Maritime SPOR SUPPORT* Unit (MSSU) Update

June 4, 2013
Outline

• What is the MSSU about?
• What does the MSSU do?
• Engaging with the MSSU*

*www.spor-maritime-srap.ca (not yet live)
What is SPOR?

• CIHR-led coalition including FPT partners dedicated to integrating research into care
  o Patients and caregivers, researchers, health practitioners, policy makers, health authorities, academic institutions, charities, pharmaceutical sector

The MSSU is part of CIHR’s attempt to get us out of Valley 2: the failure to implement clinical science in routine practice.

*Figure adapted from Steven Reis, University of Pittsburgh and Harold Pincus, Columbia University.*
Six core functions for the SUPPORT Units have been identified:

- Data Platforms & Services
- Methods Support & Development
- Health Systems, KT & Implementation
- Real World Clinical Trials
- Career Development in Methods & HSR
- Consultation & Research Services

Collective Priorities

These functions will be scoped and tailored based on the needs and aspirations of each jurisdiction. CIHR and jurisdictions will work together to develop a shared vision for their SUPPORT Unit.

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MSSU Planning Committee weekly meetings

Presentations to the Community – 2011-2013 in NB, NS, PEI

2010 // 2011
2012
Spring
2013
Fall
2013 Winter
Summer

Planning discussions among maritime provinces
Public engagement
Meetings with investigators, Departments of Health (and Wellness), health authorities, funders to plan business case
Draft Business Case
Final Business Case
Implementation Committee Meeting – May 13
?Funding allocated (retroactive to April 1)

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MSSU Vision

To improve health outcomes and enhance the patient experience by advancing learning at all levels of the health care system.
MSSU: Collaborative Model

• Infrastructure intended
  o to support efforts to implement change
  o to evaluate those changes
    ➔ in the health care system

• Government’s active participation

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MSSU Public Engagement

A key and novel element:
- promote the engagement of the public in formulating research questions and the interpreting results.
- already underway in NB and NS
MSSU Logic Model

Inputs

- Existing human and financial resources
- Maritime partnership and collaboration

Components (CIHR)

- Data platforms
- Methods Support & Development
- Consultation and Research Services
- Real World Clinical Trials
- Career Development and Methods in HSR
- Implementation

Activities (examples)

- Linked data
- Grant development
- Consultation and Research Services
- Supporting multi-site REB
- Training, Chairs
- Implementation

Reach

- Participants in Health Research Enterprise

Outputs

- Quantitative data on each activity
- Short: linked health data sets, analytic capabilities, use of data in policy and decision making
- Intermediate: other data sets, quantify trade-offs, value explicitly addressed in policy and decision-making
- Long: improved quality and access to patient care, better efficiency, better value for money

Outcomes

- Short term
- Intermediate
- Long term

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MSSU NETWORK

New Brunswick
- Institute for Research, Data and Training
- Research Chairs, Investigators

Nova Scotia
- Health Data NS (formerly PHRU)
- Research Chairs, Investigators, Research staff

PEI
- Centre for Health & Biotech Mngmt Research
- McCain Chair in Human Development and Health Applied Human Sciences

- Life and Health Science Cluster
- Canadian Longitudinal Study for Health and Aging
- Health and Environments Research Centre Laboratory
- NB Social Policy Research Network
- Stats Can Research Data Centres (Fredericton, Halifax, and Moncton)
- Atlantic Regional Training Centre in Applied Health Services Research

In future?
MATH: Maritime Assessment of Technologies in Health Priority Setting Unit
- CDHA and IWK Research Services
- Ethics Review Boards
- Atlantic Interdisciplinary Research Network
- Health and Education Research Group
MSSU Governance

Oversight Committee

Executive Committee

Development Committee

Science, Knowledge Translation, & Patient Engagement

Data & Privacy

Evaluation

Research Training & Maritime Consortium

Bill Montelpare (PEI)

Bill Gardner (NS)

Ted McDonald (NB)

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Maritime-Wide Projects

Based on the Maritime Consortium:

• Demonstration project (Business Case)

Over coming months/years:

• Standardized & Linked Data Sets
• Same Protocol in Three Provinces
• Research Training
Demonstration Project

CIHR requested a project, intended to demonstrate:

- MSSU can be made quickly operational in supporting high-quality patient-relevant health research
- highlight particular areas of concentration
- quick successes to show stakeholders MSSU’s potential
- effective collaboration across Maritimes provinces, making use of accessible and available resources.
Regionalization of hospital services in Maritimes

- Stakeholders indicate a need to evaluate current centralized provision of surgical services

- Method: compare access, outcomes and cost within and across provinces, and over time

- Focus: hip/knee replacements, cardiac surgery

- Data: administrative data from hospital discharge abstracts
  - NS – already available through the Health Data NS (formerly PHRU)
  - NB – available through the NB-IRDT this summer
  - PEI – Canadian Institute of Health Information

- Engage patients by eliciting experiences and preferences

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Objective

- Describe the prevalence of cancer conditions across PEI

Requirements

- Access to admin databases to provide estimates (Provincial Cancer Registry, Drug Information System)
- De-identified data to be provided to the research team to enable mapping of prevalence and modeling of conditions
- Selected mapping software running on a dedicated system and exporting images to the project website
PEI Demonstration Project
Mapping Cancer Prevalence

Approach

• Compare data between databases - adjust for robustness, for example, do the results identified in the Cancer Registry match the results for the Drug Information System?

• Consistent with CIHR requirements: Cancer Patient Advocacy Group linked to planning the project and interpretations.

Advantage

• Approach can be replicated for other diseases or disorders
Parallel Steps: enabling opportunities to evaluate health systems research questions

- Through the SPOR we can create a birth cohort to evaluate early years development and education outcomes
Maritime Consortium

• Build a community of patient-oriented researchers
• Real engagement of policy-makers, clinicians, public in policy, ethics and IT discussions
• Primary activity will be to sponsor meetings
• Current research infrastructure to develop links across the country
# MSSU Consortium Meetings

<table>
<thead>
<tr>
<th>Activity</th>
<th>Annual Frequency</th>
<th>Target Audience</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient-Oriented Research Seminar</td>
<td>3</td>
<td>Researchers, trainees, other interested specialists</td>
<td>Research presentations by Maritime health researchers or visiting scholars.</td>
</tr>
<tr>
<td>Health Policy Speaker Series</td>
<td>2</td>
<td>All interested parties</td>
<td>Presentations or panel discussions by policy makers, researchers, visiting scholars. Focus on major health policy decisions in the Maritimes.</td>
</tr>
<tr>
<td>Health Information Technology Seminar</td>
<td>2</td>
<td>IT specialists (academic, hospital, government, or industry) and health policy specialists</td>
<td>Presentations or panel discussions by technologists, researchers, or health system leaders. Focus on technology choices and opportunities.</td>
</tr>
<tr>
<td>Health Research Ethics Seminar</td>
<td>2</td>
<td>Researchers, provincial data guardians and regulators, trainees, &amp; other interested specialists</td>
<td>Discussions of issues relevant to health research ethics, including data ethics. Research presentations with implications for patient-oriented research.</td>
</tr>
<tr>
<td>Patient-Oriented Research Methodology Study Group</td>
<td>3</td>
<td>Research methodology specialists, interested researchers, &amp; trainees</td>
<td>A study group / journal club to promote diffusion of advanced research methods across the Maritimes.</td>
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</tbody>
</table>
| Patient-Oriented Research Lecture and Conference | 1                | All interested parties                                                          | - To be held as part of annual meeting of the MSSU.  
- Public lecture - eminent researcher/policy maker.  
- Research abstract presentation for trainees.                                                                                                    |
Research Training Program

• New patient-oriented researchers required.
• RTP will provide training/research opportunities for students in variety of academic disciplines.
• RTP will provide mentorship and project support to faculty, as well as to end users of research including DHW and Health district personnel.
• RTP will collaborate, complement, but not duplicate existing academic research training programs.
What MSSU Does

• MSSU does not fund research projects.
• MSSU does facilitate
  • access to linked health data sets
  • proactively addressing privacy & confidentiality
  • methodological consulting
  • patient-focused research
  • health services research
  • research training
  • KT & implementation
Principles to Prioritize MSSU Projects

• Does the project have high scientific quality?
• Will the project contribute to implementation or evaluation of health system change?
• Is it a sustainable research project?
• Does the project involve more than one province?
• Does the collaboration include health care professionals, decision-makers, academics, and government representatives?
Please join the MSSU!

Committee

Consortium

Ideas for projects – Intake form

The purpose is to provide infrastructure support to teams seeking to transform health care.
Where do we go from here?

• Funding announcement
• Hiring the program director is underway
• Looking for you to participate on committees
  o Science, KT & Public Engagement
  o Data & Privacy / Confidentiality
  o Training
• September 2013 Consortium activities begin
• Stay tuned: www.spor-maritime-srap.ca
• A work in progress….
A Strategy for a Patient-Oriented Research SUPPORT Unit in the Maritime Provinces

Final Business Plan

SPOR SRAP
MARITIME

2013
Executive Summary

At its best, our health care system is superb. We offer compassionate care, and we implement sound policies and programs that range from effective health promotion to complex lifesaving procedures. Our health care system enables Canadians to live longer and better lives. However, there is often a gap between the system’s potential and the care that is actually delivered. That gap may be widening due to the challenges facing the Canadian health care system including escalating costs, an older population, and growing expectations from citizens.

The Strategy for Patient-Oriented Research (SPOR) SUPPORT Unit has a vision to improve health outcomes and enhance the patient experience by advancing learning at all levels of the health care system. Patient-oriented research encompasses a diverse scientific array, all of which seeks to improve diagnosis, management, and treatment at the point of care to enhance health outcomes. Patient-oriented research also seeks to help the provinces and territories ensure rapid access to high-quality and cost-effective health care, and make that care available in a manner consistent with Canadians’ values. The challenge is to develop and apply research that will ensure more effective and cost-effective use of health resources while improving the quality of care.

Our vision is that the Maritimes will serve as a Canadian model for evidence-based care and as a center of excellence in stewardship and management of the health care system. The mission is to efficiently use scarce research resources to build capacity to address critical health issues in patient-oriented and health services research. The three core themes of this SUPPORT Unit are:

- **Data Platforms & Services**: make better use of existing administrative data sets and patient registries to develop applicable knowledge that, in turn, improves the delivery of services.
- **Health Systems, Knowledge Translation & Implementation**: build closer collaborations between policy- and decision-makers, health care professionals, citizens, and researchers.
- **Career Development**: increase the number of highly qualified patient-oriented health researchers.

The Unit is a collaboration between governmental policy-makers, health authority decision-makers, health care professionals, patients, lay citizens, and researchers in the Maritime Provinces. It consolidates and builds upon existing infrastructure and regional collaborations. The Maritime SPOR SUPPORT Unit will provide the model for evidence-based health program evaluation by aligning the research agenda with policy questions. It will examine existing health data to determine the current level of care and service, and identify gaps. This will allow the health care system to improve patient care. It will close the gap between patient care that is possible and care that is currently delivered.

**Maritime SPOR SUPPORT Unit Infrastructure Objectives**

- **Regional and Provincial Coordination**
  - Create a patient-oriented research consortium of stakeholders
  - Promote IT innovation consistent with provincial use of health data
  - Develop a research training program to increase research capacity
  - Establish the Working Group on Inter-Provincial Data Linkage Issues to facilitate data analyses spanning the Maritime Provinces

- **Health Systems, Knowledge Translation & Implementation**
- Enable computerized clinical decision-support protocols
- Work with health organizations to identify, implement, and share best practices in patient-oriented and health services research

**Consultation and Research Services**
- Develop common approaches to patient consent, confidentiality, information security, research regulations, research consent forms, and secure storage of consent forms

**Data Platforms and Services**
- Form linkages among administrative and clinical data sets to create virtual patient records for research

**Methods Support and Development**
- Supply consultation services and methodological support to local investigators writing funding applications for patient-oriented research

**Public Engagement**
- Promote the engagement the public in the formulation of research questions and the interpretation of results

**Outcomes**
The Maritimes SPOR SUPPORT Unit seeks to improve health outcomes by improving rapid access to high-quality and cost-effective care through initiatives at two levels:

1. *Universities and hospitals*: by building on existing strengths in clinical research to pose and answer questions relevant to patients and patient care
2. *Health authorities and the provincial government*: by making better use of existing Nova Scotia health data to develop and evaluate health services and policy

**Project Examples**

**Setting Chronic Disease Targets**: The Maritime SPOR SUPPORT Unit data repository has the potential to expedite effort, influence chosen targets, and enhance the ability to measure and report on achievement of those targets, and develop the best practices to implement them. For example, the Unit could evaluate targets agreed to by Canada’s Atlantic premiers in June 2012 on an Acute and Chronic Disease Target Setting Project. Concurrently, developing a framework for measuring the impacts of the provincial and regional clinical practice guidelines will be an important component.

**Planning for the Health System**: The data repository will have a central role in enabling evidence-based planning for clinical services and allocation of diagnostic and therapeutic equipment such as magnetic resonance imagers and laboratory technologies.

**Planning for Health Human Resources**: Population-based planning for health human resources will be effectively supported by the Maritime SPOR SUPPORT Unit.

**Evaluation and Accountability**: The measurement of quality outcomes and the selection of indicators in programs throughout the system will be supported by the Maritime SPOR SUPPORT Unit. The SUPPORT Unit will be a key contributor to the success of provincial accountability frameworks. For example, outcomes from the implementation of Nova Scotia’s Better Care Sooner strategy, such as the evaluation of a standards-based emergency system, will help guide these programs moving forward.