MSSU - USSM
MARITIME SPOR SUPPORT UNIT
UNITÉ DE SOUTIEN SRAP DES MARITIMES

COUNCIL OF ADVISORS - NS

Reported Findings




Strategy for Patient-Oriented Research | Stratégie de recherche axée sur le patient

SPOR SRAP

Putting Patients First | Le patient d'abord

JANUARY 29. 2016 ATLANTICA HOTEL HALIFAX

KEY FINDINGS

KEY MESSAGES

The Maritime SPOR SUPPORT Unit (MSSU) Provincial Advisory Committee's (PAC) role is to guide MSSU subject areas for patient oriented research, and assist the Department of Health and Wellness and the District Health Authorities in contextualizing study findings and implementing health policy and health service changes. The inaugural Council of Advisors stakeholder engagement events are the first opportunity for health stakeholders in the Maritimes to contribute to the priority setting process for the Provincial Advisory Committee.

The issues

Access to Care: Ability of patients and caregivers to access and coordinate health services
Industry Partnerships: Coordinating efforts among providers so as to not duplicate efforts
Data and Knowledge Translation: Obtaining meaningful data and information for decision-making
Strategic Direction: Manage public expectations with a focus on prevention
Resource Planning: Reallocation of resources with a focus on appropriateness of care
Engaging Patients: Empower patients to engage and incorporate in decision-making

Evidence needed

Operationalizing Information: Better use of locally driven, geographic-based data
Organization and Appropriateness of Care: Who has access to primary care and who doesn't?
Patient Voice and Patient Outcomes: Need better outcomes data that reflects patient values and preferences
Priority Setting and Resource Allocation: Culture change is required for a change in public expectations of healthcare system

Next steps

This process will continue in the Provinces of New Brunswick and Prince Edward Island in the winter of 2016. Each Province will use their own locally-driven engagement sessions to inform the prioritization process of their PAC. A final report will combine all three engagement sessions to inform future Maritime-wide projects that will have the greatest impact for the Maritimes as a region.

EXECUTIVE SUMMARY

The Maritime SPOR SUPPORT Unit (MSSU) is dedicated to supporting patient-oriented research and health services decision-making in the Maritime Provinces of New Brunswick, Nova Scotia, and Prince Edward Island. The MSSU's Provincial Advisory Committee (PAC) is comprised of senior representatives from the Department of Health and Wellness, Health Authorities, Health Research Foundation and patient advisors. The PAC's role is to guide MSSU subject areas for patient oriented research, and assist the Department of Health and Wellness and the District Health Authorities in contextualizing study findings and implementing health policy and health service changes.

Meeting Overview

The inaugural Council of Advisors stakeholder engagement events are the first opportunity for health stakeholders in the Maritimes to contribute to the priority setting process for the PAC. Each of the Maritime Provinces holds engagement sessions in their communities to inform the Provincial Advisory Committees of local issues and opportunities in delivering high-quality and accessible health services to their populations. The first Nova Scotia Council of Advisors session took place on January 29th, 2016, in Halifax, Nova Scotia. The principle objectives of the Council of Advisors engagement session is to gain an understanding of the common issues health stakeholders have in delivering their mandate and what evidence is required to address these issues. The event included members of the MSSU's Nova Scotia Provincial Advisory Committee and invitations to representatives from a variety of healthcare organizations and departments in Nova Scotia.

The first round of facilitated table discussions were meant to explore the common issues each organization is working to overcome in delivering their mandate. The principle question in this exercise was, "What keeps you up at night?" The most common issues from the discussions at each of the tables were identified, and a second round of discussions explored those issues in greater detail with a focus on the evidence and data required to address them. The question to the stakeholders in this exercise was, "How can we fill these evidence gaps?"

Discussion

1. WHAT KEEPS YOU UP AT NIGHT?

The following themes were identified and discussed by the table discussions:

Access to Care: ability of patients and caregivers to access and coordinate health services
Industry Partnerships: coordinating efforts among providers and not duplicating efforts
Data and Knowledge Translation: getting meaningful data and information for decision-making
Strategic Direction: manage public expectations and with a focus on prevention
Resource Planning: reallocation of resources with a focus on appropriateness of care
Engaging Patients: empower patients to engage and incorporate in decision-making

2. HOW CAN WE FILL THESE EVIDENCE GAPS?

The following themes were synthesized from the previous discussions and each table was assigned a theme to discuss in more detail. Discussion flowed in different directions at the tables and is summarized by the following:

Operationalizing Information

- Better use of locally driven, geographic-based data
- What data/information is out there and available to use? What is not?
- Need for consistent definitions and methodologies in data collection and analysis

Organization and Appropriateness of Care

- Who has access to primary care and who doesn't?
- Patients require one 'lead' caregiver
- Clinical Best practice guidelines – info and data on use and audit

Patient Voice and Patient Outcomes

- Need better outcomes data that reflects patient values and preferences
- Patient education required for system navigation, expectations, and health information
- Must include patients in decision-making and priority setting

Priority Setting and Resource Allocation

- Must involve patients in decision making using the most effective and appropriate methods
- Culture change is required for a change in public expectations of healthcare system

Moving Forward

The results from the Nova Scotia Council of Advisors engagement sessions will be used to inform the Nova Scotia PAC. The PAC will look to move some of these suggestions into action by establishing research and knowledge translation projects in order to address some of the common challenges the stakeholders face.

This process will continue in the Provinces of New Brunswick and Prince Edward Island in the winter of 2016. Each Province will use their own locally-driven engagement sessions to inform the prioritization process of their PAC. A final report will combine all three engagement sessions to inform future Maritime-wide projects that will have the greatest impact for the Maritimes as a region.

FULL REPORT

INTRODUCTION

The Strategy for Patient Oriented Research (SPOR) is a Canadian Institutes of Health Research (CIHR) initiative, focused on more effectively integrating research into care. One of the critical elements that will help achieve the vision for SPOR is local SUPPORT Units. A SUPPORT Unit is a provincial/regional centre designed to support those engaged in patient-oriented research. The acronym SUPPORT stands for Support for People and Patient-Oriented Research and Trials.

The Maritime SPOR SUPPORT Unit (MSSU) is dedicated to supporting patient-oriented research and health services decision-making in the Maritime Provinces of New Brunswick, Nova Scotia, and Prince Edward Island. The MSSU engages with patients and stakeholders from across the Maritimes and collaborates with the research community on governance, priority setting, and the planning and conducting of research. Through this collaboration, we contribute to an enhanced health system, engaged health research, and improved health outcomes.

The MSSU's Provincial Advisory Committee (PAC) is comprised of senior representatives from the Department of Health and Wellness, Health Authorities, Health Research Foundation and patient advisors. The PAC's role is to guide MSSU subject areas for patient oriented research, and assist the Department of Health and Wellness and the District Health Authorities in contextualizing study findings and implementing health policy and health service changes. The PAC pairs research projects in accordance with provincial health priorities. These annual projects are some of MSSU's primary deliverables.

MEETING OVERVIEW

The inaugural Council of Advisors stakeholder engagement events are the first opportunity for health stakeholders in the Maritimes to contribute to the priority setting process for the Provincial Advisory Committee. Each of the Maritime Provinces holds engagement sessions in their communities to inform the Provincial Advisory Committees of local issues and opportunities in delivering high-quality and accessible health services to their populations. The principle objectives of the Council of Advisors engagement session are to gain an understanding of the common issues health stakeholders have in delivering their mandate and what evidence is required to address these issues. The event included members of the MSSU's Nova Scotia Provincial Advisory Committee and invitations to representatives from a variety of healthcare organizations and departments in Nova Scotia. For a full list of the events participants, please see **Appendix A**.

The first Nova Scotia Council of Advisors session took place on January 29th, 2016, in Halifax, Nova Scotia.

FIRST EXERCISE

The first exercise was intended to explore and generate discussion on common issues each organization is experiencing. Participants were divided into small tables for a brainstorming exercise. The description for the exercise was as follows:

- *What keeps you up at night?* In the context of the DHW priorities, discover the issues Nova Scotia organizations are working to overcome to deliver high quality, accessible health services to their populations.
- *What issues affect patient outcomes?* After discussions at the tables concluded, participants shared their findings with the group and summarized their primary findings and common issues into theme groupings. While participants gathered for lunch facilitators worked with MSSU staff to compile the most commonly identified issues into groupings to inform the second session.

SECOND EXERCISE

Each table was provided one of the theme groupings to lead a more detailed discussion about the evidence required to address the issues. Specifically, what about this issue requires more evidence in order to address it, and what evidence is already available among the stakeholders? Another round of small table discussions was initiated with facilitators and recorders. The description for the exercise was as follows:

- *How can we fill these evidence gaps?* Explore which of these issues require more evidence/data and what form that evidence should take. After the table discussions, participants shared their findings with the group and summarized their discussions of evidence as it relates to the issue at their table.

DISCUSSION

WHAT KEEPS YOU UP AT NIGHT?

The following themes were identified and discussed by the table discussions:
Access to Care – ability of patients and caregivers to access and coordinate health services.
Industry Partnerships – coordinating efforts among providers and not duplicating efforts.
Data and Knowledge Translation – getting meaningful data and information for decision-making.
Strategic Direction – manage public expectations and with a focus on prevention.
Resource Planning – reallocation of resources with a focus on appropriateness of care.
Engaging Patients – empower patients to engage and incorporate in decision-making.

For a more detailed list of the themes, please see **Appendix B.**

Upon further discussion of all of the listed themes, the following issues identified as being the most relevant to the MSSU mandate:

- Putting data into action
- Better access to data
- Focus on patient experience to better inform policy and practice
- Managing patient/public expectations
- Develop working partnerships
- Organization and Coordination of care
- Manage known demographics
- Appropriateness of care

HOW CAN WE ADDRESS THESE EVIDENCE GAPS?

The earlier feedback was distilled into four broad objectives. In the second part of the session, each table was assigned one of these objectives to discuss in greater detail.

OPERATIONALIZING INFORMATION

WHAT EVIDENCE IS NEEDED?

- Relate with other indicators to make data richer
  - How do we use it to tell the story?
- How do different systems interact?
- Need more data at a level of geography
  - More Granular and relevant information
  - People are attached to local level context
  - Community level data is crucial
- Linked patient records from all service providers.
- Patient Outcomes
  - New research areas
  - Requires methods development

WHAT EVIDENCE EXISTS?

- Small Area Rate Variation (SARV) – materialized and social deprivation – tell a story by layering information
- Social Deprivation data
- Access mental health data
- Non-Governmental Organizations have important access to data compared to government and academia

WHAT ARE THE GAPS IN EVIDENCE?

- Studies and data sets people don't know exist
- Lived experience of patients and providers
- Data does not factor in contextual understanding of evidence
- Not always about treatment – preventative upstream efforts needed
- Different methodologies and definitions do not allow for regional comparison
- Layer on other measures (eg. Material/social deprivation)
  - Population health status
  - Richness of data that explains the why's
  - Mapped deprivation at community health boards
- Information not shared to a great degree with continuing care
  - Timely response/intervention not possile
  - Linkages to family practice or other practitioner
- Need to have portable record so questions don't have to be asked over and over

KEY POINTS MOVING FORWARD

1. Better use of locally driven, geographic-based data
2. What data/information is out there and available to use? What is not?
3. Need for consistent definitions and methodologies in data collection and analysis

ORGANIZATION AND APPROPRIATENESS OF CARE

WHAT EVIDENCE IS NEEDED?

- Requires transportable data shared between settings
- Non-profit organizations are not linked with DHW to share data
- Data on referrals between providers
- Data on gaps in interferences
- Who has access to tertiary and primary care? Who doesn't?
- Clinical best practice guidelines help inform decision-making
  - Are they being used?
  - Pathways of care
  - Physician outcomes
- Matching time to skills
  - How are people spending time? (Specialist vs. GP)
  - Care often delivered by physicians should be given by the appropriate provider (Levels of care includes nurses, EMTS, Social Workers, Nurse Practitioners)

WHAT ARE THE GAPS IN EVIDENCE?

- Care coordination
  - Separate boxes of care – patients fall through gaps
- How much time is wasted in seeing a physician?
- What are the gaps – where do people fall through?
  - Patient experience
  - Vulnerable patients
  - Self-care
  - Primary care
  - Case managers and navigators required
- Points of Access
  - System responses
  - Multiple clinicians are serving the same patient – patients don't know who the point person is

KEY POINTS MOVING FORWARD

1. Who has access to primary care and who doesn't?
2. Patients require one 'lead' caregiver
3. Clinical Best practice guidelines – info and data on use and audit

PATIENT VOICE AND PATIENT OUTCOMES

WHAT EVIDENCE IS NEEDED?

- What do we measure and when do we measure it?
- Patients need information about what to expect – use patient experience to do so
- Cost transparency to help patients make decisions
- Emotional experience of interaction with the system
- Measuring what info from patient outcomes measure to help system and provide rich data

WHAT EVIDENCE EXISTS?

- Expectations of patients vs. reality of care
- There are lots of quality of life measures but very different results depending on group – chronic disease, age, etc.
- Health authority public survey on priorities

WHAT ARE THE GAPS IN EVIDENCE?

- Outcomes data does not have patient voice
- Must incorporate patient voice in decision
- Do we capture what patients want? You can't only measure the end of the care process
- Information sharing – patients can take only so much info at first
  - What do they need to get through next step?
  - How will they cope?
- Impact on quality of life – if medications make me feel sick, will I take them?
- Patient priorities in daily life
  - Medication management?
  - Trouble finding help?

KEY POINTS MOVING FORWARD

1. Need better data that reflects patient values and preferences
2. Patient education required for system navigation, expectations, and health information
3. Must include patients in decision-making and priority setting

PRIORITY SETTING AND RESOURCE ALLOCATION

WHAT EVIDENCE IS NEEDED?

- Who is involved in priority setting? Relatively little engagement in healthcare by public
- Replicate Australia model of using web to determine priorities, deliberative dialogue
- Use portal to attract people to engage
  - Education
  - Peer to peer support
  - Ask the expert
  - 4 big ticket disease groups
- How to appropriately support caregivers
- How do you use technology when motivating

WHAT EVIDENCE EXISTS?

- Must do away with culture and information that more is better
- Institutional perspectives
- Culture and expectation – people think the best thing is to be in the hospital
- Move to prevention – preventing illness prevents such heavy reliance on the primary and acute healthcare system

WHAT ARE THE GAPS IN EVIDENCE?

- Little engagement from public – are they properly educated and able to make decisions?
- Information from media could be inaccurate
- Important to include qualitative data to give context to priority and public priorities
- Serve and support remote groups or those outside of HRM
- How do we inform patients well?
- Delivering information to the public
  - Smaller numbers only attend focus groups
  - Some information from politicians is inaccurate
  - Two-way communication is required – get feedback

KEY POINTS MOVING FORWARD

1. Must involve patients in decision making using the most effective and appropriate methods
2. Culture change is required for a change in public expectations of healthcare system

MOVING FORWARD

INFORMING PROVINCIAL AND MARITIME-WIDE PROJECTS

It is critical that health stakeholders in Nova Scotia help inform the priority setting process for the MSSU. Each organization and department who participated in the session bring a unique perspective on what challenges they face in delivering high quality, accessible health services to their population. While not all stakeholders face the same issues, the goal of this session was to gain an understanding of the common barriers these organizations face in hope that the MSSU can help inform future healthcare practice and policy. Additionally, by engaging in discussions and discovering linkages, the MSSU seeks to build lasting partnerships with Nova Scotia stakeholders in order to advance locally-driven projects and initiatives in the future.

The results from the Nova Scotia Council of Advisors engagement sessions will be used to inform the Nova Scotia PAC. The PAC will consider these suggestions into action by establishing research and knowledge translation projects in order to address some of the common challenges the stakeholders face. This process will continue in the Provinces of New Brunswick and Prince Edward Island in the winter of 2016. Each Province will use their own locally-driven engagement sessions to inform the prioritization process of their PAC. A final report will combine all three engagement sessions to inform future Maritime-wide projects that will have the greatest impact for the Maritimes as a region.

ONGOING ENGAGEMENT

The Council of Advisors engagement sessions will be an annual event for Maritime stakeholders to participate in priority setting. The MSSU will report on the results of the engagement sessions, the future projects that come as a result, and future opportunities to engage and collaborate with the MSSU on local initiatives.

Stakeholders are encouraged to seek support from, and partner with the MSSU on patient-oriented research initiatives. The MSSU was established to support research in the Maritimes and invites stakeholders to inquire and collaborate on initiatives. Additionally, patients play a key role in the governance, priority setting, and active partnerships on all MSSU research initiatives and connecting patients from the Council of Advisors stakeholders is encouraged.

APPENDIX A

NOVA SCOTIA HEALTH STAKEHOLDERS PARTICIPANTS

- David Milne, Doctors Nova Scotia
- Patricia Connors, Nova Scotia Physiotherapy Association
- Simon d'Entremont, Department of Seniors
- Judah Goldstein, Emergency Health Services
- Kimberlee Barro, DHW Public Health
- Perry Sankarsingh, DHW Monitoring and Evaluation
- Lewis Bedford, DHW Policy and Planning
- Michele Lowe, Northwood
- Heather Hanson, Shannex
- Louis Brill, The Lung Association of Nova Scotia
- Angus Campbell, Caregivers Nova Scotia
- Wenda MacDonald, Alzheimer Society of Nova Scotia
- Pamela A. Magee, Canadian Mental Health Association
- Kimberly Carter, ALS Society of Nova Scotia
- Sue LaPierre, United Way of Halifax

NOVA SCOTIA PROVINCIAL ADVISORY COMMITTEE PARTICIPANTS

- David Anderson, Dalhousie University
- Meredith Campbell, Nova Scotia Health Research Foundation
- Linda Verlinden, Patient Advisor
- Frank Atherton, Department of Health & Wellness
- Jill Casey, Department of Health & Wellness

NOVA SCOTIA COUNCIL OF ADVISORS FACILITATORS

- April Howe, Knightsbridge Robertson Surrette
- Alison Chandler, Knightsbridge Robertson Surrette

MARITIME SPOR SUPPORT UNIT STAFF

- Adrian Levy, Nominated Principal investigator
- Elaine Collins, Executive Director
- Suzanne Kennedy, Interprovincial Privacy Officer
- Jonathan Dyer, Patient Engagement Coordinator
- Laura Dowling, Research Project Manager
- Robyn Traynor, Knowledge Synthesis Coordinator
- Sarah Visintini, Evidence Synthesis Coordinator
- Greta Regan, Committee Coordinator
- Marsha Bennett, Office Administrator
- Wendy Walters, Communications Advisor

APPENDIX B

WHAT KEEPS YOU UP AT NIGHT?

ACCESS TO CARE
- Overcoming stigma to access services
- Better access to data and evidence to inform practice
- Patients and caregivers ability to navigate the healthcare system
- Lack of system coordination among care providers (transitions in care)
- Inequalities in accessing services among patient communities

INDUSTRY PARTNERSHIPS
- Must create vested linkages among and between sectors
- Effectively and efficiently align common goals among stakeholders
- Future research depends on partnerships
- Researchers and policy planning are required for success
- Must coordinate and not duplicate efforts

DATA, EVIDENCE, AND KNOWLEDGE TRANSLATION
- Must be able to translate 'what we know' (multiple sources of experience) into system design and implementation
- Need meaningful data for decision makers
- Lack of available evidence
- Requires detailed data at geographic level
- Not knowing what research is out there to support decision makers
- Lack of information sharing among stakeholders
- Lack of available health outcomes measures
- Better use of social data (non-medical, social determinants of health)
- Increased access to patient outcomes
- Measuring what you can measure and make measurable that which is not
- Increase data quality among all stakeholders and organizations
- Address the perceptions and realities of privacy as a barrier

STRATEGIC DIRECTION
- Less reactive healthcare
- Focus more on prevention
- Spend money to save money
- True patient/person centeredness for patient and families
- Manage the expectation of our funders and clients
- Identify and correct areas of inefficiency
- Demands are inconsistent and in competition
- Evidence based practice required
- Take better advantage of success in other jurisdictions
- Manage known demographics
- Timely access to primary care
- Greater use of evidence in decision-making

RESOURCE PLANNING
- Effective and transparent prioritization is needed
- Reallocation of resources to address current and future needs
- Reinvestment/disinvestment in resource planning
- Further work in appropriateness of care
- Public and organizational perceptions of care

ENGAGING PATIENTS
- Effectively engage patients across the region
- Provide what information is needed
- Provide information that will empower people to take active role in their care
- Teach patients and organizations how to better use information
- Patients and caregivers voice is needed in decision-making
- Empower patients to engage in healthcare


MSSU - USSM
MARITIME SPOR SUPPORT UNIT
UNITÉ DE SOUTIEN SRAP DES MARITIMES


CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada


NOVA SCOTIA


New Nouveau
Brunswick
CANADA


Prince Edward Island
CANADA


NOVA SCOTIA
Health Research
FOUNDATION


New Brunswick Health Research Foundation
Fondation de la recherche en santé du Nouveau-Brunswick

MSSU - USSM

MARITIME SPOR SUPPORT UNIT

UNITÉ DE SOUTIEN SRAP DES MARITIMES

www.mssu.ca