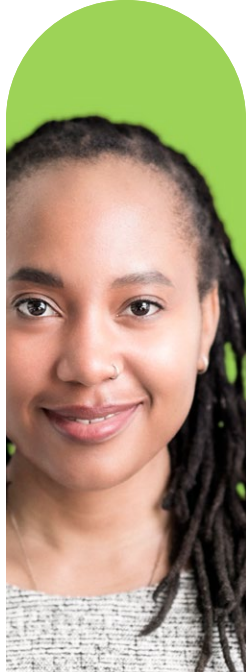
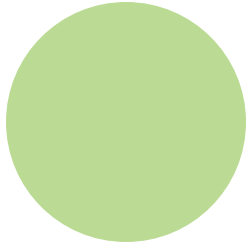


REPORT TO COMMUNITY
2019/2020



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WHO WE ARE AND WHAT WE DO

Canada's Strategy for Patient Oriented Research (SPOR) aims to improve health outcomes and the experience of care for patients by moving scientific discoveries to the bedside more rapidly.

In 2013, the SPOR Strategy was brought to life locally with the inception of the Maritime SPOR SUPPORT Unit (MSSU). One of eleven SPOR SUPPORT units, MSSU reflects the commitment of the Canadian Institutes of Health Research (CIHR) and the Maritime provinces to patient-focused and evidence-based health care. MSSU is the only SPOR SUPPORT Unit serving more than one province.

MSSU brings the Maritimes together to engage in patient-oriented health research, in collaboration with government stakeholders, health authorities, the research community, and Patient Partners and caregivers from across New Brunswick, Nova Scotia and Prince Edward Island.

BRINGING
THE MARITIMES
TOGETHER IN
PATIENT-ORIENTED
HEALTH RESEARCH



NOMINATED PRINCIPAL INVESTIGATOR MESSAGE TO COMMUNITY

MSSU is a testament to the power of collaboration—from participating in Canada’s SPOR strategy at the national level, to pan-Maritime research collaboration through shared processes and approaches.

Working together has never been more important given the rapid but necessary social changes to stop the spread of COVID-19. For provincial governments tasked with implementing many of these changes, dealing with the considerable uncertainty is an ongoing challenge.

MSSU is helping policy-makers with rapid reviews to understand successful responses to the pandemic in other jurisdictions. We are also supporting Maritime researchers to respond quickly to emerging COVID-19 related research opportunities. MSSU is proud to be providing this important service to our governments and researchers as they work to understand and respond to the pandemic.

Despite the impact of COVID-19, MSSU continues to support local researchers, enabling many notable

successful grants and providing research support ranging from guidance on approaches to conducting preliminary research and translating knowledge.

Last year, we advanced our patient engagement efforts with the implementation of a Patient Partner Compensation and Reimbursement Policy – an important milestone in supporting equitable inclusion and greater diversity of participation in patient-oriented research.

Looking forward, we are excited about our emerging partnership with the Wabanaki-Labrador Indigenous Health Research Network and the opportunity to better understand and represent the priorities of Indigenous communities in the health research we support.

As we continue to invest and grow our pool of Patient Partners, MSSU looks forward to deeper engagement with the public to shape research questions having social license, and investigate them with the assistance of data platforms available to MSSU.

In the coming year, we will support Learning Health Systems (LHS) approaches that embed researchers within clinical environments through collaboration with Health PEI, Horizon Health Network, IWK Health Centre, Nova Scotia Health and the Vitalité Health Network. We will also seek partnerships with the Governments of New Brunswick, Nova Scotia and PEI that connect researchers with opportunities to support and inform health system policy.

We will also transform our existing scholarship programs into an Embedded Scientists Studentship program co-funded by local universities and provincial agencies and offered to trainees, MSSU Associates and Affiliate Scientists.

In closing, I would like to thank our health system partners, our dedicated staff and committed Patient Partners for their ongoing contributions to MSSU. Our path forward together will lead the development of patient-oriented research, to the benefit of the health and well-being of all Maritime Canadians.

Dr. David Anderson
Nominated Principal Investigator, MSSU



DIRECTOR'S MESSAGE TO COMMUNITY

This year the work environment has undergone significant changes – we learned how to care for one another from a distance, show up for work while staying at home and work together by staying apart. The MSSU team is extraordinary and adapted to these challenges with compassion, optimism and courage.

A significant focus over the past year has been the development of the Phase II business case.

Our consultations toward a new roadmap for MSSU have been a true collaboration, featuring engagement sessions across the Maritimes, joint planning with other SPOR-funded entities and ongoing guidance from working groups comprised of Patient Partners and other stakeholders.

We are grateful for the willingness of our community to engage with us on a renewed

vision for MSSU and thank the many researchers, policy-makers, clinicians and Patient Partners whose contributions have helped secure this important investment in patient-oriented research in our region.

In addition to the core components in our Phase II business plan, we are introducing a customer service focus and a performance-driven culture, working with key stakeholders to articulate an impact measurement framework for MSSU. This impact framework will help focus our effort and demonstrate how our services help enable researchers, partners, health authorities and governments across the Maritimes in their important work.

We will also concentrate on revitalizing our governance with a new model that provides for deeper Patient Partner involvement, and better

guidance to health research on Equity, Diversity and Inclusion perspectives on timely social issues related to Sex and Gender diversity, Black and Indigenous rights.

Service and Partnership remain key themes for MSSU going forward. Working with our partners and stakeholders, we will continually improve our virtual collaboration tools and communication processes for understanding regional priorities and engaging with the community.

MSSU is dedicated to creating environments that are conducive to patient-oriented research. Our path ahead offers opportunities for us to better serve patients, caregivers, families, policy makers and health care providers toward our common goal- better healthcare and the wellbeing of our Maritime communities and people.

Marina Hamilton
Director, MSSU

A woman with dark hair, wearing a white lab coat over a patterned top, is smiling and holding a tablet. She is standing in a server room with rows of server racks and glowing green lights in the background. The image is partially obscured by a green vertical bar on the left side.

DATA PLATFORM SERVICES

OUR DATA PLATFORMS SERVE RESEARCHERS AND POLICY-MAKERS

In a time of increasing tension between health care spending constraints and a rapidly expanding world of new therapies and technologies, access to high-quality data is crucial to support evidence-based decisions about how health-care should be delivered.

MSSU helps to accelerate that decision-making by providing researchers with efficient access to administrative health data in secure environments, effectively balancing the need for data with privacy considerations.

Our data platforms serve researchers and policy-makers

MSSU provides this access through three different data platforms. Each platform contains information collected from provincial administrative health databases, clinical databases, provider and patient registries, survey datasets and other sources.

Health Data Nova Scotia (HDNS)

This data repository is based in the Faculty of Medicine, Department of Community Health and Epidemiology at Dalhousie University.

The New Brunswick Institute for Data, Research and Training (NB-IRDT)

Established in early 2015 through the collaboration of different New Brunswick government departments, this data repository is administered by the University of New Brunswick.

PEI Secure Island Data Repository (SIDR)

Currently under development at the University of Prince Edward Island (UPEI), this secure facility will provide researchers timely access to administrative health data and, in the future, data from other government departments.

In five years of operation, the MSSU has expanded its data holdings to over

100
health, community and social services databases

MSSU works across these provincial data platforms to create and strengthen data-sharing partnerships in support of patient-oriented research. We are continuously expanding the breadth of research-quality data available by adding new data sources, linking existing data in new ways, and supporting responsible data stewardship and preservation.

Some of our recent data sharing agreements demonstrate that our data sharing partnerships are growing beyond basic medical information to include whole new areas of health-related data—such as social determinants. This is particularly true in New Brunswick, where NB-IRDT has achieved a great expansion of data holdings in its five years of operation, now with over 100 health, community and social services databases at its disposal.





PEI'S EMERGING DATA PLATFORM BENEFITS FROM INTERPROVINCIAL COLLABORATION

UPEI's Centre for Health and Community Research (CHCR) is devoted to advancing research, education and knowledge within the fields of health and community well-being. As part of that mandate, the CHCR serves as MSSU host institution in PEI.

In this capacity, the CHCR has been building the Secure Island Data Repository (SIDR) on the UPEI campus. Slated to begin operation in April 2021, SIDR will provide access to administrative health data and analysis for research and health service evaluation purposes in a secure, controlled environment.

Mary-Ann Standing, CHCR Research Project Manager and SIDR implementation lead, is excited about the possibilities. "I think we all stand to benefit from what the data tells us

and using that to drive where we go in terms of change with our health care system."

In the last year, the PEI site has been refining the data governance structure, operational procedures and security upgrades necessary to securely host PEI's first ever, province-wide health data platform.

SIDR's development has also benefited from the interprovincial approach of MSSU. The prior experiences of Nova Scotia and New Brunswick with privacy-by-design considerations have informed this important design principle of the SIDR Platform.

Privacy considerations have also included consultation with PEI's Indigenous communities to better understand the unique considerations that apply to Indigenous health data holdings.

The sharing of advice, documentation, resources and lessons learned have helped streamline the process in PEI, and we look forward to SIDR's 2021 debut.

EXPLORING THE ROLE OF COMMUNITY PHARMACISTS IN PRESCRIBING MEDICATIONS

For Nova Scotians without a family doctor or nurse practitioner, accessing prescription medication can be a challenge. In 2010, Nova Scotia introduced legislation that allowed pharmacists to prescribe medication in certain situations, providing more options for Nova Scotians needing a prescription.

Though pharmacists' scope of practice had expanded, a 2014 survey found that self-reported prescribing was not common among pharmacists in Nova Scotia. Pharmacists' scope of practice in relation to primary health care access became a priority health topic for discussion at an MSSU Nova Scotia Bridge Event in November 2018. Subsequently, a team including researchers, a Patient Partner, representatives from the NS Department of Health and Wellness (DHW), the Nova Scotia College of Pharmacists (NSCP) and the Pharmacy Association of Nova Scotia (PANS) was formed to help determine why.

Led by Dr. Jennifer Isenor and supported by the MSSU, the team is working to identify pharmacists in the provider registry at HDNS and link them to Nova Scotia's Drug Information System (DIS) to examine their prescribing activities and describe patients using these services. A survey of pharmacists prescribing in NS was also conducted as part of this study to better understand the types of prescribing taking place and the supports needed to improve the uptake of pharmacist prescribing.

This foundational work is informing further research by Drs. Emily Marshall and Jennifer Isenor to identify ways to support pharmacists in providing this important primary care service for more Nova Scotians.



A FULLER UNDERSTANDING OF OSTEOARTHRITIS

MSSU is working with Nova Scotia Health, researchers, and the Atlantic Partnership for Tomorrow's Health (PATH) to better understand the needs of people living with osteoarthritis.

Led by Dr. Cheryl Kozey and Dr. Rebecca Moyer, the Current Management and Health Care Quality for Patients with Knee and Hip Osteoarthritis project leverages existing PATH data on self-reported physical activity levels and pharmacological pain medication usage in people with osteoarthritis.

In 2019, MSSU working with Health Data Nova Scotia (HDNS) helped create data linkages to augment the PATH database with physician billing, hospitalization, and drug prescribing data drawn from administrative health data.

This combined dataset creates a richer picture of how individuals living with osteoarthritis consume health services and the quality of care provided. This work will help to increase understanding of how individual characteristics, physical activity, healthy lifestyles and pain medication use in people with osteoarthritis affect their overall health outcomes and progression of their osteoarthritis.

NEW BRUNSWICK COMBINES DATA IN NEW WAYS TO INVESTIGATE FRAILITY

The prevalence of frailty amongst the elderly in New Brunswick and its contributing factors are currently not well understood. Dr. Pam Jarrett and the NB Department of Health intends to change that with the Frailty Project- working together with the New Brunswick Nursing Home Association.

The Frailty Project links information about hospital admissions from the national Discharge Abstract Database (DAD) with data from resident health assessments at a chronic care facility in Saint John. This combined dataset is being examined to better understand the prevalence and distribution of frailty among older adults. The results will be used directly in the decision-making that impacts the health of New Brunswick seniors.

SUPPORTING RESEARCHERS

QUALITY RESEARCH DEPENDS ON EXPERT SUPPORT

MSSU is committed to working collaboratively with researchers to pursue patient-oriented research that addresses Maritime health priorities. We provide customized research support for projects at all phases of development.

Our methodological contributions often directly and quite literally pay off. MSSU support has enabled successful federal and provincial research grant applications amounting to over \$2.9 million in new funding in the 2019-20 fiscal year. We continue to work with government partners to improve processes in collaboration with policy-makers and health care professionals in order to address priority health system issues.



THE FOUR PRIMARY FUNCTIONS OF OUR RESEARCH SUPPORT UNIT

General methods support

- Survey design, programming and validation
- Research project management and logistical support
- Advice on ethics and administrative data access applications



Evidence synthesis

- Assistance conducting rapid, systematic reviews
- Refining research questions
- Developing and conducting search strategies
- Data management and extraction



Data analysis

- Guidance on research-quality approaches for the analysis of health administrative data and survey data
- Guidance on the use of appropriate methodologies and software
- Advice on preparing datasets for analysis, including validity and reliability measurement



Scientific review

- Ad-hoc peer review of manuscripts for journals
- Peer review of grant applications for local implementation science projects or other sources of funding
- Scientific protocol reviews of peer-reviewed journals manuscripts



SUPPORTING INFORMED DECISIONS IN THE FACE OF A NOVEL VIRUS

When COVID-19 began to spread across the Maritimes and the world, it was completely unprecedented. With this quickly spreading virus, our governments needed to make decisions and enact policies to contain and minimize its impact. Making quick, yet evidence-informed decisions in response to a novel virus is a formidable task. For help, the New Brunswick government reached out to MSSU.

The MSSU team at the New Brunswick Institute for Research, Data and Training (NB-IRDT) quickly set to work. The team mobilized to review literature, analyze trajectories in other areas, and compile the best available information as it developed. To determine the most probable outcomes, the team prepared predictions of potential infection rates based on regions with similar demographics and public health approaches.



“When the COVID crisis arose, MSSU and NB-IRDT provided essential research capacity that we could call on to support our clinical and system decision-making,” says René Boudreau, Assistant Deputy Minister, New Brunswick Department of Health. “Their experienced teams were able to deliver valuable literature syntheses and rapid reporting at a moment’s notice.”

As the pandemic progressed, NB-IRDT continued to provide research reports about the impact on health system resources, lifting restrictions, and implications of maintaining virtual health care methods after the pandemic has passed.

“There was a real need to gather and synthesize information to support decision-making in a situation that was developing rapidly. We had the capacity to serve this function and were able to

learn from other parts of world where the pandemic was more advanced,” says Dr. Ted McDonald, NB-IRDT Director and MSSU NB Principal Investigator.

This collaboration through the spring and summer of 2020 established strong relationships between the New Brunswick Department of Health, the NB-IRDT and MSSU staff who work there. NB-IRDT and MSSU will continue supporting our partners and government in responding to the pandemic and building stronger, resilient communities.



SUPPORTING HEALTH POLICY ON THE USE OF GENERAL PRACTITIONER ANESTHETISTS

In 2019, a national shortage of anesthetists left Nova Scotia with a number of vacant anesthetist positions which was impacting local wait times for elective surgery. Nova Scotia Health needed more information on supporting anesthesia services in Nova Scotia, and asked MSSU to conduct a rapid review of available evidence on non-specialist anesthesia providers. Our report was cited by Dr. Greg Hirsch, Medical Director Perioperative Services as a “valuable, neutral, and arms-length assessment of the current literature concerning safety of non-specialist anesthesia providers”.

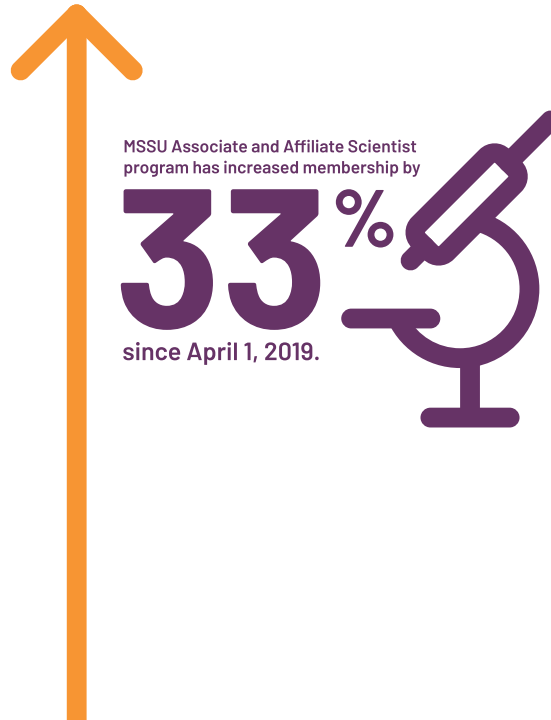
The evidence provided helped inform decision-makers and stakeholders about the potential for family practice anesthetists to play a meaningful role in addressing chronic anesthesia workforce shortages.



Meghan Rossi

NEW GRANTS SUPPORT A NEW GENERATION OF RESEARCHERS

A little support can make a big difference. In 2019, MSSU provided \$300,000 in student grants to 12 researchers at the Master and Doctoral levels. Meghan Rossi, a Doctoral Student in clinical psychology at Dalhousie University and grant recipient, says this funding has allowed her to further her research into the sexual well-being of women during fertility treatment. “The MSSU grant provided me with the support I needed to focus on my research and pursue training opportunities that help me continue learning and gaining skills as a researcher.” Grant recipients are also offered workshops on how to conduct patient-oriented research—which Meghan says provided her with new tools for engaging patients in the research process.



ASSOCIATED SCIENTIST PROGRAM SEES GROWTH IN MEMBERSHIP

Launched in 2018-2019, the MSSU Associate and Affiliated Scientists program remains an important way that we connect researchers across the region.

This program offers a forum for networking and knowledge-exchange with decision-makers and other Maritime researchers. Professional development pathways include opportunities to serve as scientific lead for MSSU Priority Projects in Nova Scotia, and the chance to help shape the future of MSSU by serving on committees. The benefits of membership also includes a fee reduction for MSSU data access services. With a 33% increase in membership in the last year, the Associated Scientist Program is a growing community of practice serving the Maritime research community.



PREPARING STUDENTS WITH STRONGER PRACTICAL RESEARCH SKILLS

The New Brunswick Institute for Research, Data and Training (NB-IRDT) knows that student researchers will be better equipped for future careers if they have real-world experience in extracting insight from data. By building skills that are in demand, students increase their marketability in the workplace and likelihood of finding meaningful work in New Brunswick.

With this in mind, NB-IRDT created the Pathways to Professions (PtP) program. PtP is a 13-week experiential learning program that provides post-secondary students with meaningful work experience, training and skills development. Students are matched with professional researchers to provide community-based organizations with relevant, data-informed evidence that can boost organizational productivity. While exposed to workplace dynamics and expectations, our students learn how to engage with stakeholders, outline and clarify research questions, choose a research methodology and variables, conduct data analysis, and hone presentation skills.

PtP 2020 was hosted remotely by NB-IRDT in partnership with the Atlantic Institute for Policy Research (AIPR) and Experiential Education at UNB, with participating students funded by FutureReadyNB and the New Brunswick Innovation Foundation. This had an additional benefit of allowing us to hire and engage with UNB students across Canada. Future challenges include scaling the program up and introducing more research streams while preserving the fidelity of the program itself.

WHO USES OUR SERVICES?



- Researchers / Academics
- Policy-makers
- Health Care Practitioners & Managers
- Other SPOR Funded Entities
- Students
- Health System / Care Professional Organizations
- Community / Municipal Organizations
- Patients / Consumers of Health System/Care

PATIENT ENGAGEMENT

ENSURING A PLACE FOR THE PATIENT'S VOICE

This year, MSSU introduced a Patient Partner Compensation and Reimbursement Policy that sets out procedures for compensating Patient Partners for their involvement in MSSU activities in all three Maritime Provinces.

The compensation provided under this new policy is a meaningful expression of appreciation for the important contributions that Patient Partners are making to MSSU and patient-oriented research across the Maritimes.

“Patient Partners are highly-valued members of our organization, and this policy is a recognition of their contributions to patient-oriented research, governance committees, and at conferences, trainings and meetings,” says Yvonne Hanson, MSSU Patient Engagement Coordinator.

Hanson led efforts to develop the policy, consulting with colleagues from SPOR SUPPORT Units across Canada and reviewing similar policies from other organizations that involve patients and the public in research. A committee was formed with equal representation from staff and Patient Partners, who played an important role in co-designing the policy.



Juanna Ricketts

“After attending the meeting with other Patient Partners, I realized that we all had the same mindset: it’s not about the money. Patients freely give their time, thoughts and experiences, while some others—for example, researchers, clinicians—are paid for their time. This policy and the compensation it provides is a show of respect and appreciation. It helps to even out imbalances around the table,” said Juanna Ricketts, a long-standing MSSU Patient Partner who helped develop the policy.

The policy will support broader engagement and open up opportunities for more people to be involved in research—for example people who are receiving income assistance, living on a fixed income or trying to balance other responsibilities. “As a caregiver to my mother, I’m grateful for this new policy, which helps offset costs associated with my participation in MSSU activities and provides me with the peace of mind to focus on the contributions that I can make,” adds Ricketts.



PATIENT PARTNERS CONNECT WITH SUCCESS

In 2017, more than 15,000 autistic adults aged 18 years and older lived in the Maritimes. The transition from adolescence to adulthood has far-reaching consequences for the autistic community. For those entering adulthood, medical, psychological, social and community needs are numerous and varied. This growing population frequently reports difficulties in connecting with care and support during this transitional period.

The CONNECT project (CONtiNuity of care and support for the autism spECTrum disorder) aimed to break down barriers and understand the needs and challenges faced by adults living with autism spectrum disorder.

Led by MSSU Research Associate Dr. Caroline Jose and Patricia George-Zwicker, Autistic activist and Patient Partner, the CONNECT project was MSSU's first patient co-led research project. Patricia comments on the importance of the CONNECT project survey noting that the more feedback received, the more we know and the more we can change things for autistic adults: "this survey is our opportunity to express ourselves and be heard."

Though the collaboration has now come to an end, Patient Partners made 2019-2020 a banner year for CONNECT. Patricia and two other autistic team partners, Louise Tardif and Aaron Bouma, helped share project findings among health and social service providers and the autistic community at national and international conferences, and co-produced two scientific articles using data and experiences from CONNECT.





SUPPORTING THE USE OF NEW KNOWLEDGE FOR BETTER CARE

The high cost of delivering quality healthcare is a global challenge. As interest in value-based healthcare—better using existing resources to provide quality care—has grown, so has interest in Learning Health Systems (LHSs).

CIHR defines a learning health system as an integrated health system in which progress in science and care culture align to generate new knowledge as an ongoing, natural by-product of the care experience. LHSs have been shown to improve health system performance and the MSSU is enthusiastic about this kind of evidence-based strategy, which is why we're working to ensure our current services align with an LHS approach. We are also engaging with our health system partners to explore how to provide support to them in implementing their LHS models.

HOW DO WE SHARE KNOWLEDGE?



HELPING TO BRING EVIDENCE TO INFORM HEALTH POLICY DECISIONS

The MSSU supports policy-makers by generating or providing evidence to inform policy decisions. The NS DHW sought to better understand issues around access and quality of health services, which resulted in a research project examining barriers and enablers to implementation of collaborative family practice teams. The MSSU was also asked to carry out research to better understand the reasons why Nova Scotians are using or not using the provincial 811 tele-health service. In New Brunswick, we are helping to evaluate a centralized process for the triage of new lung cancer referrals, and providing reports on important issues such as the impact of rural hospital closures and health service restructuring on hospital admissions. And in PEI, we helped guide program evaluation activities of Mobile Integrated Health (MIH) initiatives within the Home and Community Care sector.

FACILITATING COLLABORATION



FACILITATING COLLABORATION AND KNOWLEDGE SHARING

Collaboration is at the very heart of MSSU's work. By working closely with our partners, we can better facilitate the exchange of information. Because MSSU is not always the source of the data our partners need, we often act as a knowledge broker, connecting those holding specific types of information with those that need it.

Additionally, each site of MSSU has put great effort into establishing processes for serving policy-makers and healthcare professionals based on the individual provincial context and needs. With a focus on communication strategies, we're able to increase stakeholder awareness of emerging research and help ensure that knowledge users are partners throughout the research process.



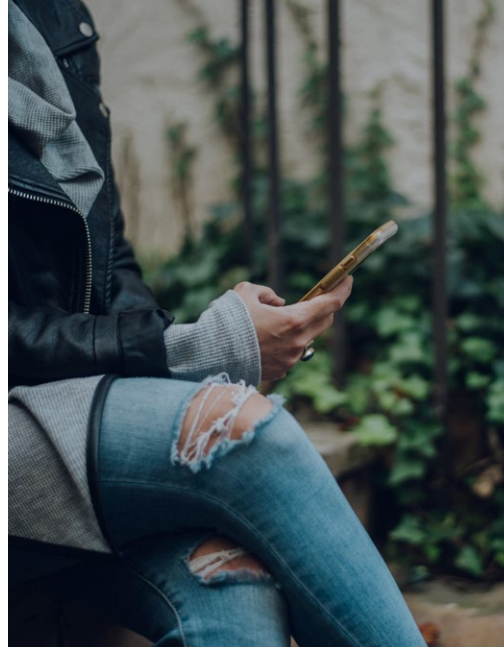
BRINGING TOGETHER NEW IDEAS FOR YOUTH MENTAL HEALTH

Across Canada, timely access to youth mental health services is a growing concern. When decision-makers, clinicians, researchers and Patient Partners came together in 2018 at an MSSU knowledge sharing event, access to these services was quickly identified as a priority health issue.

Arising from that event, the Nova Scotia Department of Health and Wellness, IWK Health Centre, and Nova Scotia Health subsequently formed a new collaborative led by Dr. Lori Wozney to examine how electronic health technologies might help youth living with mental health and addiction challenges (MHA).

UniCITY: Uniting to Connect Innovative Technology for Youth Mental Health and Addictions Services provides an opportunity for all stakeholders, including patients, to come together with people they may have not previously worked with—those within the MHA field.

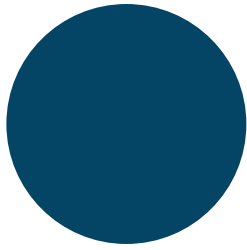
Due to these new connections, some team members went forward to develop a text messaging intervention for youth and parents that is currently being tested at the



IWK Health Centre. “This project helped to incubate and fuel some of these really early ideas and innovations provincially,” says Dr. Lori Wozney. “The review wasn’t something people would have prioritized in our routine work and without MSSU coordinating we wouldn’t have been able to achieve the pieces that are making these policy and research initiatives move ahead as embedded work.”

LISTENING TO INDIGENOUS VOICES AND PRIORITIES

MSSU has been working to create a meaningful pathway for Indigenous priorities to influence the governance and activities of MSSU. Last year, we were pleased to participate in the Wabanaki-Labrador Network Environment for Indigenous Health Research (NEIHR) Co-Learning Health Research Summit. Discussion at the summit involved the importance of respecting the oral transmission of knowledge, Indigenous languages, story exchanges and other Indigenous ways of knowing—to strengthen the research process and build lasting relationships with Indigenous communities. Looking forward, we are excited about our emerging partnership with the NEIHR Network and the opportunity to better represent Indigenous communities in the health research we support.



DETERMINING THE PRIORITIES OF MYELOMA RESEARCH—TOGETHER

Multiple myeloma, commonly referred to as myeloma, is a cancer that primarily affects the bone marrow, impairing blood production and causing bone and kidney damage. Although myeloma is considered incurable, researchers have developed innovative treatments that lead to longer remission and improved quality of life. However, more research is needed to understand this relatively rare illness.



Traditionally, research has been clinical in nature, with little investigation into the shared priorities of patients, caregivers and clinicians. The pharmaceutical and medical technology industries play key roles in developing and testing new treatments, but their priorities are often not the same as those of people living with myeloma. This can lead to a mismatch between the research being carried out and the research evidence needed.

To explore these issues, MSSU has partnered with the James Lind Alliance (JLA), a non-profit initiative specializing in priority-setting partnerships and Myeloma Canada, a registered non-profit organization.

In 2019, the project team launched a survey that gathered over 3,000 answers from almost 600 respondents. The goal was to create a “top 10 list” of patient priorities to guide future research. This

MSSU-supported project includes a national steering group of patients, caregivers and clinicians in which all members have an equal voice in the design and execution of the project. The results are currently being analyzed, and a second prioritization survey and workshop is being prepared.

The resulting priority list will be shared with research organizations through academic publications, people living with myeloma and the public through newsletters and social media. Our goal is to generate new knowledge that address the priorities of those directly affected by myeloma and improve the diagnosis, treatment and management of myeloma—ultimately enabling patients to live well with this disease.

HOW DO WE DELIVER TRAINING?

One of the ways that the MSSU supports researchers and partner organizations is by providing training opportunities on principles and best-practices in patient-oriented research



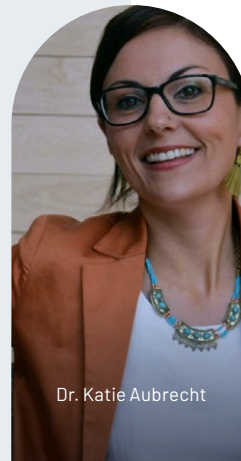
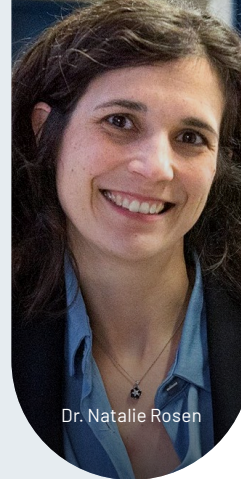
- Web-based Learning
- Participatory Workshop
- Lecture or Seminar
- Mentorship or Thesis Supervision
- Community of Practice

NEW EXPERTISE IN SEX AND GENDER BASED ANALYSIS AND EQUITY, DIVERSITY AND INCLUSION

This year, we welcomed two new Science Leads in the areas of Sex and Gender Based Analysis (SGBA+) and Equity, Diversity, and Inclusion (EDI). Dr. Katie Aubrecht, the new MSSU Science Lead for Equity, Diversity, and Inclusion (EDI), is a Canada Research Chair in Health Equity and Social Justice and Assistant Professor in the Department of Sociology at St. Francis Xavier University. Dr. Natalie Rosen, the new MSSU Science Lead for Sex and Gender-Based Analysis (SGBA+), is an Associate Professor in the Departments of Psychology and Neuroscience and Obstetrics and Gynaecology at Dalhousie University. We are pleased to have these accomplished thought leaders working with MSSU in building capacity and competency with Patient Partners and the wider health research community for pursuing research in these areas.

LEVERAGING THE SKILLS OF OUR PATIENT PARTNERS

Given that the majority of our work depends on the experiences, ideas and contributions of patients (“patient-oriented research”, or POR), MSSU decided to solicit feedback on this central topic. In the summer of 2019, we launched a Patient Partner survey to learn how we can better recruit new Patient Partners and improve their onboarding experience. In their responses, Patient Partners pointed to the importance of promoting the value and benefits of POR. Opportunities for improvement include better communication around the varied roles that Patient Partners can play in research, and the personal benefits of participating as a Patient Partner. This feedback has informed how we engage with patients going forward.



ONE MESSAGE TWO LANGUAGES

“Information access” is a foundational idea at MSSU—but that can be difficult when information is not provided in your language of communication. For this reason, we have been working hard to provide more MSSU products in both of Canada’s official languages. In the summer of 2019, we established new guidelines on the use of French and English in our communication to maximize participation and understanding. Our refreshed communication strategy is reflected in a new visual identity for MSSU—a simple belief that health-related research is about people. We are proud that the new MSSU Logo recently won a bronze award at the Summit Creative Awards, an international show for small marketing and design firms.

PARTNER ORGANIZATIONS



POST-SECONDARY INSTITUTIONS

- Acadia University
- Cape Breton University
- Dalhousie University
- Mount Allison University
- Mount Saint Vincent University
- New Brunswick Community College
- Nova Scotia Community College
- St. Francis Xavier University
- St. Mary's University
- Université de Moncton
- University of New Brunswick
- University of Prince Edward Island



GOVERNMENT

- New Brunswick Department of Health
- Nova Scotia Department of Health and Wellness
- PEI Department of Health and Wellness



RESEARCH ORGANIZATIONS

- New Brunswick Health Research Foundation
- Research Nova Scotia



HEALTH AUTHORITIES

- Health PEI
- Horizon Health Network
- IWK Health Centre
- Nova Scotia Health
- Vitalité Health Network



FINANCIAL SUMMARY

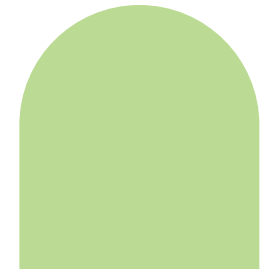
2019/2020 FISCAL YEAR

2019/20 ACTUAL (\$CDN)	
REVENUE	
CIHR	\$ 2,549,615
Provincial Partners	\$ 2,740,606
TOTAL REVENUE	\$ 5,290,221
EXPENSES	
Salaries	\$ 3,157,136
Studentships	\$ 669,450
Operations	\$ 442,784
TOTAL EXPENSES	\$ 4,269,370

Funding to MSSU supports the operation and evolution of our health research data platforms, research methods support to the research community and our role of bringing researchers, policy makers, health care providers and patients together to pursue research into health care issues important to the Maritimes.

MSSU is funded by CIHR with a 1:1 match with provincial funding partners. In fiscal year 2019-20, MSSU had a total operating budget of \$5.29 M. This was comprised of \$2.5 M from CIHR and \$2.7M in partner funding from several Maritime funding partners including New Brunswick Department of Health, the Nova Scotia Department of Health and Wellness, the Prince Edward Island Department of Health and Wellness, the New Brunswick Health Research Foundation (NBHRF) and Research NS.

CIHR and partner surpluses were carried forward as revenue for fiscal 2020/2021.





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