

COUNCIL OF ADVISORS- NS

Reported Findings

2017



Strategy for Patient-Oriented Research

Stratégie de recherche axée sur le patient

SPOR  **SRAP**

Putting Patients First

Le patient d'abord



EXECUTIVE SUMMARY

The Maritime SPOR SUPPORT Unit (MSSU) held its second annual *Nova Scotia Council of Advisors – Health Research Stakeholder Engagement* session on February 9, 2017. The aim of this meeting was to offer the Nova Scotia community of health research stakeholders an opportunity to learn about and inform MSSU research activities. The focus of the session was a demonstration of the Nova Scotia Health Atlas, with a facilitated discussion on its current and potential content and features.

Meeting Overview

Representatives ([Appendix A](#)) from healthcare and community associations, government departments, academic institutions, and private or charitable organizations in Nova Scotia were invited to attend this two-hour engagement session. Attendees from the MSSU presented a re-introduction to the MSSU and its plans for phase II, an overview of the 2016 Council of Advisors session, and an update on MSSU-supported and -led research projects. Participants were then provided with a live demonstration of the Health Atlas ([Appendix B](#)) and given an opportunity to ask questions

about the resource. The demonstration was followed by a facilitated discussion in which participants were asked, 1) what additional content and features they would like to see on the Health Atlas, 2) what data their organizations currently collect or hold that could potentially be contributed to the Health Atlas, and 3) what additional features they would like to see on the Health Atlas. The meeting concluded with a presentation and final facilitated discussion on patient engagement for data-intensive projects, such as the Health Atlas.

For more information about the Nova Scotia Health Atlas, visit www.healthatlas.ca.



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 MSSU Council of Advisors stakeholder engagement events are an opportunity for health stakeholders in the Maritimes to learn about and contribute to MSSU research. Each of the Maritime provinces holds engagement sessions in their communities, with the focus of each being driven by provincially-specific issues and needs.

The second annual *Nova Scotia Council of Advisors – Health Research Stakeholder Engagement* session gathered health research stakeholders in Nova Scotia to learn about MSSU research projects and help inform ongoing and future initiatives.

Meeting Overview

Update on MSSU Research Activities

Representatives ([Appendix A](#)) from healthcare and community associations, government departments, academic institutions, and private or charitable organizations in Nova Scotia were invited to attend this two-hour engagement session. The session began with participant introductions and welcoming remarks from Dr. Adrian Levy (Scientific Director). Dr. Levy defined patient-oriented research and described the SPOR initiative, with emphasis on the MSSU's structure, funding partners, and timeline ([Figure 1](#)).

Figure 1. Timeline of MSSU activities (2010 - present), including Phase I and Phase II

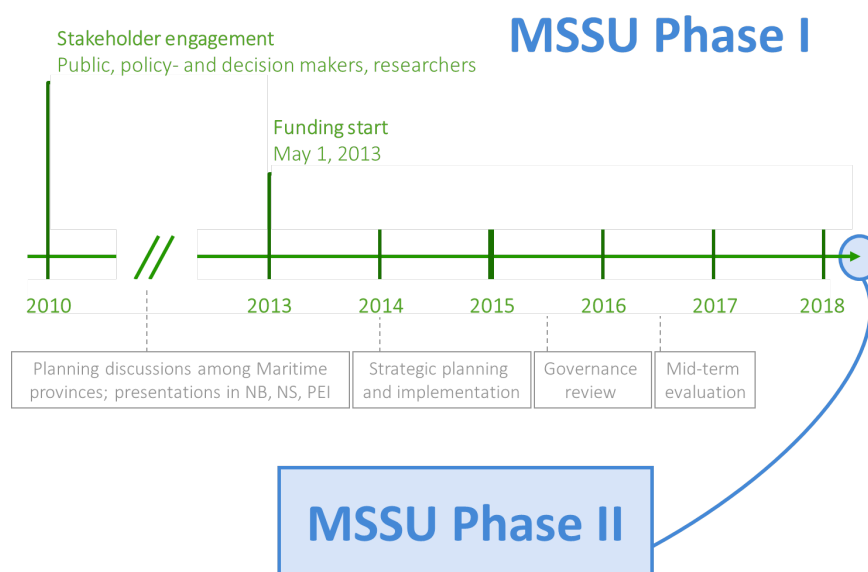
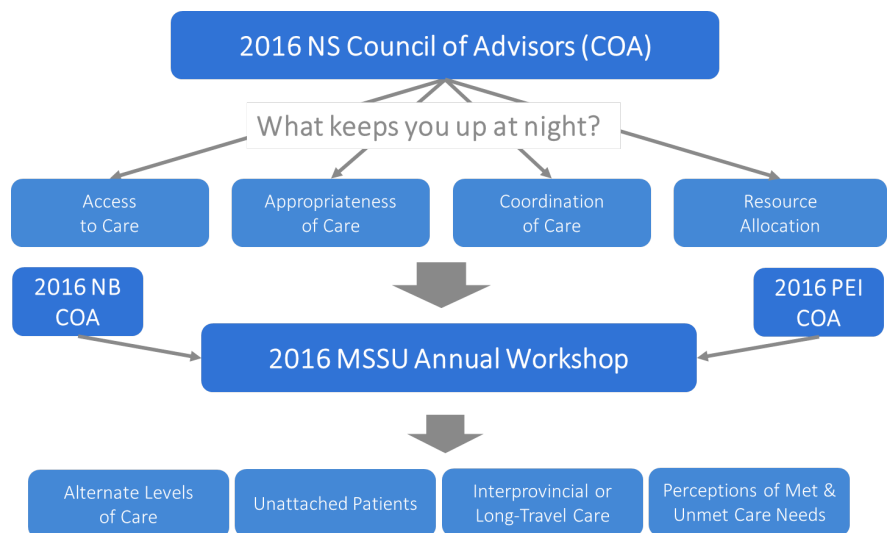


Figure 2. Summary of topics and resulting events from the 2016 Council of Advisors session

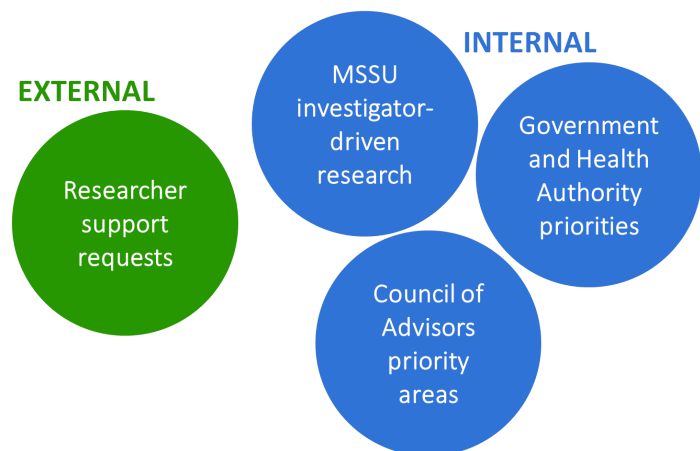


Laura Dowling (Assistant Director) discussed the importance of the patient perspective for contextualizing and interpreting data to move towards higher forms of knowledge. She also presented a summary of the 2016 Nova Scotia Council of Advisors session and the projects and activities that resulted from that event (Figure 2).

Liz Jeffers (Research Project Manager) described the types of research projects the MSSU engages in (Figure 3) and provided an overview of MSSU-supported projects and consultation services (including data access, patient engagement, knowledge translation, evidence synthesis, privacy and ethics, study design, and statistical analysis).

Adrian MacKenzie (Senior Health Policy Researcher) and Dr. David Stock (Senior Health Services Researcher) discussed two MSSU-led projects currently underway: the *Alternate Levels of Care Use* and *Unattached Patients* studies.

Figure 3. Types of research projects the MSSU supports and/or leads



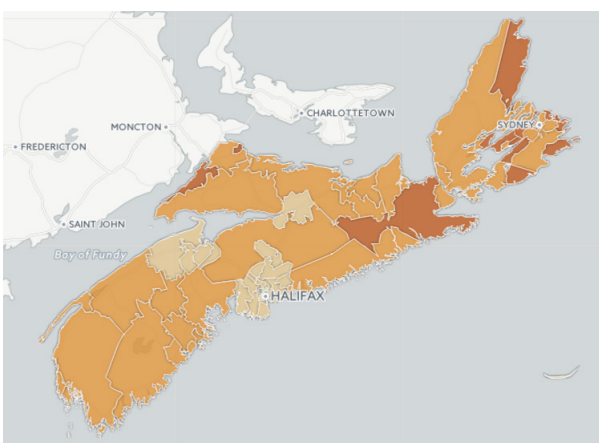
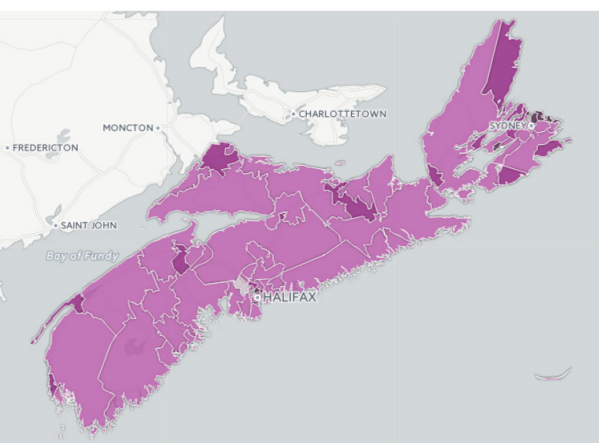
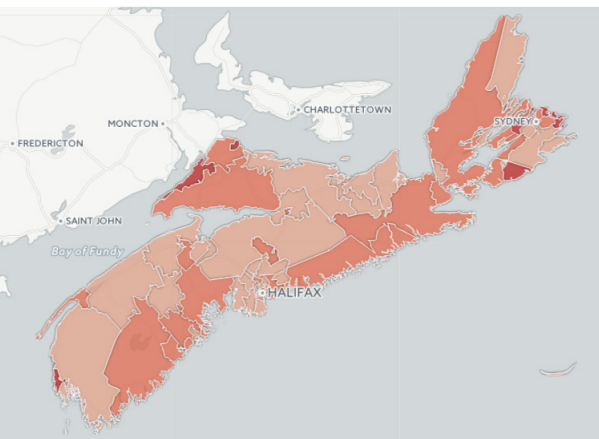
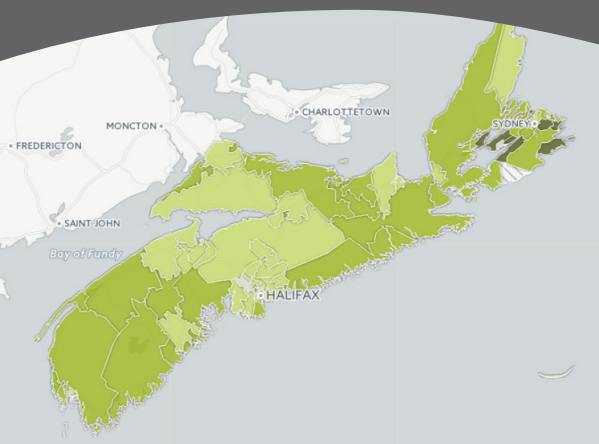
MSSU-led Projects

Alternate Levels of Care Use

Many patients stay in hospital when they no longer need hospital services or treatments because they cannot be safely discharged home. Reducing these alternate levels of care (ALC) can free up hospital beds, reduce wait times and burden on emergency services, and ensure patients are getting the care they need. This study aims to understand provincial and regional variation in ALC use across Nova Scotia, as well as any changes over time.

Unattached Patients

In 2016, the Nova Scotia Health Authority's Primary Health Care Connections service – which matches patients without family doctors (e.g. unattached patients) with primary health care practices – received more calls than in the previous three years combined. This study aims to understand the cause(s) for this unexpected increase in the number of unattached patients, and will specifically estimate changes in, 1) population need for primary health care, and 2) the supply and productivity of family physicians, between 2006 and 2016.



Nova Scotia Health Atlas

Adrian MacKenzie led participants through a demonstration of the Nova Scotia Health Atlas ([Appendix B](#)), an interactive, web-based mapping tool that illustrates differences in measures of health status, health service use, and the social determinants of health across small geographic areas of Nova Scotia (www.healthatlas.ca). The demonstration highlighted the available geographic levels (zone/network, community cluster*, dissemination area) and possible data sources – clinicians (clinical data sets), Department of Health and Wellness (administrative data), researchers (academic research), community (community-generated, open source data). Only aggregate data is held by the Health Atlas and small cell sizes are suppressed in order to uphold privacy and confidentiality standards.

The demonstration was followed by a facilitated discussion in which participants were asked, 1) what additional content they would like to see on the Health Atlas, 2) what data their organizations currently collect or hold that could potentially be contributed to the Health Atlas, and 3) what additional features they would like to see on the Health Atlas.

***A report on the Health Atlas community cluster geography is available online: <http://www.spor-maritime-srap.ca/news/all/mssu-reports>.**

Patient Engagement

Brian Condran (Patient Engagement Coordinator) concluded the meeting with a presentation on patient engagement for data intensive projects and a discussion on how best to build momentum and buy-in for these activities. With data-intensive research, where patients have not previously been involved – as participants or partners – a key component is aligning patient and researcher expectations and working to sustain engagement through patient-identified priorities, tailored engagement plans, and including patient research partners.

Patient Engagement Discussion

Patient-reported outcomes in resident quality of care – Only two long-term care facilities collect information on quality of care indicators. The group discussed how we can increase the number of facilities collecting this data, how the data would be collected, and who would analyze it. One solution may be to create a working group of relevant representatives to ensure all facilities have the capacity and resources to consistently collect patient-reported data.

Prioritizing policy issues with the patient in mind – The group asked, "What are the priorities of care?" and decided that first, the public needs to be informed. The example was given of the patient experience with pharmacists: what kind of dialogue and information exchange is required between patients and pharmacists to ensure optimal care is provided? Overall, there needs to be better continuity among all groups involved in health care, beyond this one example.

Health Atlas Discussion

What additional *content* would you like to see included on the Health Atlas?

The following data sets were identified, including where (and how) to acquire the data and some inherent challenges:

- **Leading indicator data** – Income data was identified as a possible leading indicator, specifically, to be able to make predictions on health indicators.
- **Education** – Similarly, education data was discussed. The Department of Education collects data on variables such as suspension rates, preparedness for school, educational attainment rates, and early developmental index. One option may be to have each school board represented in the Health Atlas (with the caveat that their data may differ from that of NSHA Management Zone given that while the Department of Education owns some data, school boards may opt out of participating).
- **Immigration** – Immigration-related data including settlement and mother tongue would be highly relevant, however, may pose challenges with regards to certain areas.
- **Mental health** – Mental health indicators may include mental health outcomes for adults and children, as well as indicators for positive mental health (e.g. from Public Health Agency of Canada) to reframe mental health.
- **211 services** – 211 houses a wealth of information – from over 100,000 well-documented calls and 175,000 visitors to their website per year – including social indicators of health. This group is interested in participating in population health research, as there may also be an opportunity to collect new data from individuals calling.
- **Insurance coverage** – Insurance coverage data may be available through Medavie Blue Cross.
- **First Nations communities, marginalized and/or vulnerable populations** – The challenge associated with data from these communities is the small sample size; are there any approaches (e.g. Winnipeg methodology around small cell sizes) to mitigate this issue?

What additional *features* would you like to see included on the Health Atlas?

The following additional features were discussed:

- The ability to **export information** from the Health Atlas, including images (the current option is to take a screen shot of the map and copy-&-paste);
- The option to **sort data by provincial averages**, including different geographic layers such as cluster, Community Health Network, Management Zone, or by the whole province;
- The reassurance that data holdings will be **updated periodically**, and perhaps on a regular schedule, in order to avoid lag in the available data; and
- The availability of older data sets to serve as a **comparison** with newer, updated data, such as census data (e.g. ability to compare results from 2011 and 2016 census data).

MOVING FORWARD

Informing ongoing MSSU research and engagement

The discussion at this year's *Nova Scotia Council of Advisors - Health Research Stakeholder Engagement* session will help inform the ongoing development of the Health Atlas, in particular, and MSSU patient engagement efforts related to data-intensive projects, in general. Participants were asked to indicate whether they would be interested in, 1) having the MSSU demonstrate the Health Atlas to their organizations, 2) discussing their data holdings for possible inclusion in the Health Atlas, and/or 3) being kept informed of upcoming public consultations related to patient engagement for MSSU research projects. The MSSU followed up with these participants, after the event, and is continuing to connect with them, moving forward.

The Council of Advisors engagement sessions are an annual event for Maritime health research stakeholders to participate in priority setting, health research, and/or engagement initiatives. The MSSU will continue to report on the results of the engagement sessions, the projects that result, and future opportunities to engage and collaborate. Stakeholders are always encouraged to seek support from, and partner with the MSSU on patient-oriented research initiatives.

Would you like to learn more?

If you are interested in having the MSSU demonstrate the Health Atlas to your organization, discussing your data holdings for possible inclusion in the Health Atlas, or being kept informed of upcoming public consultations related to patient engagement, please contact info@mssu.ca.



Appendices

Appendix A.

Organizations represented at the Council of Advisors session

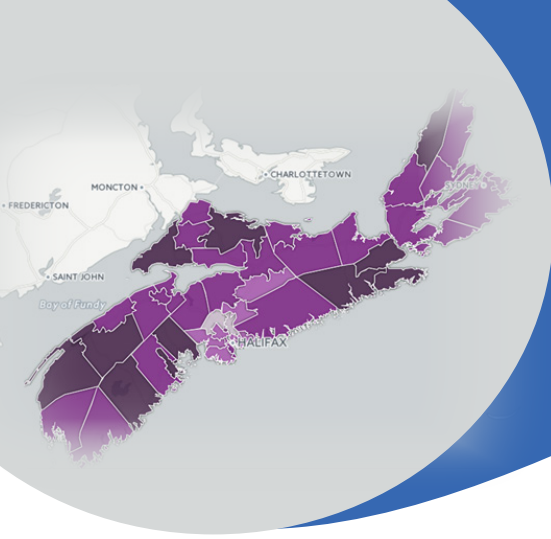
211

AIDS Coalition of Nova Scotia
Alzheimer Society of Nova Scotia
Autism Nova Scotia
Dalhousie University
Emergency Health Services (EHS)
Health Association Nova Scotia
Maritime SPOR SUPPORT Unit (MSSU)
Nova Scotia College of Pharmacists
Nova Scotia Department of Health and Wellness
Nova Scotia Health Research Foundation (NSHRF)
Nova Scotia Health Authority (NSHA)
Nova Scotia School Board Association
IWK Health Authority
Sexual Health Nova Scotia
Youth Project Nova Scotia



Appendix B.

Nova Scotia Health Atlas



What is the Nova Scotia Health Atlas?

The Nova Scotia Health Atlas is an interactive, web-based mapping tool that illustrates differences in measures of health status, health service use, and the social determinants of health across geographic areas of Nova Scotia. The first version of the Health Atlas includes aggregate census data and results from a [recent study](#)¹ on small-area rate variation (SARV) in high-cost health care use across the province.

A key component of the Health Atlas project has been the development of community cluster geography for health service planning. The community clusters are area units based on aggregated census dissemination areas (to the greatest extent possible) intended to align as close as possible with community activity. The resulting 54 community clusters are nested in two (larger) levels of geographies - 14 *community health networks*, and four *management zones*. The boundary files for the community clusters, community health networks, and management zones are available by contacting the MSSU (info@mssu.ca).

Why was the Nova Scotia Health Atlas created?

Geography is essential for health policy and systems planning. Individual and population health and wellness are strongly influenced by geography. Proximity to services, neighbourhood safety, opportunities for education and employment within commuting distance, and air and water quality all affect health. Geographic mapping of health outcomes and services is a powerful tool for decision making in health policy and planning.

The availability of population health information in a user-friendly format, through the Health Atlas, will better enable Nova Scotia's health care stakeholders to understand and respond to the health care challenges facing the province. In doing so, Nova Scotia will join other Canadian provinces and health authorities at the forefront of evidence-informed health care planning.

What are the next steps?

Our goal is to expand the Health Atlas to include more information of health system utilization, cost, and outcomes, as well as other determinants of health and wellbeing. We are interested in feedback from health stakeholders through the Nova Scotia Council of Advisors. Your contributions will enable research that will lead to better health outcomes for all Nova Scotians.

¹ http://www.spor-maritime-srap.ca/sites/default/files/SARV_Final.pdf

Health Geography Resources

Variations in determinants of health, health status, and health service use within jurisdictions have important implications for population health initiatives, as well as health service planning and delivery. These variations have garnered increasing attention from health care stakeholders in recent years and several tools for measuring and monitoring these variations have been developed. Perhaps the best known tool is the [Dartmouth Health Atlas](http://www.dartmouthatlas.org/)², which maps variations in Medicare service use across small geographic areas of the United States.

A number of other organizations and governments have also invested in the establishment of so-called 'Health Atlases' for their respective jurisdictions, including:

- International organizations such as the World Health Organization's [Global Health Observatory](http://www.who.int/gho/en/)³, the [European Centre for Disease Prevention and Control](http://ecdc.europa.eu/en/data-tools/atlas/Pages/atlas.aspx)⁴ & the [International Agency for Research on Cancer](http://globocan.iarc.fr/Default.aspx)⁵;
- State and provincial governments in other countries such as [Finland](http://www.krebsregister.nrw.de/index.php)⁶, [Germany](http://www.terveytemme.fi/avainindikaattorit/index.html)⁷, and the [United States](http://www.hnhblhin.on.ca/aboutus/geographyanddemographics/HealthAtlas.aspx)⁸;
- Canadian provincial government departments such as [Alberta Health](http://www.ahw.gov.ab.ca/IHDA_Retrieval/ihdaGeographic.do)⁹, the [Government of British Columbia](http://maps.gov.bc.ca/ess/sv/cha/)¹⁰, and [Public Health Ontario](http://www.publichealthontario.ca/en/DataAndAnalytics/Snapshots/Pages/default.aspx)¹¹; and
- Health authorities within Canadian provinces such as [Fraser Health](http://www.fraserhealth.ca/community-health-atlas/index.html)¹² (British Columbia) and the [Hamilton Niagara Haldimand Brant Local Health Integration Network](http://www.hnhblhin.on.ca/aboutus/geographyanddemographics/HealthAtlas.aspx)¹³ (Ontario).

To view the Nova Scotia Health Atlas visit:

www.healthatlas.ca

To learn more about the Maritime SPOR SUPPORT Unit visit:

www.mssu.ca

[@maritimespor](https://twitter.com/maritimespor)

² <http://www.dartmouthatlas.org/>

³ <http://www.who.int/gho/en/>

⁴ <http://ecdc.europa.eu/en/data-tools/atlas/Pages/atlas.aspx>

⁵ <http://globocan.iarc.fr/Default.aspx>

⁶ <http://www.terveytemme.fi/avainindikaattorit/index.html>

⁷ <http://www.krebsregister.nrw.de/index.php>

⁸ <http://www.azdhs.gov/phs/phstats/profiles/atlas.html>

⁹ http://www.ahw.gov.ab.ca/IHDA_Retrieval/ihdaGeographic.do

¹⁰ <http://maps.gov.bc.ca/ess/sv/cha/>

¹¹ <http://www.publichealthontario.ca/en/DataAndAnalytics/Snapshots/Pages/default.aspx>

¹² <http://www.fraserhealth.ca/community-health-atlas/index.html>

¹³ <http://www.hnhblhin.on.ca/aboutus/geographyanddemographics/HealthAtlas.aspx>



www.mssu.ca