessions 11:00-12:00

Breakout session 1a

Pinnacle I & II

Panel: BC SUPPORT Unit Methods Clusters: What progress? What successes?

Panel: Methods Clusters Leads Nick Bansback, Kim McGrail, Linda Li, Erin Michalak, Rick Sawatzky, Hubert Wong;
Moderator: Stirling Bryan

This session will provide an opportunity for attendees to hear about recent developments and progress 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 the key progress made by their cluster over the last year, and some examples of methods projects moving forward. The session will conclude with an opportunity to address session participants' questions.

Breakout session 1b

Pinnacle III

Skills-building workshop:

Patients Score the POR: Working Together to Review Grants

Presenters: Christine Andrews Stobart¹, Kate Dunn¹

¹ Saskatchewan Center for Patient Oriented Research (SCPOR)

Team members (and affiliations)

Gunderson, J. - Patient and Family Advisor. Haver, C. - SUPPORT Unit Staff, Methods Platform Lead. Keller, M. - SUPPORT Unit Staff, Patient Engagement Lead. Stobart, C. - SUPPORT Unit Staff, Knowledge Translation Lead. Plishka, C. - SUPPORT Unit Staff, Methods Platform Facilitator. Dunn, K. - SUPPORT Unit Staff, Knowledge Translation Specialist. King, M. -SUPPORT Unit Staff, Scientific Director

Workshop Goal: To provide an opportunity for patient and family advisors to develop skills to become grant reviewers for patient-oriented research opportunities.

Workshop Objectives:

- Introduce the origin of the SCPOR Patient-Oriented Research Level of Engagement Tool (PORLET).
- Learn how to use the PORLET to score research grant applications (key definitions, scoring criteria, instructions etc). The PORLET measures the degree to which a given project meets POR criteria as defined by the Canadian Institutes of Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR). Please see the scpor.ca for a copy of the PORLET. o Together, we will review a Patient-Oriented Research grant application as an example and score using the PORELT.
- Hear tips from patient and family advisors who have previously reviewed grant applications.
- Share tips on how to write a grant application to a patient and family audience.

Target Audience: Patient and family advisors interested in learning how to use the PORLET. Research teams writing a POR grant might also be interested in this workshop to strengthen grant writing skills.

This workshop is highly interactive and uses many mediums including; SCPOR Channel Youtube videos, powerpoint slides, PORLET Tool handouts and group grant deconstruction exercises. We piloted and revised this workshop in conjunction with patients and stakeholders and have since presented this workshop to Saskatchewan patient and family advisors prior to reviewing large provincial grant applications as well as trainees applying for SCPOR post-doctoral and post-graduate traineeships. Feedback from the workshops has been extremely positive. Attendees have highlighted the group exercise as a significant learning component. Workshop attendees find the exercise extremely helpful in understanding how a review committee discusses and scores grant applications. Workshop attendees have left feeling confident in their ability to contribute to POR research grant review committee.

Breakout Session 1c

Point Grey

Panel: Creating Culturally Safe Primary Care

Panel: Bernie Pauly, University of Victoria and Canadian Institute for Substance Use Research; Team members: Paige Phillips, Fred Cameron, Conor Rosen, Troy Haddad, Hailly Wagner, Bill Bullock, Cindy Trytten, Karen Urbanoski

People who use substances often face stigma and discrimination when accessing health care. Stigma is deeply embedded in health and social systems as a result of current policies that criminalize drug use and neo-liberal beliefs that people who use substances are to blame for their own problems. Primary care is a first point of entry into the health care system, and is an important avenue through which this patient population could access essential health care services. Feelings of not being safe in health care settings, due to fear of judgements and stereotyping, can lead people to delay and avoid seeking the health care they require. Cultural safety has been proposed as an approach that can help to reduce and mitigate stigma and discrimination. The concept of cultural safety was developed by Indigenous nurse scholars to contribute to more respectful care of Indigenous peoples in New Zealand. Cultural safety focuses attention on power imbalances, institutional racism, and the inequitable positioning of certain groups within these dynamics. Extending this work, Canadian nurses and researchers have identified cultural safety as a potential strategy to mitigate stigma, discrimination and marginalization in health care. Although modest in number, studies support the potential effectiveness of interventions in which people with lived experience of substance use engage with and educate physicians to improve care relationships. In fact, many innovations in services and policies have been driven by people who use illicit drugs with the goal of promoting the health and safety of their peers. Our patient-oriented research (POR) team is composed of people with lived and living experience of substance use as community researchers, academic researchers and knowledge users from the Victoria Divisions of Family Practice, Island Health and Vancouver Island Centre, BC SUPPORT Unit. Recently, we completed a CIHR funded Strategies for Patient Orientated Research Grant, that investigated the meaning of culturally safe primary care for people who use substances experiencing structural disadvantages. Our work generated a model of culturally safe primary care. With additional funding from MSFHR, we are developing and implementing several knowledge translation strategies to mobilize these findings to improve cultural safety in primary care provided by primary care physicians and other health care providers, with reach to medical students, and senior level policy makers. In this presentation, our panel of experts will address the development and implementation of three KT strategies (a postcard and bulletin, a workshop for primary care physicians and a video). A patient partner and community researcher will speak to the development of these strategies and the impact of these resources in the lives of people who use substances. A knowledge user partner will discuss their role in dissemination of these resources and strategies to enhance physician practice. An academic researcher will discuss their roles in generation and uptake of the knowledge. Participants will have an opportunity to view and interact with the KT tools and resources developed to support the implementation of culturally safe primary care.

Breakout Session 1d

Dundarave

Oral Presentations: Working Together Across the Research Life Cycle

(see Abstracts on following pages)

All presentations are 15 minutes, including time for Q&A.

1d1: *Social, Ethical, and Other Value Judgments in Health Economics and Simulation Modelling Studies*

Presenter: Stephanie Harvard, Simon Fraser University; Centre for Clinical Epidemiology and Evaluation

1d2: *Prioritizing patient perspectives in the development and design of an intervention study to examine the effectiveness of medical respite*

Presenter: Sarah Canham, University of Utah, College of Social Work, College of Architecture + Planning

1d3: *Digital Storytelling: The power of the patient voice to achieve research impact*

Presenter: Hannah Roy, Patient Partner, BC SUPPORT Unit Vancouver Island Centre

1d4: *Kidney Check: Identifying kidney disease and diabetes in BC First Nations communities*

Presenter: Catherine Turner, Can-SOLVE CKD

Oral presentation 1d1

Dundarave

Social, Ethical, and Other Value Judgments in Health Economics and Simulation Modelling Studies

Presenter: Stephanie Harvard, Simon Fraser University; Centre for Clinical Epidemiology and Evaluation

Team members

Diego Silva^{1,2} Greg Werker³; Alison McLean⁴; Don Grant⁴

¹Simon Fraser University, ²University of Sydney, ³University of British Columbia, ⁴Patient partner

Introduction and Background:

Health economics research often involves 'modelling', i.e., using computers to build representations or 'models' of health systems. Models are used to better understand health systems, including relationships between health care costs and outcomes. In the modelling process, many decisions are needed, some of which are value judgments. Value judgments in research are decisions where 1) there is flexibility from a scientific perspective, i.e., scientists agree there is more than one legitimate way of doing things; and 2) there could be social or ethical consequences following the decision. This qualitative study aimed to understand different types of value judgments in health economics modelling studies and know more about how patients and public may help inform them.

Methods:

Qualitative interviews were conducted with 22 health economics modellers in Vancouver. Data were coded and analyzed for themes and finalized by consensus between two investigators experienced in modelling. A framework for understanding modelling decisions was reviewed and refined by all team members.

Results/Findings:

Experts differed in how they described modelling decisions; a new descriptive framework was developed to help communicate about modelling decisions with patients and the public. In this framework, interview data suggest that value judgments in health economics modelling arise when deciding 1) what to represent in the model; 2) how to represent it; 3) when to conclude that something is true or likely true about the system represented in the model. Value judgments also arise during 'supportive' processes, such as building the modelling team.

Discussion/Implications:

This study helped clarify different types of value judgments in health economics modelling. Findings will inform a framework to guide patient and public involvement in modelling.

Dissemination plan/KT Approach:

In addition to academic papers and presentations, animated videos will be created to explain study results and feedback from patients will be gathered through focus groups.

Oral presentation 1d2

Dundarave

Prioritizing patient perspectives in the development and design of an intervention study to examine the effectiveness of medical respite

Presenter: Sarah Canham, University of Utah, College of Social Work, College of Architecture + Planning

Team members

Chris Danielsen¹, Joe Humphries², Scott Small³, Harvey Bosma, PhD⁴

¹Patient partner, ²Simon Fraser University, ³Catholic Charities, ⁴Providence Health Care

Background:

Medical respite is the provision of post-acute care for people experiencing homelessness (PEH) who are not ill enough to remain in hospital, yet are too sick to recover on the streets or in a traditional shelter. In light of the positive outcomes of medical respite in general population samples of PEH in other jurisdictions, the current study examined the feasibility of conducting a randomized controlled trial to test the effectiveness of a medical respite intervention for older PEH in Vancouver, BC. We examined feasibility by exploring 1) access to patient participants; 2) data availability and collection; and 3) how the intervention could be designed.

Methods:

Using principles of community-based participatory research, a patient partner and project task force was engaged during study initiation as key decision makers. Fifteen patient participants (10 male, 5 female) and eleven provider participants (5 male, 6 female) were interviewed between July and November 2018.

Findings:

Participants' reported on what a medical respite research program should involve, including 1) the qualities that researchers should have when engaged in research (e.g., building trust, 'meeting people where they are at,' and utilizing trauma-informed and culturally safe practices); 2) preferences for study design and data collection (e.g., peer researchers), and 3) participant recruitment and retention (e.g., financial incentives).

Discussion/implications:

This study builds knowledge on how to appropriately engage with vulnerable patient groups, including older PEH, when conducting research. Findings can be applied to other patient-oriented research attempting to have patient partners as proactive members of the research team.

Dissemination plan:

Based on findings from this feasibility study, the current project team aims to develop a proposal to conduct a medical respite intervention study. Patient partners are considered integral to the development of this follow-up study proposal.

Oral presentation 1d3

Dundarave

Digital Storytelling:

The power of the patient voice to achieve research impact

Presenter: Hannah Roy, BC SUPPORT Unit Vancouver Island Centre

Team members

Hannah Roy ¹ Jocelyn Chai ² Dr. Katharine McKeen ³, Dr. William Cunningham ⁴, Dr. Thomas Bailey ⁴, Tim Orr ⁴, Dr. Wendy Young ⁴, Cheryl Armstrong ⁴; Dr. Christine Lee ^{2,4}

¹Patient Partner, BC SUPPORT Unit Vancouver Island Centre, ²University of British Columbia, ³The Victoria Division of Family Practice, ⁴Island Health

Background:

Although I'm only one of the 40,000 Canadians who suffer from Clostridium difficile infection (CDI) each year, sharing my story has shaped research and is changing practice. CDI is the most common health care-associated infection in Canada, and the leading cause of death due to infectious diarrhea. Even with standard (and expensive) antibiotic treatment, 1 in 4 will experience recurrent infections (rCDI) like I did. As a participant in a clinical trial for rCDI, I was offered an effective alternative: Fecal Microbiota Transplantation (FMT), the administration of feces from a healthy screened donor. Not only did it cure my rCDI when antibiotics couldn't; FMT also put my Crohn's and Irritable Bowel Syndrome in remission. Despite its efficacy, only 1000 rCDI patients have received FMT because awareness and access are low.

Methods:

I was part of a knowledge translation (KT) grant to increase knowledge about CDI and FMT. As the Principal Knowledge User on a multidisciplinary team, I was supported in co-building a video about my journey - our KT solution. I co-wrote the script, co-approved the voice-over, and co-developed surveys to evaluate impact. The video was shared with patients and families; community and hospital clinicians; decision-makers, and members of the public at 3 events in Victoria. Post-event evaluation surveys were analyzed using descriptive statistics.

Findings:

91% of survey respondents (n=69) indicated increased knowledge of CDI and FMT post-event. 97% of physicians (n=43) said they would consider FMT as a treatment option for their rCDI patients.

Discussion:

Our project is raising awareness of FMT's effectiveness for rCDI. The video has been shared online and will be incorporated into CIHR's POR national curriculum. My involvement has helped me to better understand the research continuum and created opportunities for personal/professional growth. I hope this research can prevent others from suffering with CDI.

Oral presentation 1d4

Dundarave

Kidney Check:

Identifying kidney disease and diabetes in BC First Nations communities

Presenters: Catherine Turner and Craig Settee, Can-SOLVE CKD

Background:

Kidney disease has a strong impact on the health and wellness of Indigenous communities in Canada. Therefore, a national strategy to improve kidney health must include meaningful, culturally appropriate engagement with Indigenous peoples. The Can-SOLVE CKD Network is a pan-Canadian patient-oriented kidney research initiative that is working to improve the health of all Canadians and bring Indigenous ways of knowing into health research.

Methods:

The Can-SOLVE CKD Network is working with British Columbia Renal and the First Nations Health Authority to develop and implement a new program that will bring kidney, diabetes, and blood pressure checks to First Nations communities. Kidney Check is a screening, triage, and treatment program using point-of-care testing and trained health care teams. Each participating community has the opportunity to design and work with the Can-SOLVE CKD team to develop a locally acceptable program, which helps to identify healthy kidneys as well as those with mild, moderate or severe kidney problems. The results will be shared with participants in real time. Each person tested will also participate in building their own kidney health plan, including follow-up goals for maintaining kidney health.

Results:

Ten BC communities have been chosen through a transparent process to be part of phase 1 of the program, which is launching in Spring 2019. The ultimate aim is to roll out Kidney Check to all Indigenous communities in BC. Kidney Check programs are also under development in Alberta and Manitoba.

Conclusion:

The Kidney Check program aims to help keep kidneys healthy and is working in partnership with First Nations communities to do so.

Afternoon Breakout Sessions 2:30-3:30

Breakout Session 2a

Pinnacle I & II

Panel:

Using Film and Video to Share Knowledge with the Public: Lessons Learned

Panel: Sarah Munro¹, Stephanie Harvard², Moderator: Erin Michalak¹

¹University of British Columbia, ²Simon Fraser University

Film and video approaches to knowledge translation are an understudied but potentially powerful strategy to enhance knowledge and behavioural change with patients and the public. Film and video as "edutainment" can convey meaning, experience, knowledge, and/or emotions emerging from research through the use of a persuasive narrative, with the ultimate goal of facilitating change in audience knowledge, attitudes, and/or behaviours.

In this panel presentation, we will present on two patient-oriented BC SUPPORT Unit Methods Cluster projects that involve use of film and video to engage with patients and the public and communicate knowledge. Each presentation will describe the topic and content of the project, the process and challenges of working in a team of patients, researchers, and industry professionals, and lessons learned throughout. Perspectives and reflections will be given using a variety of media. Presentations will be followed by a moderated discussion and Q&A session about implications for future patient-oriented research involving film and video.

Presentation 1: Let Them Eat Dirt: Using Documentary as a Method of Knowledge Translation for the 'Sandwich Generation.' Microbes in our intestines play a critical role in shaping the immune system during early life. Parents and caregivers who are 'sandwiched' between childcare, work, and caring for aging parents have limited time and resources to learn this knowledge. We sought to investigate using documentary as a method of knowledge translation (KT), using the film Let Them Eat Dirt. Our multidisciplinary team involved patient partners, a microbe scientist, a documentary producer, and knowledge translation specialists. In addition to describing our key findings from in-depth interviews with parents, we will discuss how this method of KT may better meet the information and health care needs of parents and families.

Presentation 2: Healthcare Dollars, Healthcare Decisions: Can Educational Videos Help Engage Patients and the Public in Health Economics? Patients, caregivers, and the public have a right to help decide how our health dollars are spent. Deciding what to pay for can be complicated, because the resources we have- from the land and from our tax dollars - aren't enough to cover everything that everyone wants. Funding some health services means sacrificing others, so Canadians should know what is most important to them when it comes to health care. In this project, a team of researchers, patients, and filmmakers worked to start a conversation about these issues using three styles of educational video. Our presentation will describe the team's process of developing each style of video, the lessons learned, and next steps for sharing the videos and understanding their impact. Knowledge will be shared beyond the conference participants through research articles for academic audiences, presentations to the BC SUPPORT Unit Research Cluster community, and blog posts for the public.

Breakout session 2b

Pinnacle III

Panel:

Creating the Dream Team:

Success in engaging a diverse stakeholder research team

Panel: Rebekah Sandhu¹, John Engbers², Treeva Elliott¹

¹Fraser Health, ²Patient Partner

Background:

Home tube feeding (HTF) occurs when someone cannot meet their nutrition needs by mouth but is stable enough to discharge home. Successful HTF includes the ability to access community health care supports so as to avoid unnecessary hospital visits. Recent BC health care usage data demonstrated that a significant portion (75%) of adult HTF users were not accessing community dietitian services. Furthermore, these users had emergency room visits and hospital admissions for HTF issues costing more than \$14 million over 6 years. This data raised questions about the experiences, challenges and community support needs of this population. In 2018, Rebekah Sandhu received the BC SUPPORT Unit planning grant which allowed her to engage a team of diverse stakeholders. Together this team, developed and pilot tested a semi-structured interview protocol and guide. The team was not only successful this pilot study but have gone on to secure a large 3-year grant to complete a larger study that aims to reach data saturation.

Presentation #1:

So I have a question...now what? - a clinician researcher's experience. After identifying shockingly low use of community health care services and equally shockingly high hospital readmission costs, Rebekah knew she needed to conduct qualitative research to find the answers. However, she wasn't sure where to start since she was new to qualitative research. During this session, Rebekah will share her research journey and provide insights into how to find and effectively engage a diverse stakeholder team that includes patient partners. She will focus on sharing the facilitators and barriers that clinician researchers face when working with diverse research teams.

Presentation #2:

A feeding tube user finds purpose - a patient partner's experience. John will share how and why he got involved with Patient Oriented Research, and the benefits of being involved with the research team, both to himself and to the professional partners on the team. John will share his frustration with seeking answers to the many questions that he had after receiving his feeding tube, and how he has found purpose from his work with the research team.

Presentation #3:

Research for healthcare change - a health care decision maker's experience As a dietitian practice leader, Treeva was keen to be part of the research study and has come with the lens of decision making and a hope to seek answers to assist in promoting and advocating for change. Treeva will share the benefit to health care decision makers of being involved in research from the start. She will also discuss her success in disseminating of early results of the study to advocate for program development and advancement in practice to better the care for our patients.

Breakout Session 2c

Point Grey

Panel:

“Reach out, and never stop speaking out”:

Women living with HIV mobilizing knowledge to action to fight the criminalization of HIV non-disclosure in Canada

Panel: Rebecca Gormley¹, Valerie Nicholson^{1,2}; Peggy Frank^{1,3}; Mary Kestler⁴; Angela Kaida¹, on behalf of the CHIWOS and WATCH research teams.

Additional facilitators and contributors: Claudette Cardinal¹, Kath Webster¹, Melanie Lee¹, Margarite Sanchez¹, Rebeccah Parry¹, Sarah Spencer¹

¹Faculty of Health Sciences, Simon Fraser University, ²Canadian Coalition to Reform the Criminalization of HIV Non-disclosure, ³Southern Gulf Islands HIV Support Society, Gulf Islands Canada, ⁴Oak Tree Clinic, BC Women's Hospital, Vancouver BC

Women comprise nearly one-quarter of people living with HIV in Canada, but their health and social priorities are under-represented in research and programming. One of many resulting consequences is misinformation about the experience of women living with HIV (WLWH), including pervasive stigma, exemplified through Canadian laws that criminalize HIV non-disclosure. This panel of WLWH, researchers, and activists from CHIWOS and WATCH will discuss leadership in patient-oriented research focused on gendered impacts of criminalizing HIV non-disclosure, and how meaningful collaboration transforms not only research, but lives and laws. Visual conceptualizations of a 'research life-cycle,' and what can be achieved with meaningful patient-oriented research will be presented. Facilitated discussion will follow.

Dr. Angela Kaida (Principal Investigator, CHIWOS+WATCH) will discuss the current application of sexual assault law on cases of HIV non-disclosure in Canada, including why a patient-oriented research model was critical to explore the impacts of criminalization by, with, and for WLWH. Presenting a gendered analysis of the law, she will discuss why collaborating with WLWH throughout the research cycle is vital to moving knowledge past publication and into action.

Peg Frank (WATCH+CHIWOS PRA, patient-advocate, artist) will share her experiences as a WLWH and peer researcher, whose research and knowledge-to-action advocacy began not with a grant, but with her diagnosis. She will emphasize the necessity of community-driven research to understand the gendered experience of HIV non-disclosure laws through its impact on WLWH's health and safety, and how her activism fits within the timeline of HIV research and advocacy.

Valerie Nicholson (WATCH+CHIWOS PRA, Indigenous WLWH, frontline warrior) will discuss how research informs her activism, and how her activism influences ongoing research. This includes: speaking before the House of Commons to oppose the criminalization of HIV non-disclosure; leading changes to provincial prosecutorial guidelines; and founding a grassroots advocacy organization to place WLWH at the forefront of ending the overly broad criminalization of HIV non-disclosure in Canada.

Dr. Mary Kestler (Oak Tree Clinic, CHIWOS Co-Investigator): will share how criminalization impedes her ability to provide care for WLWH, and how performing research in a patient-oriented model and collaborating with WLWH shapes her medical practice.

Breakout Session 2d

Dundarave

Oral Presentations: Working Together Across the Research Life Cycle

(see Abstracts on following pages)

All presentations are 15 minutes, including time for Q&A.

2d1: *A Two-Eyed Seeing Approach to Wholistic Healing and Wellness for People With Drug Use Experience*

Presenter: Mathew Fischer, Candice Norris, & Alexandra King, Indigenous Wellness Research Group / Simon Fraser University

2d2: *Patient informed feasibility testing of two approaches to assess quality of rehabilitation care after total joint replacement surgery*

Presenter: Marie Westby, Centre for Hip Health and Mobility, Vancouver Coastal Health Research Institute

2d3: *Patient Engagement in Developing Core Outcome Sets for Rare Pediatric Diseases*

Presenter: Nicole Pallone, Canadian PKU and Allied Disorders, Board Member

2d4: *Creating and Evaluating a Parent Co-developed Tool for Families Receiving Genomic Test Results*

Presenter: Julia Handra, University of British Columbia

Oral presentation 2d1

Dundarave

A Two-Eyed Seeing Approach to Wholistic Healing and Wellness for People With Drug Use Experience

Presenters: Mathew Fischer, Candice Norris, & Alexandra King, Indigenous Wellness Research Group / Simon Fraser University

Team members

King A^{1,2,5}, Norris C⁵, Ermine W⁴, Rabbitskin N⁴, Fischer M⁵, Roberts-Poitras A⁴, Scotton E^{1,5}, Ametepee K^{1,5}, Howard T⁵, Mitchell S⁵, King M^{1,2,3,5}, Haight J, Turner D, Gonzalez S⁵

¹Simon Fraser University, ²University of Saskatchewan, ³Saskatchewan Centre for Patient-Oriented Research, ⁴Sturgeon Lake First Nation, ⁵Indigenous Wellness Research Group

Background:

Substance use is typically through an individualistic framework, where current health status results from poor lifestyle choices. However, an Indigenous health determinants framework, which emphasizes structural and sociocultural impacts on health, better explains Indigenous over-representation in substance use and related conditions. Land-based retreats have been used for wholistic wellness and being explored for their effectiveness in promoting healing in the context of substance use.

Methods:

Land- and culture-based retreats which included the Medicine Wheel Spirit Shadow Dance (MWSSD) - a wholistic, strengths-based approach developed by people living with HIV and substance use experience, to promote self-exploration and healing based on medicine wheel teachings - along with post-retreat activities, were designed with contextualization by Knowledge Holders for their specific communities. This was piloted in two sites - a First Nation community in Saskatchewan and an urban Indigenous community in British Columbia. A Two-eyed Seeing multi-pronged evaluation included qualitative analysis of intra- and post-retreat sharing circles, self-reflexivity, and an innovative First Nation self-assessment tool.

Results:

Findings identified elements of land- and culture-based healing effective at restoring and promoting wellness for Indigenous people who use drugs. The MWSSD provides a shame-free space for sharing of and both individual and collective learning from deeply personal narratives. Implications Culture and ceremony offer a promising path towards wholistic wellness for Indigenous persons and communities impacted by HCV, HIV and substance use. Yet, despite the demonstrated need, these face many challenges regarding funding. Given the extent of health inequities faced by Indigenous communities, it is imperative that these gaps in research and services be amended as soon as possible.

Knowledge Mobilization:

These will be conducted with the involvement of the peer research associates through community forums, academic conferences and publications as well as other presentations to diverse audiences including decision-makers.

Oral presentation 2d2

Dundarave

Patient informed feasibility testing of two approaches to assess quality of rehabilitation care after total joint replacement surgery

Presenter: Marie Westby, Centre for Hip Health and Mobility, Vancouver Coastal Health Research Institute

Team members

Marie Westby^{1,2}, Cheryl Koehn³, Michelle Lui⁴, Sheila Kerr⁵, Laurie Grant⁵

¹Centre for Hip Health and Mobility, ²Vancouver Coastal Health Research Institute, ³Arthritis Consumers Experts, ⁴University of British Columbia School of Population & Public Health, ⁵Patient Partner

Each year, >110,000 Canadians undergo total joint replacement (TJR) for hip and knee osteoarthritis (OA). We developed post-acute quality indicators (QIs) to inform quality rehab care that all patients should expect to receive following TJR.² To move the QIs into practice, toolkits were created with patient and clinician input to give patients the information needed to make informed decisions about their rehab options and track quality of care received. The purpose of this pilot study is to test feasibility and agreement for two QI data collection methods before implementing the toolkits.

Methods: The research and patient co-leads worked with two patient partners to co-design the QI patient questionnaire; conduct usability testing; and launch the pilot testing in three local outpatient departments. A physiotherapist (PT) at each site served as the clinical champion to recruit 20 eligible patients at time of discharge to complete the questionnaire and track feasibility data. An independent PT extracted data on 10 QIs from patient charts to permit comparison of QI pass rates between the two data sources.

Results: Eight patients between 7 and 19 weeks post-TJR participated in the usability testing, which led to small changes to the questionnaire. To date, 47 patients completed the QI questionnaire and 40 chart audits were performed. Preliminary findings show a mean pass rate of 52% (SD 26%) and 19% (SD 14%) for the patient questionnaire and chart audits, respectively.

Discussion: Patients report better quality of rehab care following TJR than that identified through chart audits. We will work with patient and clinician partners to further explore relationships in the findings and to refine both tools prior to toolkit implementation.

KT: Patient partners will co-lead lunch-and-learn sessions at each site; contribute to manuscript preparation; and lead the development of plain language summaries for website, e-newsletters and social media posts.

Oral presentation 2d3

Dundarave

Patient Engagement in Developing Core Outcome Sets for Rare Pediatric Diseases

Presenter: Nicole Pallone, Canadian PKU and Allied Disorders, Board Member

Team members:

Nicole Pallone¹, Maureen Smith²

¹Canadian PKU and Allied Disorders, ²Canadian Organization for Rare Disorders

Introduction and Background:

As patient partners, we were co-investigators on a research study to develop core outcome sets (COS) for two rare pediatric diseases, phenylketonuria (PKU) and medium-chain acyl-CoA dehydrogenase deficiency (MCADD). This is the first COS for studies evaluating care for these conditions. A key purpose of this study was to include the patient perspective so that future PKU/MCADD research is geared towards outcomes that are meaningful to patients and families.

Methods:

This study involved an evidence review, a Delphi consensus survey to ascertain the views of patients/families, health care providers, and policy decision-makers, and a multi-stakeholder consensus workshop.

Results/Findings:

A 7-member Family Advisory Forum (FAF) comprised of parents from British Columbia and Ontario reviewed recruitment materials explaining COS development, Delphi survey materials, and the definitions of the outcomes in the Delphi survey to ensure they were relatable and understandable to the target audience. Engagement with patient/family partners and advisors led to meaningful changes in the study. With thorough pre-workshop preparation and training, patient partners and FAF members were also important contributors at the consensus workshop where the final COSs were established, accounting for over 30% of workshop attendees. In a post-workshop evaluation, patients and families indicated that they were able to express their views freely and that their input was considered.

Discussion/Implications:

A tailored approach to patient engagement that is guided by patient partners has been feasible and valuable, and acknowledges that patients/caregivers can meaningfully participate in COS development. This study design can be reproduced to develop COS for other rare diseases, allowing the patient perspective to influence the direction of future research.

Dissemination plan/KT Approach:

We plan a further in-person meeting with FAF members and study investigators to collaborate on a strategy to promote the sustainable collection of our core outcome sets for PKU and MCAD deficiency.

Oral presentation 2d4

Dundarave

Creating and Evaluating a Parent Co-developed Tool for Families Receiving Genomic Test Results

Presenter: Julia Handra, University of British Columbia

Team members (and affiliations)

BC Lenahan¹, KOhs¹, IJordan¹, CGuimond², P.HBirch², N.Liang², JM Friedman²

¹Parent Research Partner, ²University of British Columbia

Introduction and Background:

Genomic testing allows us to identify changes in the DNA that may cause health concerns. It is a powerful medical tool, but the complexity of the testing process and results cause stress to many families (Wou et al., 2018). Families report feeling "abandoned and lost" after receiving genomic test results. Our team's goal was to co-create a simple, customizable tool to help families understand genomic test results, appreciate their implications, and navigate available resources.

Methods:

In consultation with parent-partners, we chose a customizable, printable e-booklet format with three sections: background, individualized genomic test results, and avenues for support. The language is family-user friendly, yet the content is rich and explanatory, as requested by the parent-partners. The booklet was edited in response to feedback from genetic physicians, genetic counsellors, and families, after which the final version was provided to families and evaluated in a genomic study of atypical cerebral palsy (the IMAGINE study). Ongoing survey and interview evaluations target acceptability and usability for both genetics professionals and patients.

Results:

Initial evaluations from six genetics professionals and five family users were universally positive about layout, content, ease of use, and potential to support families during and after sharing genomic results. Evaluation of the booklet will continue throughout the IMAGINE study, with feedback anticipated from an additional 30 families.

Discussion and Implications:

Preliminary results demonstrate that the booklet is meeting the needs of families while enabling genetics professionals to share results in an efficient, personalized manner that supplements in-person genetic counselling. We intend to make this tool available for research and clinical use beyond the IMAGINE study.

Dissemination Plan:

The tool will be shared with clinicians through in-service education for usage within the BC Provincial Medical Genetics Program. Beyond this, the booklet will be disseminated via academic conferences and publication.

ePoster Session

4:45-6:00 concurrent with wine & cheese reception

#	Poster Title	Presenter	Time	Kiosk	Room
P1	<i>Defining dementia-friendly research: Engaging people with lived experience as collaborators and advisors</i>	Jennifer Stewart	4:45-5:00	1	Foyer
P2	<i>Testing the feasibility and effects of the STABLE program on reducing fall risk among community-dwelling older adults with cancer: A randomized controlled trial</i>	Schroder Sattar	5:00-5:15	1	Foyer
P3	<i>Collaborative Peer-Review Model: Patient Partners as Equal and Contributing Voices in Patient-Oriented Research</i>	Linnea Franson	5:15-5:30	1	Foyer
P4	<i>Exploring the Health Research Priorities of the South Asian Community in the Fraser Valley</i>	Aven Sidhu	5:30-5:45	1	Foyer
P5	<i>Social and cultural considerations in engaging visible minorities in physical activity research</i>	Bushra Mahmood	4:45-5:00	2	Foyer
P6	<i>Can Speeded Walking Help with Multiple Sclerosis Symptom Management? A Patient-Oriented Project</i>	Chantel Mayo	5:00-5:15	2	Foyer
P7	<i>Growing Our Own: Photovoice and Resident Experiences of Gardening in a Long-Term Care Facility in Prince George, BC</i>	Meg Labron	5:15-5:30	2	Foyer
P8	<i>Effects of a Renal Nordic Walking Program on Quality of Life and Fitness in renal patients: A Randomized Controlled Trial</i>	Leonora Chao	5:30-5:45	2	Foyer
P9	<i>Quality of Life and Wellbeing Following Treatment for AML, and the Co-design of Community-based Care Plans</i>	Samantha Culos	4:45-5:00	3	Foyer
P10	<i>Patients as partners for collaborative healthcare improvement: A trainee perspective on the lessons learned through the experience of engaging patients throughout the research continuum</i>	Daman Kandola	5:00-5:15	3	Foyer
P11	<i>Communities of Hope: Living with stroke and brain injury in northern British Columbia</i>	Davina Banner	5:15-5:30	3	Foyer
P12	<i>Patient engagement in knowledge translation: a collaborative model for moving kidney health research into practice</i>	Linnea Franson	5:30-5:45	3	Foyer
P13	<i>The role of emotion in healthcare decision making in pregnancy: findings from a qualitative investigation</i>	Rebecca Kathleen Metcalfe	4:45-5:00	4	Caulfield
P14	<i>Sex, Pain & Endometriosis: Co-Designing an Online Resource through Integrated Knowledge Translation</i>	Heather Noga	5:00-5:15	4	Caulfield
P15	<i>Patient-Oriented Research in Emergency Medicine: Implementing and Evaluating ActionADE to Transform Medication Safety</i>	Serena Small	5:15-5:30	4	Caulfield
P16	<i>Emergency Department Patient Information Handouts - "For Us By Us"</i>	Sharla Drebit	5:30-5:45	4	Caulfield
P17	<i>Kwiis hen niip - Change: Change for Emergency Care Services in Rural and Remote British Columbia Indigenous Communities</i>	Samantha Christensen, Jim Christenson	4:45-5:00	5	Hollyburn
P18	<i>A patient-oriented approach to stroke prevention with improved cognitive benefits: An MRI monitoring study</i>	Betty Chinda	5:00-5:15	5	Hollyburn
P19	<i>Facilitating engagement in cervical cancer screening for Indigenous women in Northern British Columbia: An analysis of self-collected HPV at the intersection of Indigenous and patient-oriented research methodologies</i>	Marina Giovannoni	5:15-5:30	5	Hollyburn
P20	<i>Patient Partner Engagement: Reviewing the Literature on the Patient Experience in Rural to Urban Medical Travel</i>	Rebecca Schuss	5:30-5:45	5	Hollyburn

The 20 ePosters can be viewed on any of five kiosks available in the **Foyer, Caulfield and Hollyburn Rooms** (see venue map for locations, page 12) throughout the day and authors will present their posters at the above time and kiosk.

ePoster Contest: Remember to use your ballot to vote for your favourite before 6pm! Just colour in the number of poster that gets your vote. Your ballot is located at the back of your name badge. The ballot box is located at the registration desk. The winner will be announced in our newsletter.

Poster P1

Defining dementia-friendly research: Engaging people with lived experience as collaborators and advisors

Presenter: Jennifer Stewart, Alzheimer Society of B.C.

Introduction/Background:

People living with dementia have historically been excluded from research and, despite the current patient-oriented research movement, are largely still excluded. This is a result of the false belief that people living with dementia are unable to understand research processes or give consent. People living with dementia and their caregivers are experts in the lived experience of dementia and can contribute greatly to research.

Methods:

In October 2018, the Alzheimer Society of B.C. hosted a pre-conference workshop at the Canadian Association on Gerontology's conference. The event brought together researchers, people living with dementia, caregivers, health leaders and other key stakeholders from across Canada to start defining what dementia-friendly research could look like.

Results:

The following key points arose from participants' moderated discussions: Research is dementia-friendly when it:

- Meaningfully engages people affected by dementia before the study begins to develop research questions.
- Invites people with lived experience to take on advisory and co-researcher roles during the study.
- Commits to accessible knowledge mobilization after the study is completed.

To overcome barriers to dementia-friendly research, researchers must:

- Combat stigma.
- Educate research ethics boards on the unique needs and abilities of people living with dementia.
- Create flexible research designs.

Discussion:

Research is key to creating a future where people affected by dementia are acknowledged, supported and included. However, for this world to become a reality, research must be as effective as possible and this can only be achieved by meaningfully engaging with people affected by dementia as participants, collaborators and advisors.

Poster P2

Testing the feasibility and effects of the STABLE program on reducing fall risk among community-dwelling older adults with cancer: A randomized controlled trial

Presenter: Schroder Sattar, University of Saskatchewan

Team members

Schroder Sattar, RN, PhD¹, Eric Pitters², Darren Candow, PhD, CSEP-CEP³, Margaret McNeely, PT, PhD⁴, Shabbir Alibhai, MD, MSc^{5, 6}, Sebastian Harenberg, PhD⁸, Eitan Amir, MD, PhD^{5, 6}; Kelly Penz, RN, PhD¹; Kristen Haase, RN, PhD¹; Theresa Diane Campbell, RN, PhD¹; Haji Chalchal, MD^{7, 1} Osama Souied,^{7, 1} Shawn Kuster, MKin, CSCS³

¹University of Saskatchewan, ²Patient Partner, ³University of Regina, ⁴University of Alberta, ⁵University Health Network, ⁶University of Toronto, ⁷Saskatchewan Cancer Agency, ⁸Ithaca College

Falls are a major health concern amongst older adults with cancer due to effects of cancer and its treatments. Ample evidence in the general geriatric context demonstrates the benefits of exercise programs incorporating strength and balance training on lower body strength, balance, and fall prevention. However, little is known about the effects of exercise on fall prevention in older patients with cancer. Moreover, research shows current exercise interventions in the oncology setting lack patient input. Older patients with cancer may have unique needs that need to be taken into consideration in intervention designs and delivery which are not known in existing research. The purpose of this study is to determine the feasibility and preliminary effects of a 3-month exercise program regimen on lower body strength, balance, and falls in older adults with cancer, with an older cancer patient as an active research team member to provide input on intervention design and delivery, and data interpretation and dissemination. This observer-blinded, randomized controlled feasibility trial aims to recruit 66 older cancer patients (aged ≥ 65) referred to a cancer centre (Regina, Saskatchewan). Participants in the intervention group will undertake supervised, lower body resistance and balance training for three months. Quantitative and qualitative data collection will include sociodemographic survey, baseline and 3-month assessment, chart review, and exit survey. Quantitative and qualitative data analysis will be completed. Data generated from this research project will inform design and development of a subsequent, larger exercise intervention trial. This is an important step to establish the knowledge base regarding provision of exercise interventions as a fall prevention strategy to reduce falls and their negative outcomes in older patients in the community.

Poster P3

Collaborative Peer-Review Model:

Patient Partners as Equal and Contributing Voices in Patient-Oriented Research

Presenter: Linnea Franson, Can-SOLVE CKD

Introduction:

We aim to describe the Patient-Oriented Research (POR) Collaborative Peer-Review Model employed by the Can-SOLVE CKD Network and facilitators that enable patient partners to participate as equal and contributing voices in the research review process.

Methods:

The Can-SOLVE CKD Network includes patients and Indigenous partners, experts on research methodology and clinical research. Aspects reviewed in the peer review process include design, feasibility of implementation plan, risk-mitigation strategies, patient engagement, knowledge translation and Indigenous cultural safety and engagement. The format involves the assignment of a researcher as a primary reviewer, a patient partner as a secondary reviewer, and a reader, who contributes to the discussion. Each reviewer completes an evaluation checklist and attends a session to reach consensus on recommendations which are then collated on a letter back to the project team. Network supports may be dispatched to facilitate recommendations.

Results:

The involvement of patient partners in the peer-review process is a unique addition to what has traditionally been a highly technical, closed format. The patient partners have played prominent roles in the review as experts in the lived experience of kidney disease. They also bring additional expertise from their diverse personal and professional backgrounds. There are two pre-requisites for being an effective patient partner reviewer: 1) "comfortable with themselves" and not afraid to voice opinions, and 2) be motivated and interested in the work. An environment that cultivates progressive engagement includes: respectful and inclusive facilitation at meetings, a forum for peer support to share learning and provide the opportunity to learn on the job.

Conclusion:

The Collaborative Peer-Review Model ensures accountability of POR principles encouraging research outputs to have high impact in healthcare. This can be considered and adapted for other organizations for patient partners to have a prominent role in monitoring and governance of POR.

Poster P4

Exploring the Health Research Priorities of the South Asian Community in the Fraser Valley

Presenter: Aven Sidhu, Fraser Health

Team members

Aven Sidhu¹, Deljit Bains¹, Lovejot Bajwa¹, Lupin Battersby¹, Christopher Condin^{1,2}, Rachel Douglas⁽¹⁾, Arun Garg^{1,2,3}, Gregory Haljan¹, Sukhdeep Jassar¹, Nadia Khan³, Yvonne Lamers³, Rableen Nagra¹, Nitasha Puri¹, Swapnil Shah¹, Sonia Singh^{1,2,3}

¹Fraser Health, ²Simon Fraser University, ³University of British Columbia

Introduction:

Under-representation of ethnic minorities in research is a challenge for researchers in Canada. Barriers to participation of the South Asian (SA) community in research include: lack of interest or connection to research, stigma, misunderstanding about "what is research" and language skills. In 2018, a collaborative of researchers, decision-makers, patients and front line health providers came together to improve engagement in research with the SA community in British Columbia (BC).

Methods:

This project used the "James Lind Alliance Priority-Setting Partnership" approach to explore the health research priorities of the SA community in Surrey and Abbotsford, BC. Partnerships were established with community groups/organisations in the SA community. Surveys were conducted online and in-person in English/Punjabi/Hindi at temples, community centres, and health exhibitions. The survey was developed collaboratively with patient and community partners and collected data was thematically grouped to identify health research topics.

Results: From April to June 2019, 198 people were surveyed; 43% males and 57% females. 62% of participants were between 18 and 60 years; 38% were 60+. Most participants were of Indian ethnicity (85%). A total of 597 health research questions were collected. The five most common topics were: 1) Diet; 2) Exercise; 3) Diabetes; 4) Complementary/Alternative Medicine; 5) Mental Health.

Discussion/Implications:

The engagement of patient partners, community groups and organizations was essential to this priority setting initiative. The findings will help shape a collaborative research agenda with the SA community to build capacity, engagement, and relevant research. In October 2019, health care providers and community partners will rank and generate a top 10 list of health research priorities for the SA community.

Dissemination plan:

Identified gaps in health knowledge will be shared with relevant Fraser Health departments. A peer-reviewed journal article is under development, and results will be shared with the SA community through workshops, summary documents, and presentations.

Poster P5

Social and cultural considerations in engaging visible minorities in physical activity research

Presenter: Bushra Mahmood, PhD Candidate, Experimental Medicine UBC

Team members

Catherine Backman¹, Susan Cox²

¹Faculty of Medicine, University of British Columbia, ²School of Population and Public Health, University of British Columbia

Background:

According to the 2011-12 Canadian Community Health Survey, recent visible minority immigrants to Canada are more than twice as likely to be physically inactive when compared with established/white immigrants. In presence of an established link between low physical activity (PA) and chronic diseases (CD), and increasing evidence indicating that many CDs and lifestyle factors vary greatly between ethnic groups, it is imperative to develop targeted, culturally sensitive public health interventions that take into account the socio-cultural realities that impact everyday life of ethnic minorities. High-risk populations like visible ethnic minorities, newly arrived immigrants, specifically women - are usually hard to engage in research interventions. This also explains why POR grossly under-represents ethnic diversity of the population. Successful collaboration with ethnic communities necessitates knowledge of unique socio-cultural and religious factors that may act as barriers or facilitators to their involvement in research.

Methods:

We conducted discussions with 16 members and key informants from three ethnic groups (South Asians, Chinese and African Ghanaian) to understand what PA meant to them and the priority that was given to PA in their respective cultures. We asked about social and cultural influences that inhibit or facilitate their participation in research and what could we, as researchers, do to encourage their collaboration with the research community.

Findings:

Our participants highlighted several social and cultural factors some of which over-lapped while some were unique to each ethnic group. These included their unfamiliarity with concept of research, low health literacy, mistrust with the establishment, fear of stigma and stereotypes.

Implications:

Engaging ethnic minorities is challenging and requires constant work. Success depends upon how genuinely committed the research community is to invest the kind of resources that are required to have ethnic minorities on board.

Dissemination Plan:

A manuscript is in process to share the results of this project with research.

Poster P6

Can Speeded Walking Help With Multiple Sclerosis Symptom Management? A Patient-Oriented Project

Presenter: Chantel Mayo, Department of Psychology, University of Victoria

Team members

Colleen Lacey¹, Kristen Attwell-Pope (Department of Neurology, Island Health)²; Jodie Gawryluk (Department of Psychology, University of Victoria)¹

¹University of Victoria, ²Island Health

Introduction:

Canada has among the highest prevalence of multiple sclerosis (MS), a disease for which there is no cure. Many individuals with MS require expensive life-long treatment, and often experience on-going symptoms and medication side effects. Individuals with MS have expressed a need for additional behavioural strategies that may help reduce their symptoms. Exercise is a cost-free intervention that represents a promising means of symptom management. Based on a patient partner's questions, the objective of the study was to investigate whether a speeded walking intervention would improve symptoms of fatigue, depressed mood, and cognitive impairment for individuals with MS.

Methods:

Individuals with relapsing-remitting MS (RRMS) completed a 12-week speeded walking intervention 3 times per week. Self-report questionnaires (Modified Fatigue Impact Scale (MFIS), Beck Depression Inventory-2 (BDI-2), Perceived Deficits Questionnaire (PDQ)) and neuropsychological testing (Symbol Digit Modalities Test (SDMT]) Trails A and B, Digit Span) were completed pre- and post-intervention to assess fatigue, mood, and cognition. Statistical analyses were performed in RStudio.

Results:

Participants included 10 females and 3 males with RRMS (mean age= 58.76±11.07 years). Post-intervention, individuals with RRMS reported significantly fewer symptoms of fatigue (MFIS; $p = .049$, $d=0.61$) and perceived prospective memory problems (PDQ; $p=.016$, $d=0.78$), and also performed significantly better on the SDMT ($p=.02$, $d=.77$) compared to pre-intervention. There were no significant changes in reports of mood (BDI-2; $p=.11$), perceived cognitive problems (attention: $p=.42$; retrospective memory: $p=.91$; planning: $p=.52$), or on Trails A ($p=.43$), B ($p=.51$), or Digit Span ($p=.16$).

Discussion:

Speeded walking may help manage MS symptoms of fatigue and cognitive impairment. Future research should include controlled trials and individuals with progressive MS.

Dissemination:

Findings will be communicated in an accessible manner (e.g., infographic) to our patient partner and study participants. Results will also be shared through community lectures (e.g., Speaker's Bureau), national conferences (e.g., MS Society), and open-access journals.



Poster P7
***Growing Our Own:
Photovoice and Resident Experiences of Gardening
in a Long-Term Care Facility in Prince George, BC***

Presenter: Meg Labron, Master's Student, School of Social Work, University of Northern British Columbia

Team members

Meg Labron¹, Dr. Shannon Freeman¹; Georgia Betkus¹, Sandra Barnes², DrDavina Banner¹, DrKelly Skinner³

¹University of Northern British Columbia, ²Northern Health, ³University of Waterloo

We conducted a rigorous pilot study observing the outcomes of a patient-oriented gardening program at a long-term care facility (LTCF) in Prince George, BC. This program was co-created with the residents and included raised bed and hydroponic gardening. The goal of this work was to better understand the impact that increased and diversified forms of social engagement, such as the availability of a new activity and stimulation from garden-focused programming, might have on the quality of life (QoL) of older adults in LTCFs. The mixed methods and participatory approach to this research allowed for a truly collaborative project and ensured that the program took on an iterative process that could adapt to the needs and interests of the participants. This poster explores the project's use of photovoice with LTC residents to document their experience in the gardening program. Five residents participated in the photovoice process, which involved residents taking pictures of aspects of the project that were meaningful to them (e.g., a flower bloom they found beautiful, dirty hands in soil, a smiling face of a friend who is harvesting something from the hydroponic tower) and sharing their personal thoughts on the meaning they see in their own photos, as well as the meaning they see in the photos taken by others. Once a month, from July to September, focus groups were conducted with the residents who selected their favourite 6-8 photos to be printed and displayed on a large screen for the group to view and discuss. Information about the residents' photographs was collected through these focus groups. Individual semi-structured interviews were also conducted with residents to further explore the meaning they found in their photos. Themes that emerged from the photovoice portion of this pilot project will be discussed in this poster presentation.

Poster P8

Effects of a Renal Nordic Walking Program on Quality of Life and Fitness in renal patients: A Randomized Controlled Trial

Presenter: Leonora Chao, St. Paul's Hospital

Team Members

Leonora Chao RD MSc IOC Dipl Sports Nutr¹; Susie Neufeld PT¹; Vicky Ngo RD CSR¹; Dani Renouf RD MSc¹; Sandra Squire PT MRSc²; Alison Hoens MSc BScPT, Physiotherapy, Providence Health Care; Sameer Desai, Centre for Health Evaluation & Outcomes SciencesCHÉOS

¹Renal Program, Providence Health Care, ²Professional Practice, Providence Health Care

Many persons with kidney disease do not meet physical activity guidelines. Based on findings that hospital-based group exercise programs can reduce fears and increase exercise self-efficacy, and a survey supporting patient's desire for this programming, a Renal Nordic walking (NW) program at St Paul's Hospital was developed. Working with a Patient Partner throughout the phases from study design to dissemination, this study investigated the effects of a 3-month supervised Renal NW program on the fitness and quality of life of renal outpatients. Thirty participants, aged 45-84 were randomized to NW (n=15) or non-NW (n=15) groups. The NW group was offered 2 supervised NW sessions/week; the non-NW group continued their own activities. Outcome measurements at baseline and 3-month included weight, handgrip strength (HGS), 30-sec sit-to-stand test, 6-min walk test (6MWT), and Kidney Disease and Quality of Life questionnaire (KDQOL-36). Daily steps were recorded using Fitbit. Median changes in outcomes from baseline to 3-months were calculated between groups. Participants included post-renal transplant (n=10), pre-dialysis (n=14), hemodialysis (n=3), and peritoneal dialysis (n=3) patients. The NW group appeared less healthy compared to the non-NW group at baseline. However, the NW group had greater improvements in KDQOL-36 (Effect of kidney disease; p=0.021), 6MWT distance (41.5m), and HGS (1.1kg) at 3-month. A 41.5m improvement in 6MWT achieved in the NW group exceeded the 14.0 -30.5m Minimal Clinically Important Difference. Although a greater number of participants is needed to confirm these findings more confidently, these encouraging results indicate that a group-based supervised Renal NW program may provide meaningful benefits to renal outpatients. The program is now adopted by the hospital. Key messages were/are being shared via newsletters (i.e., allied health associations, Providence Health Care Communications internally & externally), general and targeted social media, Urban Poling, BC Renal Agency, Kidney Foundation of Canada, and conference abstracts and presentations

Poster P9

Quality of Life and Wellbeing Following Treatment for AML, and the Co-design of Community-based Care Plans

Presenter: Samantha Culos, Faculty of Health Sciences, Simon Fraser University & BC Cancer Agency

Team members

Raewyn Broady, MBChB, FRACP, FRCPC^{1,4}, Sonya Cressman, PhD, MBA^{1,2,3}, Stuart Peacock, DPhil^{1,2,3}, Cindy Toze, MD, MHSc, FRCPC^{1,4}, Alina Gerrie, MD, MHSc, FRCPC^{1,4}, David Whitehurst, PhD², Helen McTaggart-Cowan, PhD^{1,2,3}.

¹BC Cancer Agency, ²Simon Fraser University, ³BC Cancer Research Centre, ⁴Leukemia/Bone Marrow Transplant Program of BC

Introduction:

Acute Myeloid Leukemia (AML) is a form of blood cancer. Treatment for AML requires intensive chemotherapy and can have lasting impacts on the lives of patients due to potential late adverse effects. Clinical and patient-reported outcomes, such as quality of life (QoL) and wellbeing, may be improved with patient-centered community-based care plans. The study purpose is to:

- 1) Gain insight on aspects of QoL and wellbeing that matter to patients
- 2) Partner with patients to design collaborative care plans for community-based settings

Methods:

A pilot study was recently launched (May, 2019) at the Vancouver General Hospital with a goal to recruit 50 people with AML. Eligible patients are visited in hospital 7-10 days following initiation of treatment, and again 60 days later. At each time point, a survey comprising demographic questions and standardized questionnaires (EORTC QLQ-C30, ICECAP-A, and EQ-5D-5L) is administered, followed by a debriefing interview. The debriefing interview allows us to engage patients by asking them their opinion on the clarity and relevance of the questionnaires, what aspects of QoL and wellbeing matter most to them, and whether they would be interested in being part of the research team in the future.

Results:

An interim analysis on the results from the debriefing interviews will be presented, which will include patient feedback on the questionnaires and their interest in joining the research team. 90% of the patients we invited have joined the study, and early results suggest that most people are interested in becoming more involved as research partners.

Discussion/Implications:

The results from the debriefing interviews will be used to inform the design of the future scale-up version of the study.

Dissemination plan/KT approach:

The knowledge gained from this study will be shared with physicians through publications in scientific journals and at conferences.

Poster P10

Patients as partners for collaborative healthcare improvement: A trainee perspective on the lessons learned through the experience of engaging patients throughout the research continuum

Presenter: Daman Kandola, University of Northern British Columbia

Team members

Kandola, D^{1,2}, Payne, G³, Croome, B⁴, Pelletier, C¹, Snadden, D⁵, Ramsay, P⁶, Banner, D²

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Health systems are increasingly facing challenges in developing services that are sustainable, of high value, evidence-based, and responsive to patient needs. We share this study that uses a multi-method approach to examining the use of emergency health services by stroke patients across northern British Columbia. We focus on the qualitative component, which uses semi-structured interviews to provide context and insight into the decision-making processes of patients and their caregivers. First, we explore the collaborative decision-making and priority setting activities that this process has encompassed. Second, we outline the lessons learned through a partnership aimed at exploring the decision-making process for seeking emergency care for stroke in a northern health region. Finally, we discuss the insights into the healthcare system and policy environment that this opportunity has encouraged. Early and sustained efforts to engage patients in a meaningful way have provided a solid foundation for ongoing collaboration to respond to critical clinical and health service issues. This has further cemented a strong commitment to addressing health system priorities around stroke care and fostered the creation of much-needed capacity in this underserved area.

Poster P11

***Communities of Hope:
Living with stroke and brain injury in northern British Columbia***

Presenter: Davina Banner, University of Northern British Columbia

Team Members

Banner D¹, Croome B², Hadi H³, Massey K⁶, Transken S⁷, Holler J⁸, Richards S⁸, Koopmans J⁹, Shepherd V⁹, Kandola D^{1,10}

¹School of Nursing, University of Northern British Columbia (UNBC), ²Patient Partner, ³Northern Medical Program, UNBC, ⁵Faculty of Medicine, University of British Columbia, ⁶Northern Health Authority, ⁷School of Social Work, ⁸UNBC Women and Gender Studies, UNBC, ⁹Prince George Brain Injured Group

With a rapidly aging population worldwide, the increase in expected stroke burden highlights an urgent need to better understand patient experiences in part as an effort to improve services and care. We undertook an exploratory arts-based project aimed at harnessing the power of storytelling to gather invaluable frontline insights, identify research priorities and questions and to determine interest in potential collaborations to undertake further research to systematically investigate stroke care in northern British Columbia. A central aspect of this work was to provide an avenue for the 'patient voice' through the sharing of personal stories of stroke experiences through various art modalities including poetry, painting, drum-making, and pottery. Sharing of experiences in navigating care, challenges, barriers, and opportunities were all encouraged. We will present an overview of this work including the arts events and community celebrations and key themes from the discussions that ensued will also be shared. We hope to highlight how we as researchers, healthcare providers, and decision-makers can listen and learn from patients to improve stroke research, prevention, and management as well as further our understanding of the dynamic and diverse experiences of this particular population.

Poster P12

Patient engagement in knowledge translation: a collaborative model for moving kidney health research into practice

Presenter: Linnea Franson, Can-SOLVE CKD

Introduction:

Effective knowledge translation is the process of moving research evidence into clinical practice. Can-SOLVE CKD is a pan-Canadian patient-oriented kidney research network with an established Knowledge User (KU) and Translation (KT) Committee that includes two patient partners as integral members. This committee provides guidance, expertise, and direction for all KT activities undertaken by research projects within the network and ensures KT approaches are patient centered. This presentation defines key concepts related to KT, outlines the role of the KU/KT Committee in supporting kidney health research, and highlights the contributions of patient partners on this committee.

Methods:

The KU/KT Committee provides core infrastructure support for 18 research projects within the Can-SOLVE CKD Network. Membership includes national representation of patients living with kidney disease, policymakers, health care professionals and researchers with KT expertise. We co-developed two KT reporting templates for research teams to complete, reviewed project KT plans, and discussed our KT assessments among the committee. The committee also provides ongoing support for stakeholder engagement and helps projects tailor their KT strategies for communicating, implementing and sustaining their findings in practice.

Results:

As the main stakeholders in health research, there are opportunities for patients to participate in KT. Two patient partners contribute as full KU/KT committee members and maintain links with the Network's Patient Council and Indigenous Peoples' Engagement & Research Council (IPERC). The patient partners are uniquely positioned to understand real-world implications of the research findings. Continued acknowledgement of the patient voice in KT will help encourage ongoing relevant research, novel approaches to KT, and the translation of evidence into practice.

Conclusion:

Our multi-stakeholder KU/KT Committee promotes patient-oriented research and supports the translation of kidney health research into practice. Patients can identify unique KT considerations, provide meaningful feedback to research teams, and encourage the generation and application of relevant research

Poster P13

The role of emotion in healthcare decision making in pregnancy: findings from a qualitative investigation

Presenter: Rebecca Kathleen Metcalfe, School of Population & Public Health, University of British Columbia

Team members

Mark Harrison^{2,3}, Mary Lewisch⁴, Maki Muramatus⁴, Joel Singer^{1,2}, Anna Hutfield⁵, Laura A Magee⁶, Nick Bansback^{1,2}

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Background:

The leading cause of maternal morbidity and mortality worldwide, hypertensive disorders of pregnancy affect between 5% and 10% of pregnancies in Canada. New clinical guidance for management of pregnancy hypertension recommends considering women's preferences before making treatment decisions. While new work has investigated women's preferences and decisional needs for pregnancy hypertension, research has yet to explore emotional responses to diagnosis and treatment, despite evidence that anxiety is heightened during pregnancy and emotional responding is important for decision-making.

Methods:

A qualitative approach was used. Working with two patient partners, we developed an interview approach and topic guides for focus groups and individual interviews. Semi-structured focus groups and individual interviews were conducted in an iterative fashion, with memoing and debriefing after each group meeting or interview. All interactions will be transcribed for constant comparison grounded in a critical realist perspective. Codes will be developed inductively and collected into themes that will be reviewed with the patient partners, and then the research team for face validity.

Results:

28 women participated in two focus groups and 20 individual interviews. Preliminary analysis identified three broad themes relating to emotional responses in the context of pregnancy hypertension:

- 1) Information seeking/avoidance
- 2) Importance of self-care
- 3) Taking cues about anxiety and stress from others
- 4) Anxiety caused by treatment requirements

Discussion:

Preliminary analysis indicates that emotion plays a large role in how women experience and navigate healthcare decision-making in pregnancy hypertension. Next steps will be exploring if ability to manage emotions impacts aspects of healthcare decision-making in pregnancy (i.e., ability to understand and remember new information).

Dissemination Plan:

Results from this work will be shared at conferences directed at patient and professional audiences and will be incorporated into the design of a publicly available patient decision aid.

Poster P14

Sex, Pain & Endometriosis:

Co-Designing an Online Resource through Integrated Knowledge Translation

Presenter: Heather Noga, Women's Health Research Institute

Team members

Heather Noga, M.A.¹, Fuchsia Howard, PhD^{1,2}, Kiran Parmar, BSc³, Aziz Ghafoor, Endometriosis Patient Research Advisory Board^{1,4}, Paul Yong, MD, PhD^{1,3,4}.

¹ Women's Health Research Institute, ² School of Nursing, University of British Columbia, ³ Department of Obstetrics and Gynaecology, Faculty of Medicine, University of British Columbia, ⁴ BC Women's Centre for Pelvic Pain and Endometriosis, BC Women's Hospital + Health Centre

Background:

Endometriosis is a gynaecological disease that affects 1 in 10 women and is characterized by the presence of endometrial cells outside the uterus leading to painful periods, pelvic pain, and sexual pain. Painful sex occurs in 50% of women with endometriosis, negatively influencing their sexual functioning and interpersonal relationships. Despite the prevalence and impact, there is limited accessible, evidence-based information to help people understand their symptoms, seek appropriate health care, and make treatment decisions. Guided by patient-oriented research, the aim of this project was to develop an online platform for people with endometriosis-related sexual pain.

Methods:

Firstly, we conducted stakeholder focus groups with patients, clinicians, researchers and endometriosis organizations to determine the appropriate audience, content, mood and feel of the online platform. Secondly, we evaluated existing online resources for readability, suitability, and quality using validated eHealth tools. Finally, we developed content for the online platform informed by user-centred iterative design.

Results:

Hope, de-stigmatization, empowerment, connectedness, depth of information and credibility were identified by our stakeholder groups as important for an online platform. Our review suggest that existing online resources use medical/technical language, offer limited content, include long blocks of text and are not visually appealing. As a result, all content for our site including types of sexual pain, physical and psychological mechanisms, management and treatment options were conveyed through short plain language messages, visual images and design.

Implications:

The end product was an appealing, informative public website for a diverse audience. Further development and qualitative interviews will explore the user experience to determine additional information, support needs and self-management strategies leading to better health outcomes for people with endometriosis and painful sex.

KT Approach:

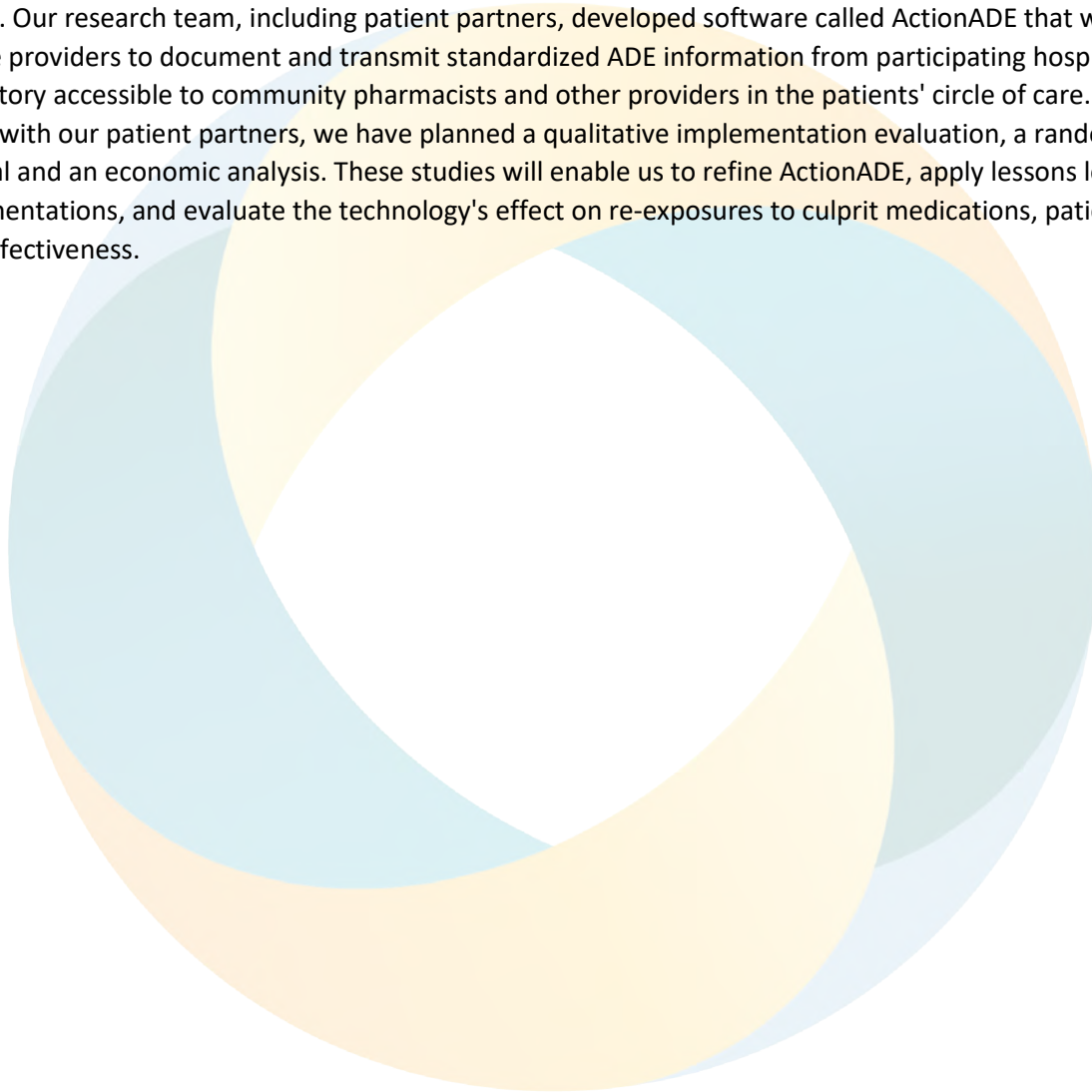
The cornerstone of this project was Integrated knowledge translation (iKT), which allowed for stakeholder/researcher co-design to ensure the product was fit for knowledge users.

Poster P15

Patient-Oriented Research in Emergency Medicine: Implementing and Evaluating ActionADE to Transform Medication Safety

Presenters: Serena Small, BC Emergency Medicine Network, Department of Emergency Medicine, UBC

Patients are commonly re-exposed to medications that previously caused harm, which can result in repeat adverse drug events (ADEs). Our research team, including patient partners, developed software called ActionADE that will enable front line care providers to document and transmit standardized ADE information from participating hospitals to a central repository accessible to community pharmacists and other providers in the patients' circle of care. In collaboration with our patient partners, we have planned a qualitative implementation evaluation, a randomized controlled trial and an economic analysis. These studies will enable us to refine ActionADE, apply lessons learned to future implementations, and evaluate the technology's effect on re-exposures to culprit medications, patient outcomes and its cost effectiveness.

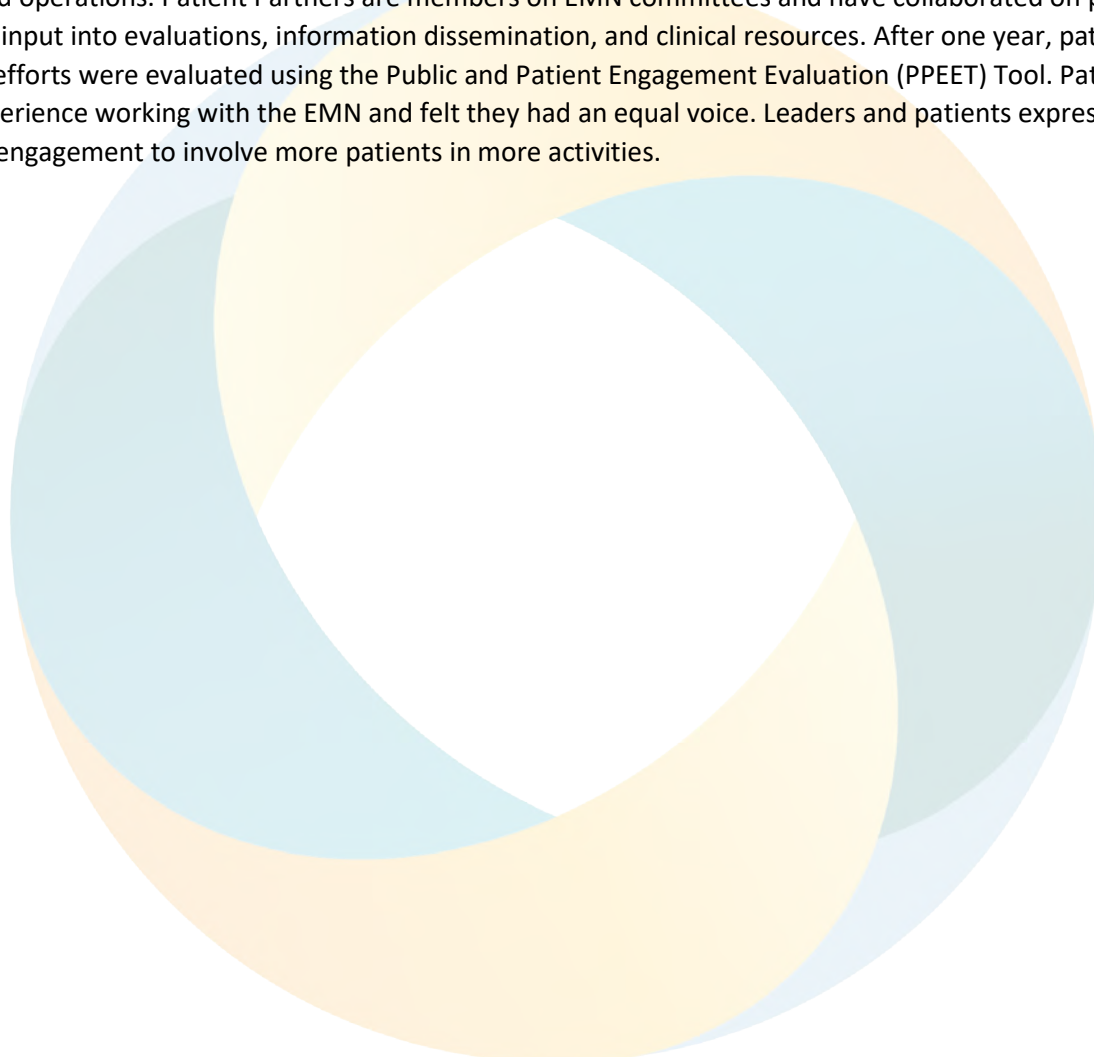


Poster P16

Patient Engagement in the BC Emergency Medicine Network

Presenters: Sharla Drebit & Rosemarie Hoefsloot, BC Emergency Medicine Network, Department of Emergency Medicine, UBC

The BC Emergency Medicine Network (EMN) is a clinical support and knowledge translation network working to improve patient care in BC. The EMN is strengthening the patient voice in emergency care by involving patients in Network leadership and operations. Patient Partners are members on EMN committees and have collaborated on publications, and provided input into evaluations, information dissemination, and clinical resources. After one year, patient engagement efforts were evaluated using the Public and Patient Engagement Evaluation (PPEET) Tool. Patients reported a positive experience working with the EMN and felt they had an equal voice. Leaders and patients expressed a need to scale patient engagement to involve more patients in more activities.



Poster P17

Kwiis hen niip - Change: Change for Emergency Care Services in Rural and Remote British Columbia Indigenous Communities

Presenters: Samantha Christensen & Jim Christenson, BC Emergency Medicine Network, Department of Emergency Medicine, UBC

Health inequities remain widespread in Indigenous communities across Canada. Many communities are rural or remote, compounding problems by preventing timely and effective emergency care. The resulting increased need for emergency care services and lack of effective, coordinated systems to provide timely and quality care results in elevated risk of mortality and morbidity. The BC Emergency Medicine Network is working to improve emergency care in four remote Nuu-Chah-Nulth communities through community engagement, partnerships and research. Through community dialogue, four critical priority areas of improvement were defined. Next, we will address the priority needs by co-designing, implementing and evaluating interventions. Ultimately, this project will seek evidence of transferable interventions and a successful, practical approach to improving equitable emergency care in remote Indigenous communities.

Poster P18

A patient-oriented approach to stroke prevention with improved cognitive benefits: An MRI monitoring study

Presenter: Betty Chinda, MSc. Candidate, Department of Biomedical Physiology and Kinesiology, Simon Fraser University; SFU ImageTech Lab, Surrey Memorial Hospital

Team members

Bob Strain¹, Dr. William Siu - Interventional Radiologist^{2,3}, Simon Liang⁴, Kim Williams-Crook¹, Dr. George Medvedev^{2,3}, Dr. Xiaowei Song^{5,6}

¹Patient Partner, Patient Voices Network, ²Royal Columbian Hospital, ³Fraser Health Authority, ⁴Department of Medicine, University of British Columbia, ⁵Department of Biomedical Physiology and Kinesiology, Simon Fraser University, ⁶SFU ImageTech Lab

Introduction:

In this patient-oriented study, we engage with patient partners and relevant stakeholders to understand how Carotid Artery Stenting (CAS) can benefit overall patient health and wellness. CAS is surgery that widens narrowed carotid arteries (stenosis) supplying blood to the brain.

Methods:

Patient partners will be recruited and fully engaged in study design, improving patient research experience, results interpretation, manuscript preparation and dissemination. Also, patients (n~10) with flow-limiting stenosis scheduled for CAS will be recruited to have 3 MRI scans - 1 before the CAS and 2 follow-up scans after CAS. Each MRI scan will be accompanied by cognitive testing. At each time-point, we will compare changes in patient-prioritized outcome measures including cognition, brain function, cerebral circulation, stroke prevention and risks reduction to improve overall health and wellness of patients.

Results/Findings:

We have successfully recruited 2 patient partners with relevant and distinct experiences since early 2019 and have engaged them in the study leading to better quality of research design by incorporating patient perspective. Team members also undertook patient-oriented research trainings that will facilitate the project. We have designed and optimized the study procedures to increase patient understanding and comfort. Preliminary MRI results will be ready by the conference date as participant recruitment has just begun.

Discussion/Implications:

This study will explore the benefits of CAS for patient wellness. We anticipate that the involvement of patient partners and relevant stakeholders will lead to relevant results that could potentially improve healthcare for patients with stroke risks.

Poster P19

Facilitating engagement in cervical cancer screening for Indigenous women in Northern British Columbia: An analysis of self-collected HPV at the intersection of Indigenous and patient-oriented research methodologies

Presenter: Marina Giovannoni, University of British Columbia & University of Northern British Columbia

Team members

Dr. Sheona Mitchell-Foster, University of British Columbia & University of Northern British Columbia, Dr. Travis Holyk, Beeskiah, EdD, MA, Carrier Sekani Family Services

Purpose:

To understand patient objectives with respect to the CervixCheck self-collected cervical cancer screening project for under screened Indigenous women in NBC. To identify outcomes of priority for patients with respect to CervixCheck screening project, and women's health in general. To identify areas of improvement for CervixCheck.

Hypothesis:

We expect the screening intervention to be highly acceptable, and for patient's priorities to be largely in line with projects objectives. We also expect there to be areas of research and barriers that have been missed during the initial rollout of the program that will be identified during this project.

Justification:

This research is critical to the success of a large scale screening intervention aimed at women who do not regularly attend CCS. This will allow for the program to be adapted to best suit the needs of individual communities. This will also allow for future research projects to be projects that were asked for by these communities, meaning they will be more accepted by communities and have the potential to cause positive impacts in communities.

Primary Objective:

To identify patient-oriented objectives for research for CervixCheck self-collected HPV cervical cancer screening for under screened Indigenous women

Secondary Objectives:

- Evaluate acceptability of screening kit, and access to follow-up care
- Identify ongoing barriers to self-screening, and determine strategies for circumvention of barriers
- Determine the role of partner participation in screening participation
- Determine whether stigma surrounding the sexually-transmitted nature of HPV affects screening participation

Research Design: Women will be recruited from participating CSFS communities to participate in focus group meetings and complete a survey.

Poster P20

Patient Partner Engagement:

Reviewing the Literature on the Patient Experience in Rural to Urban Medical Travel

Presenter: Rebecca Schuss, University of Toronto

Denise Jaworsky, University of British Columbia, University of Northern British Columbia

Team Members

Rebecca Schuss¹, Sabrina Trigo², Simran Jawanda³, Dave Sohi⁵, Howard Chafin⁴, Judy Chafin⁴, Denise Jaworsky^{3,5}

¹University of Toronto; ²Northern Ontario School of Medicine; ³University of Northern British Columbia; ⁴Patient Partner;

⁵University of British Columbia

Introduction and Background:

Little is known about the experience of patients who need to leave rural/isolated communities to receive medical care in urban centres. Experiences during transfer, while away in tertiary centres and upon return to home communities can be stressful for patients and families. There is a need to identify ways to improve these experiences in BC where nearly 6,800 patients are transferred by air ambulance annually.

Methods:

This patient-oriented study formed a Patient Partner Steering Committee (PPSC) in Northwestern BC. Their role was to ensure the study focuses on patient priorities so the findings will be relevant to patients/families. Under supervision of a librarian, three research trainees developed a scoping review protocol to address the question: "What is known about the experiences of patients or patients' families who travel from their homes in rural/isolated communities to urban centres for medical care?" Several search terms limits required definition (participant age, study time frame and country) and this decision was brought to the PPSC for input.

Results/Findings:

The PPSC, based on their experiences accessing medical care in Northwestern BC, suggested the literature review focus on individuals aged >18 as support services available to children are different from those available to adults. They recommended a 10-year range (2009-2019) as advances in wireless technology have significantly changed access to care for isolated communities. They also suggested expanding the review beyond Canada to include countries with similar geographies and healthcare resources (e.g. Australia, Norway).

Discussions/Implications:

These are a few examples of how patient partners informed study design, provided insights that may not have otherwise been considered, and how they continue to enlighten the research process with their own rich experiences.

Notes





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