

SUMMARY REPORT

INTERPROVINCIAL BRIDGE EVENT

THURSDAY
JUNE 13, 2024



**MSSU
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Maritime SPOR SUPPORT Unit
Unité de soutien SRAP des Maritimes

www.mssu.ca

About our event

Supports and Services: Identifying the gaps for older adults with complex needs in the Maritimes



The Maritimes have the highest proportion of older adults per capita in Canada. Supporting the health and well-being of older adults requires individualized and often complex supports from many sectors.

Dr. Elaine Moody approached the Maritime SPOR SUPPORT Unit (MSSU) team in Nova Scotia about opportunities to involve stakeholders in identifying research priorities to help close the gaps in supports and services for older adults with complex needs in the Maritimes. This focus became the theme for the first MSSU Interprovincial Bridge Event held on June 13, 2024.

The gathering adapted the MSSU Bridge Event process, which started in 2018 as a way to engage Nova Scotian stakeholders to identify and conduct patient-oriented research focused on health system priorities. The Planning Committee developed the program and identified priority topics.

Together, participants aimed to:

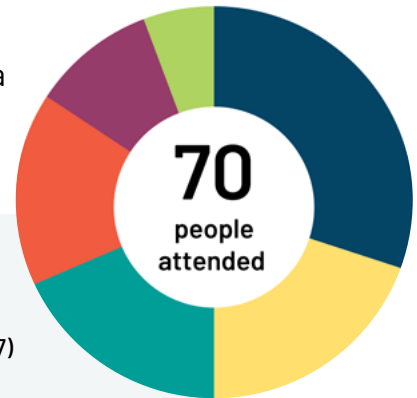
- **Share local practices and latest research** into improving access to or managing information about resources and supports for older adults with complex needs living in the Maritimes.
- **Create connections** with other stakeholders involved in designing programs, providing supports and services, and older adults and caregivers from across the Maritimes.
- **Identify emerging issues and priorities, and co-create research ideas** to drive innovative approaches to supporting seniors to age-well in their communities.

The highly interactive, full-day event included:

- Opening remarks about policy context
- A Patient/Public Partner panel discussion
- Short research presentations
- Facilitated group discussions on priority topics

Who participated?

The event brought together **70 participants** from Nova Scotia (52), New Brunswick (13), and Prince Edward Island (5). Most participants were women (66).



Participants' Roles:

- Researchers (21)
- MSSU Staff and Facilitators (14)
- Community Organization Representatives (13)
- Policy-makers (11)
- Health System Administrators (7)
- Patients and/or Caregivers (4)

Knowledge sharing

Opening remarks from government representatives

Government representatives from New Brunswick, Nova Scotia, and Prince Edward Island shared the policy context in each province, and outlined provincial priorities related to supports and services for older adults—highlighting many shared challenges across the region and opportunities to learn from one another.

Prince Edward Island

Christina Phillips, Director, Seniors Health, Department of Health and Wellness

Christina discussed the current challenges facing Atlantic Canada for older adults with complex needs, including changing population demographics, competing demands for resources, and continued pandemic recovery. PEI has developed the Seniors' Health Services Plan as a 5-year path to transform health and community-based services for older adults. The priority areas to focus on as next steps included:

- Continued investment in home-based services.
- Launch of a caregiver recognition benefit.
- Implementation of Long-Term Care (LTC) renewal projects including: a. legislative update to reflect new national standards, b. strengthened health human resources in LTC (including Nurse Practitioners and allied health professionals, as well as Infection Prevention and Control personnel), and c. implementation of the [interRAI tool](#) in public and private LTC homes.

New Brunswick

Mary Williams, Director of Home Care, Department of Health

Mary spoke about relevant priorities of both the Departments of Social Development and Health including those outlined in the [New Brunswick's provincial health plan](#). This plan contains policy actions to improve access to primary health care, surgery, and addictions and mental health services, and to enhance healthy system collaboration and support for older adults to age in place. She also discussed the [Healthy Seniors Pilot Project](#), co-funded by the Government of New Brunswick and the Public Health Agency of Canada, which encompasses a range of applied research initiatives examining how to better support older adults in their homes, communities, and care facilities. Several initiatives continue to evolve under these programs, including:

- The creation of [NB Health Link](#), a temporary medical home for all New Brunswickers unattached to a primary health care provider.
- The [Nursing Homes Without Walls](#) program, which facilitates healthy aging at home by providing access to essential knowledge, support, and services.
- Enhanced Clinical Services in Special Care Homes, where the New Brunswick Extra-Mural Program delivers an increased level of clinical support to special care home residents in New Brunswick to delay LTC placements and avoid hospitalizations.
- Mobile X-ray services where Diagnostic Imaging Technologists use mobile equipment to provide the service where people reside, such as LTC facilities.
- The Enhanced Community Pathway assesses older adults presenting to the Emergency Department at risk of hospitalization, and develops a care plan and implements supports to help these individuals to stay at home safely.

Nova Scotia

Kim Silver, Director of Home and Continuing Care, Department of Seniors and Long-Term Care

Kim discussed the current challenges facing Nova Scotia for older adults with complex needs, as well as the opportunities it presents to change the way we work together to support them. Nova Scotia has developed and expanded the Centre On Rural Aging and Health (CORAH) in partnership with Nova Scotia Community College (NSCC) to provide fitness and other learning and engagement opportunities led by and for older adults. The province has also increased investments in all aspects of publicly-funded home care—community nursing, agency home support and direct funding. After spending the past few years stabilizing the system after the pandemic, the focus is now on innovation in continuing care workforce planning, reducing barriers to access, and improving quality oversight and accountability of care providers and funded partnerships.

Patient/Public Partner panel



Lisa MacDougall, MSSU Patient Engagement Coordinator, facilitated a panel discussion with Patient/Public Partners Brian Irving (NB), Karen Irving (NB), and Donalda MacIsaac (NS). The panel shared their lived experiences as both patients and caregivers, highlighting the complex and varied health and personal challenges older adults and caregivers face.

- Key take-aways:**
- Issues facing older adults and caregivers are often invisible and complex. That's why engaging people with lived experience is so important.
 - Avoid assumptions—for example, many older adults are caregivers too!
 - Show up for the things that don't work—it's not just about filling gaps, we need to co-create connected systems of *care* that connect with and include home care.
 - Caregivers are a crucial and sometimes neglected piece of the puzzle.
 - Life keeps going—it doesn't just stop and wait while you are being a caregiver.
 - Caregivers' situations can be overwhelming and lead to burnout. Self-care is important—caregivers need support to rest and recharge.



Research snapshots

After the Patient/Public Partner panel, researchers presented on three projects focused on the meeting the needs of older adults in the Maritimes.

Mapping Dementia Supports in Community: From Assembly to Supported Decision Making

Dr. Katie Aubrecht

St. Francis Xavier University



Katie used the concept of ‘supported decision making’ to story three dementia care projects in Nova Scotia communities. Each story highlighted a tool or support that helps with decision-making. This included: 1. a collaborative, community owned and controlled interactive map that provides up-to-date, easy-to-use information about dementia-relevant resources, services and supports in NS; 2. the inclusion of someone who can assist with activating a frame (mental representations that reflect the worldview and lifeworld people with lived experience of dementia), as illustrated by a scoping review which used the Quadruple Aims and Health Equity for All to examine individualized funding for dementia; and, 3. a commitment to participatory parity (fairness) and intergenerational reciprocity, as illustrated by a case study that included interviews with caregivers, a review of caregiving welfare policies and programs, and an analysis of public and policy discourses on rural aging.

ACTing Collectively Project

Dr. Grace Warner

Dalhousie University



Grace shared how the ACTing Collectively project gathered data on the needs of, and available resources for, community-living older adults to support aging well in their communities. The project used a 56-question assessment developed by Age Care Technologies (ACT™), linked to a customizable online database, to systematically collect data on the care needs of 222 community-dwelling older adults (aged 65 and older) living in one of three municipalities in Cape Breton. Participants were relatively healthy, well-educated, mostly female, and half were from rural areas. The top concerns were bodily pain (72%), loneliness (49%), sleep (47%), and bereavement (44%). Interestingly, 20-72% of older adults identified a number of mental health concerns. Older adults’ concerns were linked with community resources through individual action plans. Summarized data on needs and resources were used to create community summaries for each municipality. Grace also shared insights from follow-up interviews with participants, and implications for policy and practice, including a need for resource mapping and navigation supports; working at the community level; supporting older adults and caregivers to plan for the future; and improved internet connectivity and digital literacy. Finally, the presentation highlighted the impact the project is having with key partners including Nova Scotia Health, NS Department of Seniors and Long-Term Care, Canadian Association for Retired Persons (CARP) NS, Northwood, and Dalhousie University.

Navigating Dementia NB

Dr. Alison Luke,

The Centre for Research in Integrated Care, University of New Brunswick



Alison presented on the Navigating Dementia NB/Naviguer la démence NB, a Healthy Seniors Pilot Project, that implemented and evaluated a patient navigation program for people with dementia, their care partners, and the care team. The program operated at six sites in New Brunswick from July 2022 to July 2023. To tailor the program to the needs of local communities, it was co-designed with researchers, patient partners, and representatives from Regional Health Authorities. Patient navigators (4 anglophone and 2 francophone) were embedded in primary care clinics/health centers in urban and rural settings. Alison presented the program structure, demographics of participants, and lessons learned from their mixed methods evaluation which collected data from patient navigator charts, satisfaction surveys, and semi-structured interviews. In all, 150 people participated in the program (56 completed satisfaction surveys). Participants indicated several reasons for contacting the program including connecting with social services and supports at home, receiving dementia-specific information and resources, advance care planning, community resources, and home health care. Overall, participants reported a high-level of satisfaction with the program (85%), highlighting several benefits including improving their knowledge of (78%) and access to (76%) health and/or social services and resources. Participants also recommended ways to improve the program (e.g. making it available sooner) and highlighted a need to address systemic barriers to accessing services (e.g. financial, wait-times). Findings suggest that patient navigation, embedded in existing primary care clinics/health centers, is a flexible model of care that is beneficial for both people with dementia and their care partners.

LEARN MORE

- [Spatializing Care Lab, St. Francis Xavier University](#)
- [Navigating Dementia NB](#)
- [ACTing Collectively Project](#)

Breakout groups

How they worked

The Planning Committee identified five topics for the breakout group discussions. Participants indicated their first and second choice topics when they registered for the event. To match as many participants as possible with a topic of their choosing, participants were pre-assigned to one of five breakout groups:

- Groups 1A and 1B: Navigation and awareness of supports
- Group 2/3: Two topics related to neurodegenerative illness
- Group 4: Built environment needs in community
- Group 5: Psychological needs of older adults and caregivers

Prior to the event, participants were sent brief background summaries on their assigned topic(s). These summaries highlighted key information about the topics from the literature, and served as a starting point for discussions.

Each breakout group discussion was led by an experienced facilitator, and focused on: 1. capturing what we already know about the topic; 2. identifying gaps and evidence needs; and, if time permitted, 3. co-developing potential directions for research.

The topic summaries below highlight key discussion points, the evidence gaps and potential directions for research. Several issues and themes were cross-cutting and discussed by more than one breakout group.



Group 1A: Navigation and awareness of supports



Evidence gaps

Caregiver training: Participants discussed how there are good resources for caregivers available through multiple organizations and through the health system, but these tend to focus on psychological supports (e.g., preventing burnout) and less on supporting the physical demands of caregiver that would prevent or reduce the likelihood of experiencing injuries. Many of the main areas to receive support are morbidity specific (e.g., ALS society), and there is a need for organizations like Caregivers Nova Scotia across the Maritimes.

Resources: There was also discussion around where to find out about existing resources, with 211 identified as a navigation mechanism available in all provinces. Although 211's processes may be thorough once you connect (e.g., screening process to identify needs, resources offered close to where caller lives), there was still felt to be a lack of awareness of 211 and how 211 can support access to resources. The importance of getting people access to the right information at the right time was emphasized with respect to both training and access to resources.

Hospital care: Person-centered care specifically in a hospital setting was discussed, where both the patient and family should be in the circle of care. Participants also discussed the need to personalize navigation based on factors relevant to patients, and to ensure that hospital-based navigation is linked to community supports. This would help people to get information when and where they need it.

An overarching theme was the need for continuity and government commitment to ensure that programs, supports, and services are sustainable and scaled-up as needed.

Potential directions for research

Although there were several potential directions for research identified, the group ended up centering on the idea that there are a lot of existing resources in place and the greater need is empowering patients to learn and access resources, tailoring information to patient needs. Creating better access and navigation to resources can be supported through a "Health Neighbourhood" where trusted sources (e.g., health care providers, neighbours, friends), community leaders, and key organizations (health system, community organizations) need to collaborate and share knowledge efficiently.

Group 1B: Navigation and awareness of supports

Evidence gaps

Fragmentation across systems: The group highlighted that there are many great Maritime resources and programs currently in place, but frequent duplication of effort limits effective progress. Better connection between the health care system and community organizations would enable the development of shared resources and services and promote a “one-stop shop” for services, which would enable patients to find the appropriate resources before their need reaches a crisis.

LTC challenges: LTC is often considered the worst thing that can happen to a person. These negative perceptions may stem from traumatic experiences, and it is difficult to change these perceptions even if the quality of care has improved. The process and wait-time for LTC services is challenging, with limited beds and staff to meet current and future needs among our aging population.

Attitudes and perceptions: The group discussed the gendered perceptions of caregiving and the failure to consider informal caregivers of older adults as part of their care team. Intergenerational research and programs that engage young people can be so valuable, but often can be hindered by ageism.

Potential directions for research

There is a need to examine the impact of integrating health system services and community supports to provide enhanced access to health and social care services for older adults. Specifically, there was interest in measuring the impact of integrating community and health system supports for access to services and care for older adults to maintain and/or improve quality of life, with a goal of enhancing cross-sector collaboration to reduce duplication of effort and improve efficiency in developing programs and services that provide access to community supports and health care services all in one place.



Group 2/3: Neurodegenerative illness

Evidence gaps

Markers of disease: There is a need to define markers of neurodegeneration that explore mechanisms of symptom presentation. Neurodegeneration occurs naturally as part of aging, yet only some people will experience symptoms of neurodegeneration. While we know there are some protective factors (diet, exercise, smoking/alcohol consumption), the mechanism for how this protects and slows progression is not well understood.

Diagnostic tools: There is a need to better understanding how to best implement diagnostic tools into routine care including expanding who can do these tests (e.g. allied health professionals) and who can refer patients to neurodegeneration specialists once symptoms occur. Diagnostic tools also have gaps in their use, and there was discussion around understanding where a person might score on these tests before signs and symptoms of neurodegeneration occur.

Early diagnosis: The systemic and personal barriers to diagnosis in the Maritimes were a key concern. There are gaps around how best to address known barriers such as access to specialists and lack of understanding of early signs of neurodegeneration. More work is needed to fully understand barriers to diagnosis, including what people with neurodegenerative illness want community members to know about neurodegeneration, and what they wish they would have known before their diagnosis.

Patient journeys: There is a need to better understand the patient experience through the stages of neurodegeneration, from diagnosis through to end-stage disease, and if experiences differ based on different factors (e.g. early or late diagnosis, rural vs. urban living). Mapping these journeys for patients in the Maritimes could help identify opportunities to improve, where resources were needed, and what helped patients and families cope along the way. Patient journeys need to be understood through the patients' and families' lenses to fully capture nuances of the disease.

Rehabilitation: For people diagnosed with neurodegenerative disease, rehabilitation can help mitigate effects and slow progression. Participants discussed whether rehabilitation approaches from Amyotrophic Lateral Sclerosis (ALS) research could be tailored to other neurodegenerative diseases, and how this could work from diagnosis through progressive stages. There is not enough knowledge on the experience of patients receiving rehabilitation for neurodegeneration, or what strategies patients want, depending on where they live.

Potential directions for research

Participants identified two overarching questions. The first centered on the potential to expand pathways to diagnosis. In particular, how can allied health care professionals help overcome barriers to diagnosis and help support earlier, timely diagnosis, and how can patients be empowered to recognize the signs and symptoms? The second question focused on 'bending the trajectory' by implementing a rehabilitation model to neurodegenerative therapeutics (e.g., physical rehab, pharma) in the Maritimes. Several aspects could be explored, including what happens after diagnosis, which rehabilitation models patients prefer, differences in rural context, and using rehabilitation to provide a more hopeful outlook after diagnosis.

Group 4: Built environment needs in community

Evidence gaps

Meeting care needs at home / in community: Improved strategies are needed to meet the needs of older adults at home and in the community to prevent deterioration in health. Discussions highlighted a navigational component and a need to better understand how needs are assessed (e.g., screening health status, frailty).

Understanding perspectives of older adults and caregivers: Older adults and their caregivers need to be engaged in research, service provision and evaluation. Gaps include the extent to which preferences of older adults are reflected in needs assessment; how loneliness impacts older adults; how changes in living arrangements impact identity; and cultural perspectives on aging (e.g., honouring Elders, multigenerational living). We need to better understand the needs of underserved communities and 'invisible older adults' (those with limited interactions with the system and/or social connections).

Building a broader understanding of 'built environment': Retrofitting older buildings is challenging, but safety at home is more than physical structures—it includes accessibility, technology, and other supports. There are many unanswered questions about accessible transportation, opportunities to cluster services into 'hubs' (e.g., Swedish cluster communities), purpose-built communities for specific populations (e.g., retirement communities, dementia villages), and the social dimensions of aging in place (e.g., what role older adults play in supporting each other to age well in their own communities). Participants also discussed social and ethical implications of technology-based supports (e.g., passive vs active technologies); transitions and connections between living in community and other settings; and the potential impacts of climate change.

Evaluation and sharing promising practices: Many challenges and potential solutions are shared across the region (e.g., navigation programs, investments in retrofitting, caregiver grants). Participants highlighted the need to move past pilot projects, support scaling up interventions, and define indicators for evaluation and create opportunities to learn from other jurisdictions (e.g., case studies, communities of practice).

Potential directions for research

The group explored an idea for a mixed methods project examining the challenges and strengths of people wanting to age in place. Involving older adults and caregivers on the research team, alongside non-profits and/or service providers is essential. Qualitative data could help investigate social aspects and learn about challenges / strengths from 'end user' perspectives. The group discussed opportunities to gather data (e.g., from navigators doing assessments, LTC admissions, home care assessments), as well as available quantitative data in different jurisdictions and what it really tells us (e.g., LTC admissions, level of activity, length of stay, wait-times). Available data could help to refine the focus. Findings could help to better understand the 'support context' by identifying areas where people are well supported or not (e.g., under-/over-subscribed services) and engage communities to understand why. This information could improve the overall match between available supports and communities.

Group 5: Meeting psychological needs

Evidence gaps

Limited caregiver support: Participants discussed the challenges faced by caregivers as their homes become workplaces, with limited control and inadequate support for their own well-being. Many caregivers are seniors themselves, and therefore have unique needs both as older adults and as caregivers. Caregiver psychological wellness is an invisible but foundational part of care and the need for caregivers to be recognized and supported in their essential role was established as an overarching theme.

Policy and system navigation challenges: The group discussed the challenges brought on by short-term funding and shifting responsibilities that hinder research and policy progress. Psychological needs of older adults and caregivers are complex and there is limited research to support effective policy change. Effective change requires early involvement of decision-makers and collaboration across organizations to optimize resource use and focus on client needs.

Turning research into action: Participants expressed great support for the need for research on caregiver needs and stressed the importance of research leading to actionable recommendations and pilot projects, with broad involvement from stakeholders to ensure successful implementation.

Potential directions for research

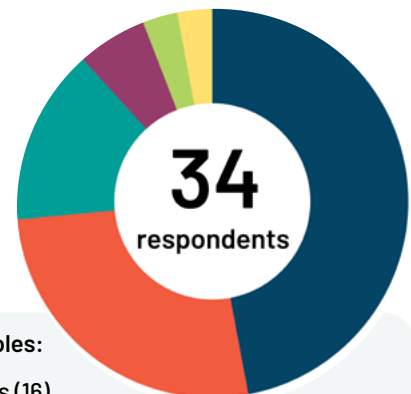
The group determined that the specific psychological needs of older adults and caregivers must be better understood in order to establish a foundation for this research focus. This knowledge can then support how to effectively use existing resources to address the psychological needs of caregivers and evaluate policies and programs through an equity and diversity lens.

Next steps

The Bridge Event was a unique opportunity to connect stakeholders from across the region. This interprovincial collaboration has the potential to spark new ideas and shared approaches to common challenges—none of which can be solved in a day. To build on that momentum, the MSSU is facilitating follow-up discussions with each breakout group to continue these conversations and explore opportunities to address evidence gaps. Our goal is to develop research questions that align various interests and expertise, in order to produce evidence that will inform government and health system policies and support initiatives that address community needs. Outputs from each discussion group will vary, but may include supporting an application for an MSSU Priority Project, supporting a grant application for external funding, or facilitating connections for ongoing work. Continued involvement and feedback from participants will be essential in driving these initiatives and ensuring the impact of our collaboration.

Evaluation at a glance

Nearly half of participants (49%) completed an event evaluation survey that gathered information about respondents (role, province, and breakout session topic), and their feedback on event organization and outcomes. The survey was completed by participants from all three Maritime provinces (NS 68%; NB 20%; PEI 12%) and representing all five breakout groups.



Organization

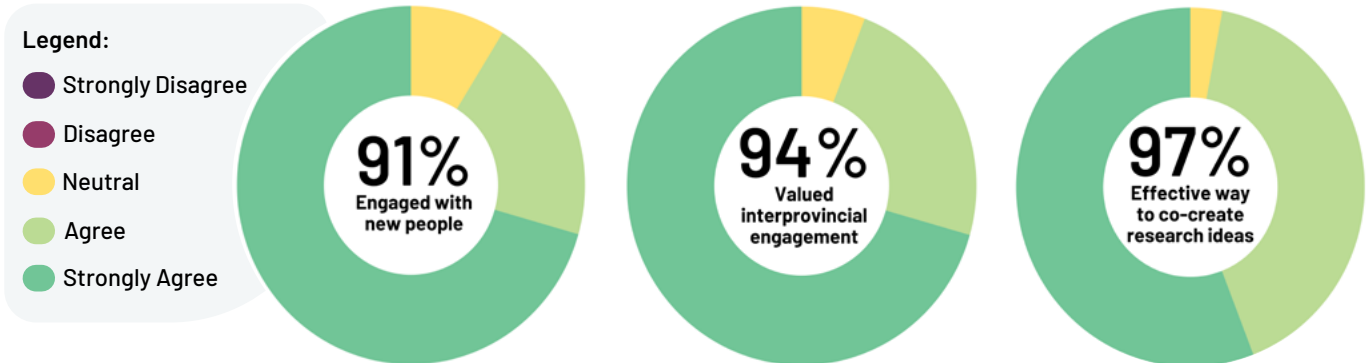
Most respondents (91%) were positive (strongly agree or agree) about the event organization. Suggestions for improvement included increasing the diversity of perspectives, a more narrow focus for breakout groups, and sharing facilitation questions beforehand.

Respondents' Roles:

- Researchers (16)
- Policy-makers (9)
- Community Organization Representatives (5)
- Health System Administrators (2)
- Patients and/or Caregivers (1)
- Other (1)

Outcomes

Respondents were positive about achieving the event objectives. The majority indicated a greater understanding of gaps and policy needs (79%) and their breakout group topics (94%).



Respondents also suggested several ways that they'll apply what they learned, including:

- Exploring new connections and collaborations
- Supporting policy and practice advocacy
- Developing research ideas, incl. seeking funding
- Informing policy work and planning

"...the change of environment and context around problem discussion and idea generation was the most fun for me because it changes the way you think about things and can take those new conversations and questions back to pollinate into your own environment." - Policy-maker, NS

"I learned about projects that may be relevant to my work, and also learned new names of people with whom we might be able to collaborate to achieve shared goals." - Health System Administrator, NB

With thanks...

The Planning Committee

- Dr. Elaine Moody, Associate Professor, Dalhousie University
- Diana Nichols Nelson, Chief Operating Officer, Brain Repair Centre
- Dr. Amy Grant, Director of Research, MSSU
- Elizabeth Lappin, Research Manager, MSSU
- Xavier Couture, Senior Program Advisor, Government of New Brunswick
- Rachel Giacomantonio, Knowledge Translation Coordinator, MSSU
- Brian Irving, Patient/Public Partner, MSSU
- Karen Irving, Patient/Public Partner, MSSU
- Claire Keenan, Research Assistant, MSSU
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- Heather McDougall, Research Coordinator, Dalhousie University
- Wendy McVeigh, Director, Community Transitions, Nova Scotia Health
- Shelley Strickland, Administrative Coordinator, MSSU
- Dr. Grace Warner, Professor, Dalhousie University

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