



*The Person-Centred
Care Research Team*

YEAR IN REVIEW 2024



**UNIVERSITY OF
CALGARY**

<https://cumming.ucalgary.ca/research/person-centred-care>



Dr. Maria J. Santana

Principal investigator

MESSAGE FROM PRINCIPAL INVESTIGATOR

In the spirit of collaboration and innovation, our team—a diverse group of researchers, clinicians, and patient partners—continues to drive meaningful advancements in person-centred care. I am so proud to share the work we have done over the past year, and look forward to working together to ensure that the voices, values, and lived experiences of patients and families remain central to the care and research we undertake.

Together, we can make person-centred care a reality.

Wishing you a Happy Holidays.

Maria J. Santana

At A Glance



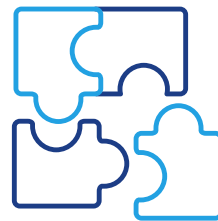
Publications

25+ publications

10 under review

3 submitted

1 E-book



Collaborators

6 International Collaborators

50+ Local Collaborators



Digital Stories

4 Stories



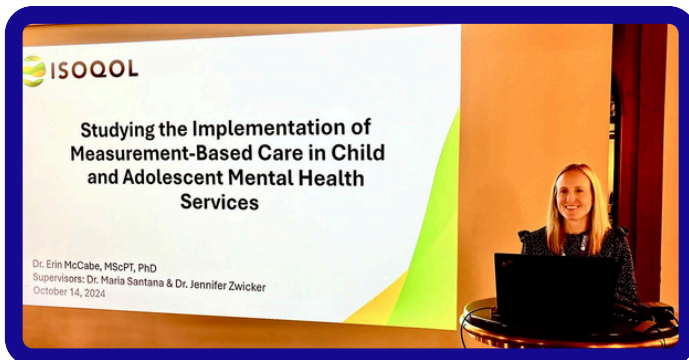
Presentations

46 Presentations

PATIENT-REPORTED OUTCOMES (PROMS) IMPLEMENTATION IN YOUTH MENTAL HEALTH

We conducted a project to select a PROM for youth mental health clinical care, by engaging with youth, families, and clinicians to make the use of PROMs more person-centred in a clinical setting.

[Read more about it here](#)



PATIENT EXPERIENCE & PATIENT-REPORTED EXPERIENCE MEASURES (PREMS)

2024 saw two published manuscripts from patient experience/PREM data. The first was published in *BMJ Open Quality* and focused on the association between person-centered quality indicators (PC-QIs) and unplanned acute care use. The second focused on the experiences of Albertans who were hospitalized due to diabetes and was published in the *Canadian Journal of Diabetes*. Additionally, our collaborators presented work on hospital noise and the experiences of children hospitalized due to cystic fibrosis and sickle cell anemia.

We recently had an article accepted about using natural language processing to understand patient-reported in-patient experiences from free-text comments, to appear soon in JMIR Medical Informatics.



IMPLEMENTING PERSON-CENTRED QUALITY INDICATORS (PC-QIS) IN PRIMARY CARE IN ALBERTA

We started this year off by completing our first Interim Report to the College of Physicians and Surgeons of Alberta, the sponsors of this research project. The AbSPORU Patient Engagement Team supported the research team in recruiting 9 members to a **Patient Advisory Council (PAC)**, which would support the activities of the research team for the PC-QI project.

The project was initiated with the four University of Alberta, Department of Family Medicine Teaching Clinics, with significant support from the Director of Health Services. In August, our partners at the HQCA distributed the PC-PREM survey to over 13,000 patients of the UAlberta Teaching Clinics. Just over 3,000 patients consented to participate, for a 23% response rate. PC-QI PAC Members completed the PC-PREM in October and provided the research team with high-quality feedback about their experience with completing the PC-PREM.

We presented a poster at the [CAHSPR 2024 Conference](#), held in Ottawa, detailing our learnings about collaborative research partnerships, and the key role they play in implementation. The co-chair of the PC-QI PAC, the Research Coordinator, and Dr. Kimberly Manalili co-presented on the PC-QI project at the [Fall 2024 Person-Centred Care Forum](#), hosted in Calgary.

What Next?

The Research Team plans to expand in the New Year by welcoming a prospective Master's student and two additional staff members.

We are now in the pre-implementation phase with the Primary Care Networks in Grande Prairie and the Central Zone and is planning for surveying to occur in clinics starting in January. Post-implementation efforts with the UAlberta Teaching Clinics will commence in December, leading into the New Year.



PATIENT & COMMUNITY ENGAGEMENT RESEARCH (PACER) HIGHLIGHTS



The Patient and Community Engagement Research (PaCER) program is a one-year experiential-based qualitative health research learning program under the academic and scientific direction of Dr. Maria Santana and Dr. Paul Fairie of the University of Calgary Person-Centred Care Team. In 2024, PaCER teams and alumni were able to share highlights of the PaCER program as well as the many innovative PaCER projects at the [Gothenburg Global Conference on Person-Centred Care 2024](#); [Canadian Healthcare Navigation Conference \(CHNC\) 2024](#); [American Heart Association Annual Conference 2024](#); [2024 SPOR Northwest Collaborative Forum](#) and others.

We have also enjoyed some publications about PaCER projects – see publication list [here](#). There are currently four PaCER project-based manuscripts under review (long COVID, Maternal Health, YYC Refugee Health and Seeing the Invisible Resiliency (STIR)) with another readying for submission (Healthcare Navigation in Alberta). The Fall 2023 teams (Healthcare Navigation in Alberta and Dementia Disrupters) concluded their projects this summer and the work from both projects is continuing forward.

PACER HIGHLIGHTS CONT'D

The two Fall 2024 teams are finishing Course 1. We are looking forward to their novel and inclusive, person and community-centred work.

'I See You' Team

Sponsor: Dr. Michael Goldfarb, Jewish General Hospital, Montreal, PQ.

Our research seeks to understand the barriers, facilitators, and motivations for Intensive Care Unit (ICU) patients, family members and caregivers to engage in research studies related to the ICU experience. The limited participation in these types of studies highlights a gap in patient engagement research that must be addressed. By exploring these experiences, we hope to foster a more supportive and inclusive research environment, improve patient and caregiver experience, and enhance outcomes for critically ill patients. Ultimately this work will contribute towards advocacy strategies and promote patient-oriented research (POR) in the ICU setting.

'Honoring Life' (Two teams)

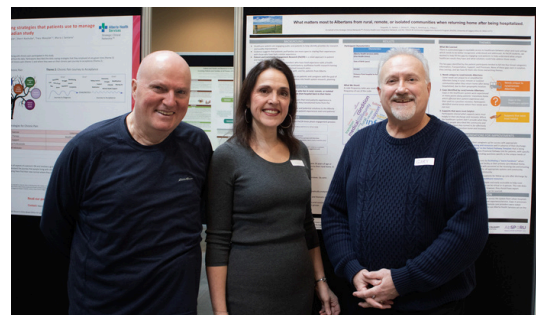
Sponsor: Alberta Health Services Indigenous Wellness Core and University of Lethbridge, Department of Indigenous Studies

Team Niitsitapiiksi (Real People/Blackfoot People)

Our team is dedicated to learning and understanding the ways Indigenous communities are overcoming substance and alcohol addictions by using traditional Blackfoot frameworks and methodologies to identify the possible solutions to assist Blackfoot community members overcome addictions. We aim to highlight culturally grounded strategies, community resilience, and innovative approaches that promote healing, inspiration, and long-term recovery. This work is vital because addiction has disproportionately impacted Indigenous populations, often as a direct result of historical trauma, systemic inequalities, and disruptions to cultural connections.

Team Aapahsupii (Buffalo Seekers)

This teams hope to focus on an Indigenous 'culture as wellness' approach to life promotion in Indigenous communities and people. Using culturally grounded and strengths based Indigenous research methodologies and knowledge frameworks the team will look to learn and understand ways culture, community, language, Elders, land and Indigenous ways of knowing and knowledge sharing are integral to holistic health and wellness in Indigenous life promotion.



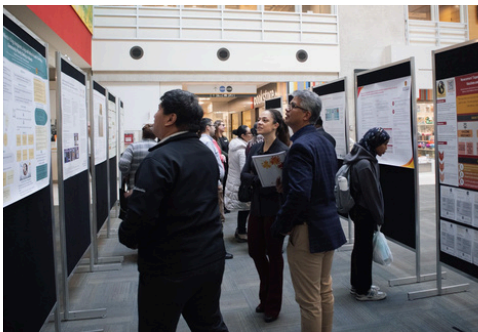
Patient-Centred Care (PCC) Forum

Winter 2024

The **Winter PCC Forum** explored “Opening Health Research to Patients, Families, and Communities: International, National & Local Perspectives.” Highlights included global perspectives from Sweden and Ireland, an engaging poster presentation, insights from the PaCER program, and a PaCER Sponsor Panel.

Fall 2024

The **Fall PCC Forum** explored “Impact of Patient Engagement in Health Care Research & Education.” The forum showcased the transformative role of patient engagement in advancing research and education. Highlights included presentations on patient involvement in medical education, the PaCER program, AB4HR Collaborative Council initiatives, and innovative approaches to measuring patient experience and care outcomes.



DIGITAL STORYTELLING HIGHLIGHTS

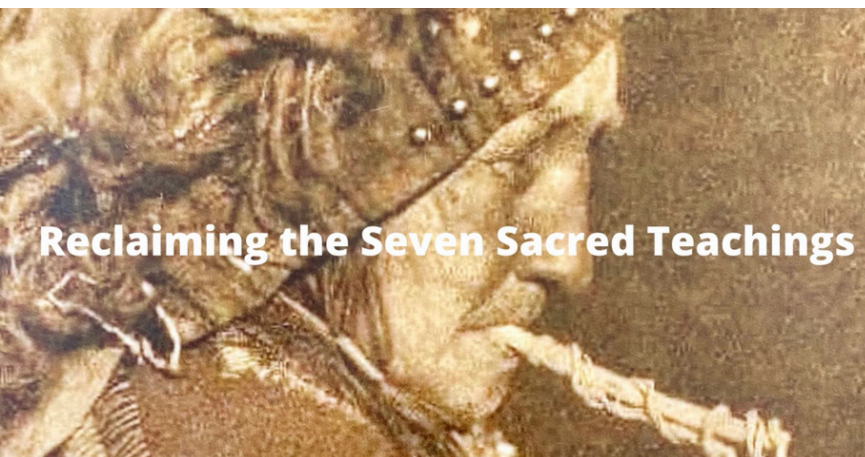
Indigenous Grandmothers' Stories

In February 2024, Sandra and Sadia were invited by University of Alberta researchers Sarah Demedeiros and Stephanie Montesanti to lead a digital storytelling workshop with Indigenous Grandmothers. The workshop focused on restoring and strengthening healthy Indigenous family systems. Sandra and Sadia travelled to Edmonton for a full day of in-person relationship-building with the Grandmothers and the research team.

Over the following weeks, they supported each Grandmother in completing their digital stories online. Once all the stories were finished, they reconvened in person at Kihcihkaw Askî - Sacred Land to celebrate each Grandmother's story and reflect on the process.

Presentations

Sandra and Sadia presented their digital storytelling work at various local and international conferences and events. Sandra delivered an oral presentation at the Global Person-Centred Care Conference in Gothenburg, Sweden. Both Sandra and Sadia presented at the Person-Centred Care Forum in Calgary and the ISOQOL conference in Cologne, Germany.



Reclaiming the Seven Sacred Teachings



For more information or to request a digital storytelling workshop:

- visit absporu.ca or
- contact Sandra and Sadia directly at sandra.zelinsky@ucalgary.ca and sadahmed@ucalgary.ca

INTERNATIONAL COLLABORATIONS



We have been collaborating with our international partners to guide Person-Centred Care initiatives and Patient-Oriented Research projects.

- University of Gothenburg, The Centre for Person-Centred Care, Sweden
- Picker Institute Europe
- INSPIRED, The University of Texas MD Anderson Cancer Center, Houston, USA
- University of Lausanne, Switzerland
- Amsterdam University Medical Centre (AMC) - Emma Children Hospital
- International Society for Quality of Life (ISOQOL) PROMs and PREMs in Clinical Practice Implementation Science Group

The 2024 International Society for Quality of Life Research (ISOQOL) Conference

Cologne, Germany

Our team members Maria, Sandra, Sadia, Bishnu, Erin, Marina & Kalpana attended and presented their work! Presentations included:

- Enhancing Patient-Centric Care: The Role of PROMs Utilizing SRS-30 in Pediatric Scoliosis Management
- Studying the Implementation of Measurement-Based Care in Child and Adolescent Mental Health Services
- Engagement and Activation of Children and Youth in Pediatric PROM/PREM Research Workshop



- **Dr. Sumedh Bele** (*PCC Team Alumnus*) received the Donna Lamping Emerging Leader Award
- **Kalpana Thapa Bajgain** (*Research Assistant*) received Student and New Investigator Award



PRESENTATIONS

Global Conference on Person-Centred Care (GCPCC)

Gothenburg, Sweden

The University of Gothenburg Centre for Person-Centred Care (GCPCC) hosted the first *Global Conference on Person-Centred Care*. Our team members Maria, Ingrid, Marina, Jaqueline and Sandra were able to attend and present their work!

Key Note Speaker at GCPCC

Gothenburg, Sweden

Dr. Maria J. Santana was a keynote speaker at the GCPCC. She presented "From Classroom to Community: Strengthening Healthcare Professional Education by Engaging Patients and the Public."

American Heart Association (AHA), 100th Annual Conference

Chicago, USA

Ingrid presented about 'Patient and Community Engagement in AbSPORU and PaCER'.



PRESENTATIONS CONT'D



ACHRI/Owerko Centre Summer Student Research Symposium

Calgary, Canada

Angelina presented an oral presentation. Huzaifa, Marta, Jasman and Victoria had the opportunity to do poster presentations. Congratulations to all the summer students for their great work!



Key Note Speaker at Learning about Person-centred care in Higher Education (LearnPCC)

Gothenburg, Sweden

Dr. Maria J. Santana was a keynote speaker at LearnPCC. It is a new scientific conference about students' learning of person-centred care.

COMMUNITY ENGAGEMENT

Year after year, we have maintained and expanded a strong network across rural, urban, and remote Alberta, building trusted relationships with multidisciplinary collaborators such as Alberta Health Services (AHS), Primary Care Networks (PCNs), organizations representing Black communities, immigrants, ethnocultural groups, youth, indigenous, seniors, patient partners, LGBTQ2S, individuals experiencing homelessness, academics, government representatives, etc. These collaborations reflect our commitment to Equity, Diversity, and Inclusion (EDI) principles and amplify the voices of Albertans in health research.

We would like to extend our heartfelt thanks to all our collaborators, partners, and the entire community engagement network for your incredible support throughout this year. We would not have been able to succeed in amplifying Albertans' voices in health research without your dedication and contributions.

We look forward to continuing our work together, collaborating, sharing, learning, and supporting each other as we move forward into 2025!



ENGAGEMENT ACTIVITIES



Equity, Diversity, and Inclusion (EDI) Mental Health World Café

The EDI Mental Health World Café was held in Red Deer on June 15, 2024, thanks to an amazing partnership with the Red Deer Local Immigration Partnership. We conducted the exercise to discuss mental health care in the community while making sure to address barriers to participation, like providing language interpretation, childcare, and transportation. Reports were shared after the event to allow community members and organizations to learn from the activity, and use the results to inform future strategies.



Albertans4HealthResearch (AB4HR) Collaborative Council

The AB4HR Collaborative Council consists of 40 committed members, including patient partners, representatives from AHS, researchers and members of communities and organizations from across Alberta. This year the council presented at the 2024 AbSPORU Collaborative Forum and the Fall 2024 PCC Forum



The Alberta Youth Health Advisory (AYHA)

The AYHA is a dynamic and passionate group representing youth from across the province, playing a key role in our work. This year, the Advisory has been working to document the process of their creation and presented at the 2024 Northwest AbSPORU Collaborative Forum and the PCC 2024 Forum. The AHYA provide insights of contemporary issues affecting youth, helping shape future changes in areas that matter most to them.

OUR TEAM

Maria J. Santana, MPharm, PhD, Principal Investigator

Paul Fairie, PhD, Senior Research Associate & Associate Director

Kyle Kemp, PhD, Senior Research Associate

Kimberly Manalili, MPH, Senior Research Associate

Sumedh Bele, PhD, Assistant Professor Pediatrics, Emory University, USA

Sadia Ahmed, MSc, Research Associate

Bishnu Bajgain, Research Coordinator and PhD Student

Ingrid Nielssen, MA, Research Coordinator, PaCER Instructor

Tiffany Barbosa, Community Engagement Coordinator

Matthew Luzentales-Simpson, MSc, Research Coordinator

Erin McCabe, PhD, Post-Doctoral Fellow (completed August 2024), Assistant Professor (UAlberta)

Marina Rosa Filezio, MSc, MD, Post-Doctoral Fellow

Sandra Zelinsky, PaCER Grad, Lead Patient Research Partner

Kalpana Bajgain, Research Assistant

Ambar Ortega Pinto, Communications Lead, Operations Assistant

Students

Sarah Rabi, MSc Student (completed Summer 2024)

Farwa Naqvi, MSc student (completed Fall 2024)

Jacqueline Wilson, PhD Student

Alessandra Paolucci, PhD Student

Joel Adekanye, PhD Student

Seema King, PhD Student

Jake Jennings, PhD Student

Minnie Antonio, MSc Student

Duaa Fatima, MSc Student

Angelina Horta, 2024 Summer Student

Marta Ravani, 2024 Summer Student

Jasman Sangha, 2024 Summer Student

Victoria Duffy, 2024 Summer Student

Community Partners

We sincerely thank our community partners and collaborators for working with us on Person-Centred Care initiatives and Patient-Oriented Research projects.



Funders

We sincerely thank our funders for supporting us in carrying out our work.



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Alberta SPOR SUPPORT Unit



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CIHR IRSC

Strategy for Patient-Oriented Research

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Putting Patients First

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