



COUNCIL OF ADVISORS - NB

Reported Findings



FEBRUARY 25, 2016 WU CONFERENCE CENTRE UNB FREDERICTON

KEY FINDINGS



Maritime SPOR SUPPORT Unit (MSSU) collaborates with the research communities in New Brunswick, Nova Scotia and Prince Edward Island on governance, priority setting, and the planning and conducting of health research. To inform future research priorities in the province, New Brunswick's Provincial Advisory Committee (PAC) engaged stakeholders on February 25, 2016 to gain insight into current barriers to and opportunities for research. The discussions focused on six broad themes; some were very broad and speak to operational and strategic areas of focus for the MSSU, whereas others were specific research questions that can directly incite collaboration with participants in the room and be generative of concrete evidence needs.

General Strategic Themes

Participants were interested in the MSSU's role in:

- **Knowledge Transfer and Translation:** Supporting transfer of valuable research knowledge to private/non-profit healthcare sectors, and from these groups to policy makers that directly impact patients.
- **Patient Voices and Engagement:** Fostering quality collaborations, tools and measures to best capture patients' perspectives and what matters most to them as users of the healthcare system.
- **Data Access:** Facilitating access for New Brunswick healthcare researchers to the New Brunswick Institute for Research, Data, and Training.

Specific Research Topics

Evidence was requested to answer the following research topics:

- **Long-Term Care in the Province:** The effect of more nursing home beds on reducing the large proportion of ALC patients; and whether community-based and/or family-based models of long-term care will lead to improved outcomes.
- **Access to Primary Health Care:** The impact of limitations to access primary health care on healthcare outcomes; the use of telemedicine in addressing barriers introduced by geography; and whether geography and travel are true barriers to accessing primary health care.
- **Models of Healthcare:** Developing and evaluating patient-directed models of care and models for orphan patients, and using patient success stories as evidence for new "made-in-New Brunswick" solution.

Next steps

The results from this event will be summarized and collated with information from similar NS and PEI events, so that the MSSU can establish Maritime-wide research priorities for the unit. Additionally, these results will be circulated back to the participants, with the goal of establishing new partnerships with interested stakeholders in New Brunswick's health research enterprise.

EXECUTIVE SUMMARY

Maritime SPOR SUPPORT Unit (MSSU) collaborates with the research communities in New Brunswick, Nova Scotia and Prince Edward Island on governance, priority setting, and the planning and conducting of health research. Within each province is a Provincial Advisory Committee (PAC), which is responsible for the oversight of MSSU goals and objectives, and for the establishment of a framework to prioritize, conduct, collaborate and report on patient-oriented research projects in each province. In New Brunswick, the PAC assists the NB Department of Health, and the two regional health authorities (Horizon and Vitalité) in providing context to study findings and in implementing health policy and health service changes.



MEETING OVERVIEW

To inform future research priorities in the province, New Brunswick's Provincial Advisory Committee (PAC) engaged stakeholders on February 25, 2016 to gain insight into current barriers to and opportunities for research. Twenty-four (24) stakeholders from 18 organizations participated in the workshop, representing a range of non-profit, academic and governmental bodies. An additional 2 participants were unable to attend but provided their opinions via electronic survey.

Following presentations from the MSSU, participants were first asked to independently note, in their view, the top 3 issues that affected patient outcomes and their ability to deliver on their respective mandates. These issues were shared within the discussion groups to develop an understanding of the commonalities and priorities across the province. Participants were

then asked to explore which of the broader issues required more data/evidence, in order to answer clinical questions, inform policy and practice, and influence patient outcomes. This included discussions of evidence currently available for each organization, and the gaps that need to be addressed in order to answer priority questions.

Discussion

The discussions focused on six themes; some were very broad and speak to broad operational and strategic areas of focus for the MSSU, whereas others were specific research questions that can directly incite collaboration with participants in the room and be generative of concrete evidence needs.

General Strategic Themes

Knowledge Transfer and Translation

Participants were interested in clearly understanding the role of the MSSU in New Brunswick's health research, and how the Unit could support transfer of valuable research knowledge to private/non-profit healthcare sectors (and from these groups to policy makers that directly impact patients). Can there be a forum for stakeholders to provide input into their evidence needs? The group also wondered how the MSSU could best leverage its internal expertise to support both novice and experienced clinicians, and what other services could be provided to better foster patient-oriented research in New Brunswick.

Patient Voices and Engagement

Participants recognized the importance of patients' perspectives in healthcare research, and were keen to learn more about incorporating patient-reported outcome measures into their own studies. They viewed the MSSU as a key driver of patient-oriented research and look to the Unit to foster quality collaborations and communicate best practices (e.g., tools and measures) in capturing the patient voice. It also became clear that the term "patient" may not capture the prevention and promotion side of health, nor the breadth of other individuals and groups who also have key perspectives to share, such as families, caregivers and employers.

Data Access

There was significant interest for stakeholders in the room to work with the MSSU to support comparative Maritime-wide and national research, with a particular focus on accessing the New Brunswick Institute for Research, Data, and Training. Specifically, it was important for them to have a better understanding of available and forthcoming datasets, and whether the MSSU could support research with private sector datasets (e.g., employer sickness data). It was also noted that some key data is not collected if not publicly funded, but should be.

Specific Research Topics

Long-Term Care in the Province

New Brunswick has a rapidly aging population; examining delivery of long-term care for seniors in the province is important from both policy and practice perspectives. Seniors placed into alternate levels of care (ALC) are a key population to examine, in particular the pathways that different patient groups take to an ALC designation, as well as their subsequent journeys into other care facilities, and the outcomes associated with these different pathways. Participants believed it would be valuable to evaluate community-based and/or family-based models of long-term care, and whether these would lead to improved outcomes. The lack of publicly available data on uninsured healthcare services was also discussed as a potentially rich source of evidence.

Access to Primary Health Care

Participants believed that there are issues with the current family physician as gatekeeper model. More evidence is needed relating to the impact of limitations to access primary health care (e.g., socioeconomic determinants of health, access to treatment, wait times, literacy) on healthcare outcomes, the use of telemedicine in addressing geographic barriers, and whether geography and travel truly challenges to access to primary health care. Generating a roadmap of potential healthcare resources for patients is an important KT opportunity for the MSSU.

Models of Healthcare

There were also conversations on how primary health care is currently delivered, and whether there are alternate, holistic models that would lead to improved healthcare outcomes – for example, developing and evaluating patient-directed models of care and new models for orphan patients.

Participants also cited the importance of using patient success stories as evidence for change – seeking out alternate but successful models in other areas and analyzing the key features to be replicated in a new, “made-in-New Brunswick” solution.

Next Steps

The results from this event will be summarized and collated with information from similar NS and PEI events, so that the MSSU can establish Maritime-wide research priorities for the unit. Additionally, these results will be circulated back to the participants, with the goal of establishing new partnerships with interested stakeholders in New Brunswick’s health research enterprise.

FULL REPORT

Maritime SPOR SUPPORT Unit (MSSU) engages with patients from across New Brunswick, Nova Scotia and PEI, and collaborates with the research community on governance, priority setting, and the planning and conducting of research. Through this collaboration, the MSSU contributes to an enhanced health system, engaged health research, and improved health outcomes, all the while reflecting the needs and values of Maritime patients.

Meeting Overview

The NB MSSU Council of Advisors meeting took place on February 25, 2016, at the University of New Brunswick in Fredericton. The aim of the meeting was to inform the NB MSSU PAC of its stakeholders' priorities for future health research initiatives in New Brunswick. By engaging in these discussions, the NB MSSU PAC would not only gain valuable insight into the barriers to and opportunities for healthcare research, but also would continue to establish valued partnerships with interested stakeholders in New Brunswick's health research enterprise.

Stakeholder Representation

Twenty-four (24) stakeholders from 18 organizations across the province participated in the workshop, representing a range of non-profit, academic and governmental bodies. An additional 2 participants were unable to attend the meeting but expressed interest in contributing; these opinions were gathered via an electronic survey distributed to potential participants following the meeting, and are incorporated in this report.

Activities

Following short presentations from Ted McDonald (NB Lead of the MSSU) and Dr. Tony Reiman (Chair of the NB MSSU PAC), Phil Leonard (health economist with MSSU) presented findings from the MSSU's demonstration project (Geographical Variation on Coronary Artery Bypass Surgery and Hip/Knee Replacement Surgeries) as an example of the type of potential research supported by the MSSU.

Participants were then organized into small discussion groups, with MSSU staff present at each table to assist in facilitating the discussions and acting as scribes. Facilitators from Knightsbridge-Robertson-Surette moderated the overall discussion and helped the participants generate high-level summaries of the conversations. Participants were first asked to independently note, in their view, the top 3 issues that affected patient outcomes and their ability to deliver on their respective mandates. These issues were shared within the discussion groups to develop an understanding of the commonalities and priorities across the province.

After the MSSU staff and facilitators synthesized these issues for the groups, the participants were then asked to explore which of the broader issues required more data/evidence, in order to answer clinical questions, inform policy and practice, and influence patient outcomes. This included discussions of evidence currently available for each organization, and the gaps that need to be addressed in order to answer priority questions. Evidence needs were again shared with the larger group.

The day ended with communication of next steps and how MSSU would report and use of stakeholders' input moving forward.

DISCUSSION

The discussions focused on six broad themes; some were very broad and speak to broad operational and strategic areas of focus for the MSSU, whereas others were specific research questions that can directly incite collaboration with participants in the room and be generative of concrete evidence needs:

GENERAL STRATEGIC THEMES

- Putting data into action
- Get better access to data
- Focus on patient experience to better inform policy and practice
- Managing patient/public expectations

SPECIFIC RESEARCH TOPICS

- Develop working partnerships
- Organization and Coordination of care
- Manage known demographics
- Appropriateness of care

GENERAL STRATEGIC THEMES

Knowledge Transfer and Translation

For the attendees, knowledge transfer and translation was broader in scope than simply disseminating research findings; the participants took it to mean the bidirectional flow of evidence between knowledge users and policy makers. There were numerous concerns from representatives of private/non-profit healthcare sectors, who are frequently access points for patients (e.g., dentists, pharmacists, optometrists), but where they are outside of the publicly funded system, information on these interactions may not be captured and included in decision-making and policy development/evaluation.

- Can the MSSU support transfer of valuable research knowledge from studies to these groups, and from these groups to the policy makers that directly impact what is then provided to their shared patients?
- How can the Unit effectively incorporate more private sector and non-profit organizations in its knowledge translation practices?

Many of the participants noted that their attendance, in part, was to better understand the MSSU and its role as a member of the New Brunswick health research landscape. Participants wanted to have more resources on MSSU: its' mandate, what the Unit can and cannot do for researchers, and what research questions were "worthy" of MSSU resource allocation. As a key barrier to research is the lack of a research culture within the healthcare sector, it will be important for MSSU to clearly define its role in supporting clinician researchers. There is no dedicated research time under the provincial Medicare system, and as such clinicians rely on their off-hours to conduct research activities.

- While recognizing that the MSSU cannot be all things to all groups, how can the Unit best leverage its internal expertise to support both novice and experienced clinicians keen to conduct research but who lack the resources to do so?
- What other services could the Unit provide to better foster patient-oriented research in New Brunswick (e.g., linkages to funding opportunities for patient-oriented research)?

Participants also noted the need for a forum to provide input into their evidence needs. Relating to this are the opportunities to develop: an inventory outlining the current gaps in the provincial research landscape; stronger collaborations with stakeholders to ensure "pain points" can be communicated to the Unit (so that the voices of smaller groups – "not cancer and not cardiac" – can be heard equally); and, a clear understanding of how MSSU will liaise with its stakeholders and prioritize incoming requests for evidence. It was also recognized that opportunities to collaborate with the MSSU do not have to be large-scale projects, but that there are many opportunities to engage and partner with groups on smaller pilots.

Patient Voices and Engagement

Participants recognized the importance of the patient perspective in healthcare research and were interested in understanding how their own research can become more patient-oriented. How can the MSSU foster quality collaborations, tools and measures to best capture the patient perspective and what matters most to them as users of the healthcare system? There was particular interest in best practices associated with the use of patient-reported outcome measures, a rapidly developing methodology in healthcare research.

As discussions evolved throughout the day, though, it was clear that the term “patient” may be disempowering for individuals, focusing exclusively on illness and not on health prevention and promotion. Further, patient may be too narrow a term, not reflecting the breadth of individuals and groups who equally have critical voices on the healthcare system and its impacts, such as families, caregivers, and employers.

Data Access

The New Brunswick Institute for Research, Data and Training (NB-IRDT) was recently opened in May 2015 by the provincial government, and provides researchers access to anonymized but linkable administrative datasets. Currently the Institute holds hospital discharge abstracts, information on citizens registered under Medicare and on the healthcare providers billing under Medicare, and vital statistics, with many more still in development.

Not surprising, then, there was and is great interest in the ability for New Brunswick healthcare researchers to work with the MSSU to access the Institute and integrate such data into their research studies. To foster stronger collaborations with researchers in the province, participants believed it is essential to know what data is available and what data is forthcoming to the Institute, and what data can be shared with which partners. Also, participants were interested in knowing how the MSSU could support the access, development and use of private sector datasets (e.g., employer sickness/absence data). It was also noted that some key data is not collected if not publicly funded (e.g., medication review at discharge from hospital, dental health on nursing home admission), so there are opportunities to collect new data to inform the research landscape in the province. Finally, having the ability to conduct comparative Maritime-wide and national research is important to researchers, to understand similarities and differences across provinces.

SPECIFIC RESEARCH TOPICS

Long-Term Care in the Province

With the oldest provincial population in Canada¹, examining the delivery of long-term care for New Brunswick seniors' is critical. Participants identified two broad research opportunities around alternate levels of care and healthcare options for seniors, and the current lack of data and research on uninsured health services.

Seniors placed into alternate levels of care (ALC) – when a patient is residing in an acute care facility but no longer requires such intensity of healthcare service delivery² – are a key population to examine. It would be helpful for participants to have evidence of the different pathways that patients take to an ALC designation, as well as their subsequent journeys into nursing and special care homes, and the outcomes associated with these different pathways (e.g., do those patients who arrive in nursing homes via hospitalization have poorer health outcomes?) With such research, one can then examine such policy questions as:

- Will the ALC issue be resolved simply with adding more nursing home beds, or will other solutions be key to also develop? (E.g., would a daily medication review for seniors positively impact hospital admissions?)
- Would a community-based and/or family-based model of long-term care instead lead to improved outcomes – and what would this model look like?
- What is effective family mental health care and its role in seniors' health? Nursing homes currently and informally provide it. Participants also discussed the lack of publicly available data on uninsured healthcare services, such as dentistry, pharmacy and optometry. These areas may serve as important indicators of other health outcomes, but this information is only held currently in private practice databases.

- How can MSSU help support interested researchers in the province in studying all aspects of individuals' health-care, and not just those components available through public sector data holdings?

Access to Primary Health Care

Primary health care in New Brunswick is currently provided through a family physician as gatekeeper model, whereby patients access their family doctor before having access to other service providers available through Medicare. New Brunswick is also unique in that it has a fairly significant population that would be defined as rural, as well as a large number still without a primary care provider – still seeking out care from emergency rooms and/or after hours clinics. Participants believed that there are issues with the current family physician model, and believed that a number of potential research questions were key to evaluating current models and informing potential policy and practice change:

- How do limitations to access to care (e.g., socioeconomic determinants of health, access to treatment, wait times, literacy) impact healthcare outcomes?
- Can the use of telemedicine address barriers introduced by rurality/geography, and thus lower healthcare costs? Are geography and travel truly challenges to access to primary health care?

Participants also recognized that patients' knowledge and healthcare choices will play a key role in any primary care research and remodeling of the system that may result. Generating a roadmap of potential healthcare resources for patients is an important knowledge translation opportunity in the province as well as in understanding access to primary healthcare.

As well, it was discussed that existing data should be captured in an inventory, so that researchers can be aware of what data currently exists to inform research on primary healthcare, and what new data needs to be generated. More cross-jurisdictional data, and the ability to conduct such research, is required. Electronic medical records are also key to future studies. Also, as mentioned earlier, data on uninsured health services is important. Also important are other places where individuals seek support, such as after-hours clinics. What are the practical research questions that need to be asked? Benchmarks to measure success should also be measured – how will we know when we have done better?

Models of Healthcare

Related to the discussion on access to primary health care were conversations about how that care is currently delivered, and whether there are alternate models that would lead to improved healthcare outcomes for patients. It was believed that primary care physicians are increasingly performing tasks outside of their scope of practice out of necessity (e.g., mental health care, links to social services). This highlights the need for more holistic solutions and recognizes that there are many healthcare professionals that provide primary healthcare and whom should be incorporated into a patient's routine care. Would other models of primary healthcare (e.g., family health teams, advanced care paramedics, health coaches) improve healthcare outcomes?

Ultimately, three themes emerged from the discussions with participants. First, participants discussed the concept of patient-directed models of care, in which the patient assumes a greater proportion of responsibility for their successful healthcare. Is it possible to have an effective and efficient system in which primary health care is customized to patients' individual and family needs and is respectful of community/cultural differences – and if so, how? Evidence for more tailored healthcare delivery could be generated through comparative research on existing standard of care versus newer models, and the associated clinical and economic impacts of each.

Participants also cited the importance of using patient success stories as evidence for change – seeking out alternate but successful models in other areas and analyzing the key features to be replicated in a new, “made-in-New Brunswick” solution. As well, it is key to generate more research into models of care for orphan patients (i.e., those patients without a primary healthcare provider) and on their healthcare outcomes. Where are different models working successfully, and can they be adapted for the patients of New Brunswick? What are the contributing factors leading to their lack of care?

MOVING FORWARD

Overall, the event was successful in both understanding new potential research topics and evidence needs, and in creating new partnerships with stakeholders. The results from this event will be summarized and collated with information from similar NS and PEI events, so that the MSSU can establish Maritime-wide research priorities for the unit. Additionally, these results will be circulated back to the participants, with the goal of establishing new partnerships with interested stakeholders in New Brunswick's health research enterprise.

REFERENCES

1. Statistics Canada. (2015, Sept.) Canada's population estimates: Age and sex, July 1, 2015. Retrieved March 7, 2016: <http://www.statcan.gc.ca/daily-quotidien/150929/dq150929b-eng.htm>
2. Canadian Institutes of Health Information (2012, Nov). Seniors and Alternate Level of Care: Building on Our Knowledge. Retrieved March 7, 2016: https://secure.cihi.ca/free_products/ALC_AIB_EN.pdf

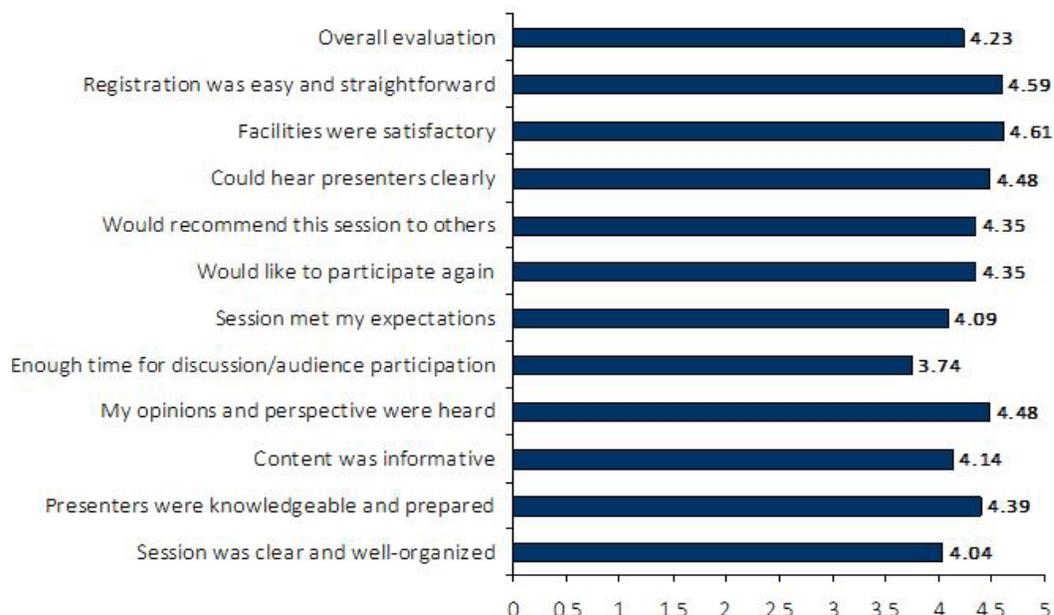
APPENDIX A

Stakeholder Representation at the NB Council of Advisors

Non- Profit Organizations	Canadian Cancer society Heart & Stroke Foundation
Health Authorities	Reseau de Santé Vitalité (Planning and Decision Support) Horizon Health Network (Research Services; Stan Cassidy Centre for Rehabilitation)
Health Facilities	Shannex NB York Care Centre
Private Professional Organizations	NB Association of Nursing Homes Nurses Association of NB NB Dental Society NB Pharmacists' Association Inc.
Research Networks	Social Policy Research Network NB SPOR on Primary and Integrated Community Health Care Network
Academic	St. Thomas University (Dept. of Sociology) University of New Brunswick (Faculty of Science, Applied Science and Engineering; Institute of Biomedical Engineering)
Medical Schools	Centre de Formation Médicale Nouveau-Brunswick Dalhousie Medicine New Brunswick
Gouvernement	Canadian Agencies for Drugs and Technologies (CADTH) Government of New Brunswick – Dept. of Health (Child and Yout-Services; NB Cancer Network)

APPENDIX B

Participant Feedback



What did you like about the session?

- Helpful, opportunity to hear from people
- Diversity of participants (2)
- Structure was good
- Topics were appropriate
- Great venue to exchange information and learn from others (7)
- Shared concerns (validated) (2)
- Networking (6)

What would you improve about this session?

- Didn't like Vitalite participants being at one table, felt excluded
- Clearer questions linked to area of influence. Began too broad.
- More time (7)
- More opportunity for large group discussion
- Some did not speak loud enough. Difficult to hear
- Clearer outline in advance

What did you learn and how will you use this information in your work, research, or education?

- Pursue opportunities for research
- Made useful contacts will use them to work on shared issues

- May be ways to get at data we thought was inaccessible
- Help set direction of MSSU
- Got a sense of pervading issue
- Learned how to access REB outside university
- Work happening at RHA and opportunities to collaborate
- Expanded my network
- I will be providing a report of the session to management
- Learned about MSSU and its role/objective (2)
- Will link for information purposes
- Better understanding of resources of MSSU and use in building teams

Please provide any general comments

- Well organized!
- Good session (5)
- Suggest follow up session
- Communication between MSSU and other networks needs to be improved
- Bilingual organization/groupings would have been appreciated
- Impressed with the work of MSSU



MARCH 2016