

## 2018 AbSPORU Studentship Award Recipients (10)

### Sadia Ahmed – University of Calgary

**Project:** *Understanding patient and caregiver experiences of advanced cancer care in Alberta*

#### Biography



Sadia graduated with a Bachelor of Health Science (Hon) degree at the University of Calgary, majoring in Health and Society.

Her undergraduate degree led her to develop an interest in health research, pursuing research opportunities with the Wolb Pack (under the supervision of Dr. Wolbring) and also The Methods Hub (under the supervision of Dr. Santana) at the University of Calgary. She worked as a Research Assistant with her current supervisor at the Foothills and Alberta Children's Hospital, before deciding to pursue graduate studies at the University of Calgary.

Sadia developed a passion for patient-centred care research, and patient-oriented research through the projects she was involved in. Some of the projects she helped coordinate are the development of patient-centred care quality indicators, and priority setting with patients and families for cardiovascular health research.

Sadia is a first year Master's student in the Department of Community Health Sciences (under the supervision of Dr. Santana). She hopes to gain expertise in qualitative, patient-oriented methodologies, and skills to be able to coordinate multiple projects under the umbrella of improving health services for patients and families, and patient-centred care. From her thesis, she aims to understand the experiences of advanced colorectal cancer patients and family caregivers, to inform the refinement of an early palliative care pathway in Alberta.

In her spare time, Sadia enjoys planning student conferences, volunteering, hiking, the outdoors, playing board games, and tacos.

#### Project Summary

Palliative care is an added layer of support for patients and their families or loved ones, who

are living with a serious illness. This type of care is focused on providing relief from symptoms and stress of a serious illness. Patients with an advanced care diagnosis and their families face significant distress leading to reduced quality of life.

In Alberta, most cancer patients continue to receive late palliative care (defined as less than 3 months before death). However, patients who receive early palliative care supports tend to use less aggressive interventions at the end of their lives. Early palliative care is also associated with improved quality of life, reduced family distress, and reduced healthcare costs.

Currently, the Canadian healthcare system struggles to provide early palliative care across care sectors such as homecare and primary care. Sadia's proposal aims to understand the experiences of patients and family caregivers of the healthcare services received for their cancer, and their perceptions of palliative care.

This information will be used to support the development of an early palliative care pathway for advanced cancer care, where patient and family priorities are incorporated. This will be done by interviewing advanced colorectal cancer patients and family caregivers (one-on-one) from Calgary and Edmonton. Patients and their caregivers will be asked about their experiences with their cancer care in Alberta to identify gaps and barriers in care, leading to a greater understanding into how we can improve the quality of care for patients and families.

## Brooke Allemang – University of Calgary

**Project:** *Experiences of Young Adults with Comorbid Health and Mental Health Issues Transferring to Adult-Oriented Services*



### Biography

Brooke Allemang, MSW, RSW is a first-year doctoral student in the Faculty of Social Work at the University of Calgary. She completed her Master's of Social Work at the University of Toronto and brings four years of clinical social work experience to her doctoral studies.

Most recently, she worked in a cross-appointed Transition Navigator role at The Hospital for Sick Children and University Health Network. In this position, she developed the first successful joint pediatric-adult transition program in Canada dedicated to the hemoglobinopathy population. Initially a 6-month pilot project, she quickly demonstrated the importance of the transition program and established it into a five-year program which continues to operate today. This work was recognized at the national level when the

Transition Navigator role in hemoglobinopathies was awarded a Leading Practice designation by Accreditation Canada in 2016.

Brooke has been invited to speak at various international conferences including the National Institutes of Health Sickle Cell Disease Forum and the Chronic Illness and Disability Conference at Baylor College of Medicine. Her rich experiences as a Transition Navigator motivated her to pursue her PhD in Social Work in order to explore the experiences and psychosocial development of transition-age youth with comorbid chronic health conditions and mental illness.

### Project Summary

Twenty percent of Canadians aged 12-19 have a chronic health condition which limits their activities of daily living. Rates of mental illness are 2-3 times greater in adolescents and young adults (AYA) with chronic health conditions compared to their healthy peers. The presence of mental illness in AYA with chronic health conditions diminishes capacity for self-

management and results in prolonged hospital stays, decreased medication adherence and higher morbidity.

The transfer from pediatric to adult care is a high-risk period for AYA, associated with a decline in health and mental health care utilization, high drop-out rates, and poor health outcomes. At transfer, AYA who have more than one diagnosis exit multiple pediatric services during emerging adulthood, a challenging developmental period, where they are pursuing post-secondary education, employment and solidifying their identity.

Research exploring the impact of comorbid chronic health conditions and mental illness on AYA's psychosocial development is scant. Little is known about the barriers they face when they leave pediatric care and how comorbid diagnoses affect AYA in the context of emerging adulthood. Research is needed to design programs which support AYA with comorbidities to effectively transition to adult care and access timely, developmentally appropriate services.

In-depth, semi-structured interviews will be conducted with 30 AYA to explore their transition needs and psychosocial development. Straussian grounded theory will be used to analyze the qualitative data. Study findings will help develop best practice guidelines for transitioning AYA with chronic health conditions and mental illness from pediatric to adult services in Canada.

## **Jaimie Beveridge**

***Project: Examining the Cumulative Risk of Maternal Chronic Pain and Trauma on Adolescent Chronic Pain***

## Michelle Flynn – University of Calgary

**Project:** *Investigating Intranasal Oxytocin as a Treatment for Women’s Chronic Pelvic Pain*

### Biography



Michelle first became passionate about scientific research during her first year of undergraduate studies in psychology at Dalhousie University. To nurture this interest, she pursued research opportunities in childhood development (Dalhousie) and school-based health promotion programming (The Hospital for Sick Children).

For her Honours thesis, she investigated sexual communication patterns among couples coping with vulvovaginal pain. During this time, she discovered her interest in clinical health psychology, and she became dedicated to developing her skills as both a researcher and a clinician.

Upon completion of her undergraduate degree (BA, First Class Honours in Psychology), she moved to Calgary to pursue studies in Clinical Psychology (MSc/PhD) under the supervision of Dr. Tavis Campbell at the University of Calgary. Her Master's thesis was a feasibility trial investigating intranasal oxytocin as a treatment for women's chronic pelvic pain. For her PhD, she will continue to investigate this line of work. Ultimately, Michelle wishes to pursue a career in which she independently conducts clinical health psychology research.

### Project Summary

Chronic pelvic pain (CPP) refers to a pain condition with pain in the lower abdomen or pelvis occurring for six months or more. Up to 27% of all women experience CPP. Beyond experiencing pain itself, women with CPP report adverse psychological and physical health outcomes. Numerous treatments are available, but few treatments are supported by scientific research.

Oxytocin (OT) naturally occurs in the body, can be taken like other pharmaceutical substances, and may decrease pain. Administration of OT has been shown to reduce pain among patients with various chronic pain conditions. OT may have different effects on women with CPP because there is an abundance of OT receptors in the uterus, so the region in

which pain occurs may be particularly sensitive to the effects of OT.

OT's ability to reduce pain among women with CPP has yet to be investigated; this is the objective of the current study. Women with CPP will take an OT nasal spray for two weeks, no nasal spray for two weeks, and a nasal spray without the active OT ingredient (a placebo) for two weeks. Women will report their pain and impairment due to pain throughout the study.

The study hypothesizes that OT nasal spray will result in greater pain reduction than the placebo. Women will be asked about their experiences taking oxytocin nasal spray, to determine if this potential treatment is acceptable for those with CPP. The results of this study will be used to inform treatments of chronic pain and CPP.

## Saryn Hingston – University of Calgary

**Project:** *Embracing the Spectrums: What Responses from Clinicians do Gender Diverse Autistic People Find Beneficial?*



### Biography

Saryn is a Master's student in Community Rehabilitation and Disability Studies in the Department of Community Health Sciences at the University of Calgary. She graduated from the University of Calgary with an honours degree and silver medallion in Women's Studies in 2016, after transferring from a science-based program at the University of Saskatchewan. Her honours thesis was a qualitative research study examining the experiences of marginalized parents and included a knowledge translation tool being used in numerous non-profits and community resources in the Calgary region. Saryn has also researched the use of head coverings as a rite of the passage in a rural isolationist religious group and went on to start a peer support group based on this work.

Her research passions are based on her life experiences, from global health work in India, to working with children and teens with disabilities in Saskatchewan. She uses critical feminist theory, theory of intersectionality, queer theory, and crip theory in her work. Saryn finds the most rewarding part of her research work is in bringing out the voices and stories of people who not only are unheard, but erased as well.

### Project Summary

Gender diverse individuals such as transgender and non-binary people are at a heightened risk for suicide. This risk has distinct meaning for gender diverse individuals who are also on the autism spectrum, with autistic people being nearly eight times more likely to be gender diverse than neurotypical people.

Risk factors for suicide for transgender and non-binary people include transphobia and victimization, while suicide protective factors include social support, self-acceptance, and health care that affirms their gender identity. Gender diverse autistic people frequently report negative reactions to their gender by health care professionals.

Much of the established literature used to guide health and social services practice with autistic people contains evidence of transphobia and gender diversity erasure and these forms of rejection can be life threatening.

Individuals who have both a formal autism diagnosis and who self-identify as being gender diverse will be invited to participate in semi-structured interviews about their experiences of interacting with authority figures such as medical professionals. The interview structure and processes, along with analysis and dissemination, will be developed in collaboration with participants.

The purpose of this study is to first contribute to understandings of the kinds of clinician responses to gender diversity that are beneficial to those on the autism and gender diverse spectrums. The study then aims to translate these understandings in ways that can inform clinical guidelines for supporting gender diverse autistic patients.

## **Alysha Keehn – University of Calgary**

***Project: Defining Research Priorities for Young Women with Breast Cancer: A Priority Setting Partnership***



### **Biography**

Alysha obtained her Bachelor of Science in Nutrition from the University of Alberta. She subsequently worked at the Stollery Children’s Hospital and in cancer research prior to completing her Doctor of Medicine at the University of Calgary.

Alysha is currently a third-year resident physician in General Surgery concurrently completing her master's degree in Health Services Research under the supervision of Dr. May Lynn Quan. She aspires to obtain sub- specialty training in the field of surgical oncology and work as a surgeon- scientist whereby her clinical work can inform her research and transform the way she and others care for patients.

Alysha is passionate about cancer care and her work is dedicated to improving patient experiences and outcomes through quality improvement and health services research. One particular focus of her work is dedicated to understanding the patient experience and giving patients a voice in the research agenda. Her master's thesis, in partnership with the Reducing the Burden of Breast Cancer in Young Women (RUBY) study, will survey patients, family members, caregivers and clinicians affected by, or are intimately involved in the care of, young women with breast cancer.

### **Project Summary**

Five percent of cases of breast cancer are diagnosed in women under the age of 40. Young women with breast cancer often have a biologically distinct disease with poorer outcomes compared to older women. Evidence-based medicine may not apply to many aspects of care for young women as the majority of the literature is based on all-comers. Research priorities, traditionally set by academia rather than those with the “lived-experience,” may result in a mismatch between research performed and the information that patients and clinicians need to make informed decisions.

This project aims to bring patients, caregivers and clinicians together to identify uncertainties

for young women with breast cancer and establish a prioritized list of “Top 10” questions to guide future research from a patient-oriented perspective.

To achieve this, a balanced steering committee will approve an online survey promoted to a large network of young women with breast cancer as well as clinicians and caregivers involved in their treatment. The survey will be open-ended and ask respondents to provide questions they have over the spectrum of disease from diagnosis to end of life issues. It will remain open until theme saturation is achieved. A list of questions currently unanswered by the literature will be redistributed to participants through an interim prioritization survey formulating a list of 30 potential research questions. A one-day workshop will be held and through a nominal group technique, a list of “Top-10” unanswered questions will be agreed upon. The results will be used to inform future research for this population.

## Chelsea Moran – University of Calgary

**Project:** *Motivational Interviewing for Cardiovascular Disease Prevention: A Randomized Controlled Trial to Improve Statin Medication Adherence*



### Biography

Chelsea is a first year PhD Student in Clinical Psychology at the University of Calgary. She completed a BSc in Psychology at the University of Ottawa, studying a psychological intervention targeting fear of cancer recurrence in breast cancer patients. She also graduated with a Master's in Counselling Psychology from McGill University, where her research examined barriers to skin self-examination practices in melanoma skin cancer patients.

Her research interests include discovering new ways to facilitate healthy behaviours and to help patients cope with chronic illness. She is also interested in learning about best-practice research methods and open science initiatives in psychology.

Chelsea is currently the Chair of the Student Section of the Canadian Psychological Association (CPA) and has represented students in psychology on the CPA Board of Directors since 2017. After completing her training, Chelsea hopes to become an independent research and clinical psychologist to contribute to the ongoing effort to provide holistic patient care emphasizing prevention and treatment.

### Project Summary

Cardiovascular disease is the second leading cause of death in Canada and can be prevented and treated by managing blood cholesterol levels. A certain amount of cholesterol is necessary for normal body function, but high levels of “bad” cholesterol such as low-density lipoprotein (LDL) can create narrowing in blood vessels, including those supplying the heart and brain. This increases the risk of heart attack, stroke or other complications.

There is strong evidence that a class of medications known as statins are effective at lowering LDL. Statins are prescribed to about 10% Canadian adults to reduce their risk of cardiovascular disease, however, about half of patients stop taking this life-saving medication within a year after prescription.



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The aim of this study is twofold: first, a brief one-on-one intervention will be designed to help patients explore internal motivations and uncertainty related to taking their statin medication. Each patient will be offered three confidential 30-minute sessions with a doctoral-level psychology trainee. These sessions will focus on providing information about statins, discussing benefits and risks, and exploring internal motivations. In this first phase, a small group of patients will be recruited to request their feedback on how to improve the sessions.

Next, a larger number of patients will be assigned at random to this new approach or to the current standard of care to determine which is more effective at helping patients adhere to statins. The study predicts that patients who receive these motivational sessions will experience increased statin adherence, ultimately improving their cardiovascular health.

## Camila Orsso – University of Alberta

**Project:** *A Model of Metabolic Load-Capacity in Pediatric Obesity: Implications for Metabolic Health and Interactions with Gut Microbiota*

### Biography



Camila is a Master's student in the Nutrition and Metabolism program at the University of Alberta. She completed a BSc in Physical Education at the Federal University of Technology in Paraná, Brazil. Her passion for research started in her first year of university, in which she pursued a project investigating the physiological responses to exercise in athletes.

Afterwards, she was employed as a research assistant for a metabolic study in postmenopausal women. Later in her undergraduate program, she received a scholarship from the Brazilian Government to study and work as a research intern at the University of Alberta.

Once in Edmonton, she worked for Drs. Carla Prado and Andrea Haqq at the Human Nutrition Research Unit and learned different techniques of body composition assessment. She also developed a particular interest in examining body composition phenotypes in children and the implications of muscle mass on metabolic health. Upon completion of her undergraduate degree, she worked as a research volunteer at the University of Toronto, where she improved her knowledge in measuring muscle mass and strength and acquired skills to organize patient-oriented seminars.

Now she is back in Edmonton for her Master's degree, and her current research aims to investigate the implications of low muscle mass on metabolic health of children with obesity. She also plans to study the interactions between gut microbiota, body composition, diet and physical activity in predicting metabolic dysfunction. In addition to her graduate program, she serves as a member of the Alberta Diabetes Institute Trainee Working Group.

### Project Summary

The pathophysiology of metabolic dysfunction in childhood obesity is not completely understood; factors other than high fat, poor diet and low physical activity (PA) may negatively impact children's metabolic health. In adults, the metabolic load-capacity index

(ratio between body fat and lean mass) explains the metabolic implications of having both high fat and low lean mass. Studies also propose the gut microbiota as a key contributor to metabolic dysfunction in adults and animal models. However, there is no evidence yet supporting the metabolic load-capacity index or gut microbiota as additional predictors of metabolic health in children. Camila's research will evaluate if the metabolic load-capacity index, gut microbiota diversity, diet quality index (DQI), PA or interactions between these factors are predictors of metabolic health in pediatric obesity.

In the study, ninety children with obesity (10-16 years) will be categorized as metabolically healthy or not based on results of a comprehensive metabolic profile. The metabolic load-capacity index will be calculated as the ratio between body fat and lean mass. Fecal sample will be collected to analyze gut microbiota, and blood sample for metabolic and inflammatory markers. DQI and PA will be measured using a 3-day food record and accelerometry, respectively.

Camila hypothesizes that metabolic health will be strongly predicted by a model combining metabolic load-capacity index, gut microbiome diversity, DQI, and PA rather than one single factor alone. Her study should provide targets for early treatment of children with obesity and metabolic dysfunction, including personalized dietary strategies targeting the gut microbiota.

## Lilla Roy – University of Alberta

**Project:** *Aligning Values and Preference with Health Economic Decisions and Policy – Investigating Health Outcomes in Minority and Indigenous Populations of Canada*



### Biography

Born and raised in the Maritimes, Lilla spent most of her adult years living, exploring, and working as an emergency nurse in different parts of the country (Nova Scotia, Ontario, Alberta, British Columbia, and Northwest Territories).

Lilla completed a BScN at Laurentian University in 2008, and a MSc in Pharmaceutical Sciences at the University of British Columbia in 2013. Her Master's research focused on measuring health utilities and preferences related to infant respiratory disease. Most recently, Lilla has been working as a nurse educator with Cape Breton University, in eastern Canada.

This past fall, Lilla began a PhD program in Health Services & Policy Research under the supervision of Dr. Jeffrey Johnson. Her research interests include advocacy for patient and population health outcomes through the study of health policy, health economics, and health related quality of life. Her PhD research aims to investigate the extent to which current approaches to measuring patient reported outcome measures (PROMs) and health preferences may misrepresent values and preferences of important Canadian subgroups.

### Project Summary

This research proposes to investigate the application of traditional approaches to measuring and valuing health in sub-groups of the Canadian population, particularly Indigenous and immigrant people, based on a better understanding of their preferences and values.

The objective of the study is to explore the application of traditional choice-based health valuation tasks within specific Canadian sub-populations; and to make recommendations for the application of current approaches to health policy decisions relevant to these sub-groups.

The project will incorporate a mixed methods approach. A careful review of the literature will be conducted to explore methodologic nuances of measuring, interpreting, and applying sub-



## Alberta **SPOR SUPPORT** Unit

group preferences within the context of Canadian health policy decisions. Significant consideration will be given to understanding cultural differences in the conception of health, time preference, language and word choice, health literacy levels, and framing bias. Empirical studies will be developed, collecting qualitative and quantitative data on health state preferences, using various decision theory methods, to explore variation in samples from Indigenous and immigrant populations.

This research will determine the extent to which current approaches to measuring health state preferences may misrepresent the values and preferences of important Canadian population sub-groups. Recommendations will be made regarding the application of existing tools in these populations, and modifications or methodologic approaches that may benefit sub-groups. Through the exploration of these methods, Lilla believes we can advocate for individual and population level health care decisions that appropriately reflect respective sub-group preferences and values, ultimately improving the health of communities and the nation.

## Jackie Ryan – University of Alberta

**Project:** *Nothing About Us Without Us: Towards Increased Self-Determination for Adolescents and Adults with Autism Spectrum Disorder*

### Biography



Jackie has worked in the autism field for 18 years. This work was initially motivated by her youngest son, now 23 years old, who has autism. She was diagnosed with autism in 2014. Her diagnosis, and her son's transition to adulthood, strongly influenced her initial interest in self-determination for autistics. Her motivation now is to improve outcomes for all autistic people and the professionals who support them.

In her work at a large, interdisciplinary, not-for-profit service provider in Edmonton, the Centre for Autism Services Alberta, she created Quest for Independence, a post-secondary transition program for young adults with ASD, focused on teaching skills for independence. She also led the Edmonton implementation of CommunityWorks Canada®, a program aimed at giving autistic high school students volunteer experience.

She completed a Master's degree in Leadership in 2016, receiving the Royal Roads University Founders' Award for exemplifying the qualities of leadership, sustainability and personal development, by including autistic individuals in her research project as participants and as a member of her advisory committee. This research led to the creation of a Self-Advocates Advisory Group on Self-Determination at the Centre for Autism Services Alberta, whose primary role is to provide guidance on how to encourage self-determination of autistic individuals as an intrinsic part of the organization's culture.

Jackie's doctoral research will be guided by a Research Advisory Committee that includes autistic individuals who will participate in all phases: participant recruitment, interview question creation, pilot testing and refinement of interview guides, data analysis, and results sharing.

### Project Summary

Much of the research related to autism spectrum disorder (ASD) has addressed genetics,

risk factors, neural and cognitive systems, diagnosis, and treatment/interventions (Pellicano et al., 2014). These priorities for research have been identified primarily by scientists, professionals, and families with autistic members.

Autistics are advocating for more of a role in autism research, including setting the research agenda. Autistics identify that research related to their quality of life is essential (Pellicano et al., 2014). One indicator of quality of life is self-determination. However, youth and adults with ASD are less self-determined than their non-autistic peers (Wehmeyer & Shogren, 2008). An important foundational skill for self-determination is autonomous goal setting.

Through direct involvement and collaboration with autistic adolescents and adults, this research aims to improve self-determination in goal setting for autistic adolescents and adults. Studies one (with autistic individuals who communicate in traditional ways) and two (with autistic individuals who do not communicate in traditional ways) will (1) identify strategies to support autonomous goal setting for individuals across the autism spectrum, and (2) identify approaches to enable health, education and rehabilitation professionals to adopt these strategies and support attainment of goals identified by autistics.

Study three will involve developing a tool to support professionals working with people with ASD, and pilot testing this tool in one organization (Centre for Autism Services Alberta). Together, these studies, directly informed by patient engagement, will be relevant to people with ASD across the spectrum, and health professionals across health, education and community sectors.