

Care Now

An Action Plan to Improve Care for People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS)

FINAL REPORT OF THE TASK FORCE ON ENVIRONMENTAL HEALTH

December 2018

<http://www.health.gov.on.ca/en/public/programs/environmentalhealth/>

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Letter to the Minister

Dear Minister Elliott:

On behalf of the Task Force on Environmental Health, I am pleased to present our final report. It sets out a practical, evidence-based action plan that will allow Ontario to create a comprehensive, cost-effective, patient-centred system of care for people living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia (FM) and environmental sensitivities/multiple chemical sensitivity (ES/MCS) – one that will support patients, families and providers. It will improve access to timely, high quality care. It will shift responsibility for care out of acute care hospitals and into the community, closer to where people live. It will make highly efficient use of the skills of both primary care and specialized providers. It will actively engage patients and families in managing their health. Most importantly, it will provide urgently needed care now and, in the process, gather the data and enable research that will help Ontario understand, diagnose and manage these poorly understood conditions more effectively. It will also help raise awareness and reduce the stigma associated with ME/CFS, FM and ES/MCS.

The need for action is urgent. About three-quarters of a million Ontarians are suffering with these debilitating conditions, and they and their families deserve effective care and support now.

We are aware that this is not the first time a group of qualified experts has been asked by the Ontario government to recommend ways to support patients with these conditions. Here are some key recommendations from earlier reports:

“Create a multi-disciplinary investigative and therapeutic research unit that can develop educational materials intended for the public and courses intended for the medical community.”

**1985 - Ontario Report of the Ad Hoc Committee on
Environmental Hypersensitivity Disorders**

“An environmental health centre is long overdue. It is time to invest in a comprehensive program to gather and synthesize the evidence to support the education of health care professionals so that they understand the impact that the environment plays in the health of the population.

“Family physicians are the most trusted health care professionals to address these concerns but they do not have the education and training required to support their patients.”

**2008 - Ontario College of Family Physicians Feasibility Study
for a Centre of Excellence in Environmental Health**

“Develop a system of care that meets the full range of health and social needs of individuals with these conditions. This model includes enhancing primary care, providing access to inter-professional teams with specialized training and the creation of a single provincial hub. The hub can provide care in severe cases, as well as education, research and a centralized database.”

**2013 - Ontario Centre of Excellence in
Environmental Health Business Case Proposal**

Our report echoes and amplifies many of these recommendations. Some solutions – a comprehensive system of care, better education and support for providers, specialized skills and support, and more research – haven’t changed. They have only become more pressing and urgent.

We believe that Ontario has the potential to become a global leader in the diagnosis and management of ME/CFS, FM and ES/MCS. Our proposed action plan provides a cost-effective way for Ontario to significantly improve care for people living with these conditions while reducing the need for them to seek care in emergency departments and acute care hospitals.

We are asking you to take the critical steps recommended in this report to enhance awareness of ME/CFS, FM and ES/MCS, improve knowledge and care, and lay the foundation for a patient-centred system of care for people living with these devastating complex chronic diseases.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Ray Copes', is written over a light grey rectangular background.

Ray Copes

Chair

Task Force on Environmental Health

Executive Summary

More than 740,000 Ontarians¹ live with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia (FM) and environmental sensitivities/multiple chemical sensitivity (ES/MCS). **These profoundly life-altering, stigmatizing chronic conditions have a devastating impact on people's health and quality of life.**

Despite the large number of people affected, these conditions are under-recognized, under-researched, poorly understood, regularly misdiagnosed and poorly managed. Care providers lack the knowledge, resources and support they need, which means people with these chronic conditions struggle to get care, support and accommodation. More often than not, the care provided does not work for patients or their families.

Because so few doctors understand the symptoms or know how to treat them, the people affected often end up getting many unnecessary tests and seeing many different specialists, which creates a financial burden for the health care system. Many patients are told that “it's all in your head”, which is both frustrating and stigmatizing. In fact, people with these conditions face significant stigma and discrimination within the health care system, the workplace and society at large.

The Task Force on Environment Health was established by the Ministry of Health and Long-Term Care to provide advice on how to overcome the gaps in knowledge, care and attitudes. Over its three years of deliberation and countless hours of volunteer time, members of the task force – clinicians, patients, researchers, advocates, representatives of health organizations and government technical advisors – have developed a practical, evidence-based action plan for a **comprehensive, patient-centred system of care** that will:

- improve the quality, consistency and accessibility of care for these conditions now
- establish a cost-effective, shared-care, chronic disease management model that reduces wait times, moves care out of acute care settings into the community – closer to where people live – and gives both clinicians and the people affected the skills, tools and support they need to manage these conditions
- develop a skilled, knowledgeable health workforce
- support the data collection and research required to enhance Ontario's capacity to understand, diagnose and manage these debilitating conditions.

¹ Includes Ontarians age 12 years of age or older. Source: Canadian Community Health Survey (CCHS), 2016, MOHLTC Share File, Statistics Canada.

Summary of Recommendations

Recommendation 1

Develop a one-to-three year awareness campaign that targets the general public, health care facilities and providers and primary care settings.

Recommendation 1.1 – Develop awareness materials that target the general public and specifically engage priority groups, starting with employers and landlords.

Recommendation 1.2 – Create materials and tools designed to promote awareness of ME/CFS, FM and ES/MCS and explain how to accommodate patients with these chronic conditions in priority health care settings, starting with hospitals, long-term care homes and key home care providers.

Recommendation 1.3 – Increase awareness of ME/CFS, FM and ES/MCS, clinical tools and information, and the need for accommodation, in all primary care settings in Ontario.

Recommendation 2

Develop and disseminate clinical tools and information that support evidence-informed treatment and management.

Recommendation 3

Establish a system to develop and support a cadre of primary health care and specialized providers skilled in managing ME/CFS, FM and ES/MCS.

Recommendation 3.1 – Establish a community of practice to provide training and support the network of primary care clinics that will provide chronic disease management for people with ME/CFS, FM and ES/MCS across the province.

Recommendation 3.2 – Fund a comprehensive strategy to increase the pool of skilled, specialized providers to reflect the high demand for interdisciplinary care.

Recommendation 4

Create and support a network of enhanced primary care programs throughout Ontario.

Recommendation 5

Develop a shared care planning tool.

Recommendation 6

Modernize the OHIP K037 fee code to include all three conditions and use it to help gather data on their prevalence.

Recommendation 7

Support research to fill critical gaps in knowledge about the pathogenesis, prevention and treatment of ME/CFS, FM and ES/MCS.

Recommendation 7.1 – Leverage the Health System Research Fund (HSRF) to fund priority research into patients’ experience with the health system and improve care and efficiency.

Recommendation 7.2 – Work with funding organizations such as the Canadian Institutes of Health Research (CIHR) and the US National Institutes of Health (NIH) to support funding research projects that explore questions related to the pathogenesis and prevention of ME/CFS, FM and ES/MCS.

Recommendation 8

Create a centre of excellence in ME/CFS, FM and ES/MCS care, education and research in Ontario.

Recommendation 9

Establish a transitional implementation committee to provide the leadership in the initial phases of putting this plan into action.

Recommendation 10

Provide regular updates and progress reports on the implementation of the proposed action plan.

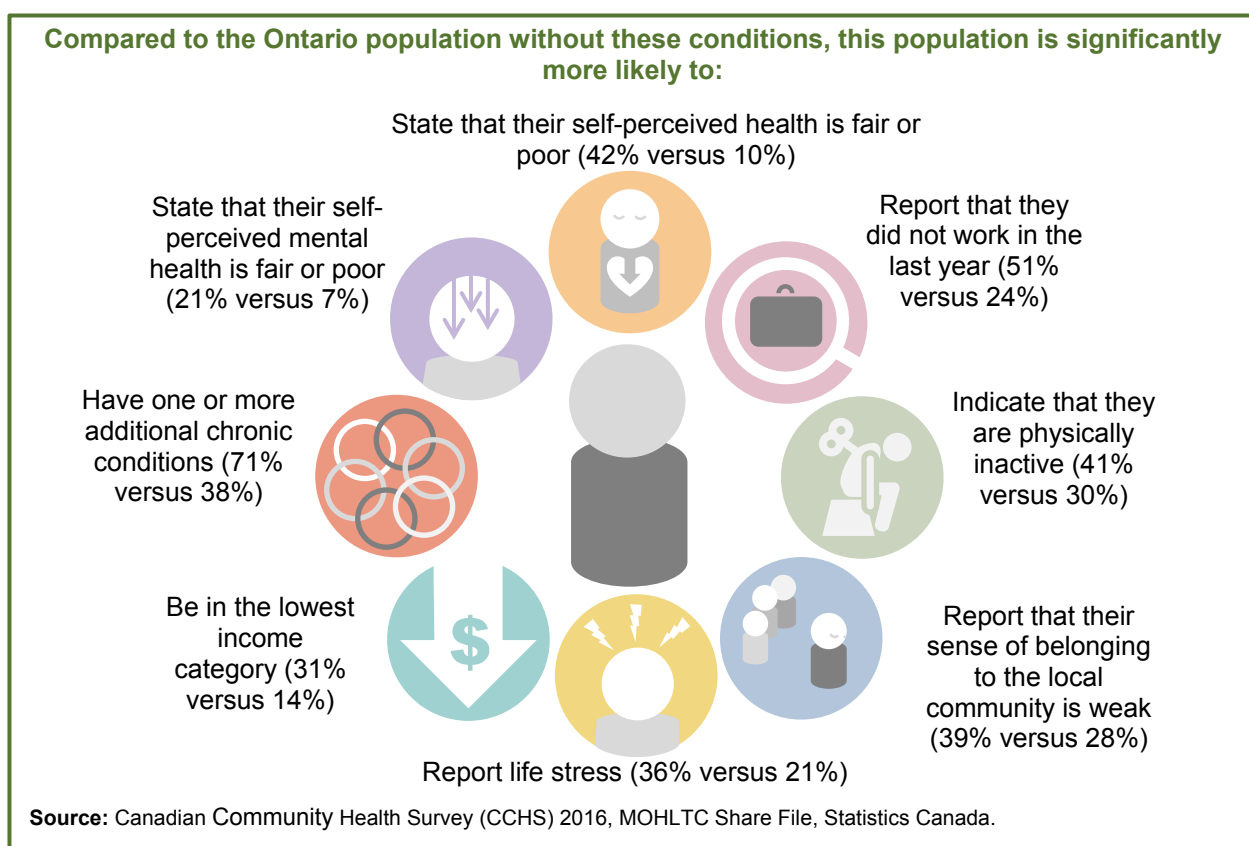
Task force members all agreed with and support these recommendations. The task force also discussed in detail another recommendation on additional funding for the Environmental Health Clinic at the Women’s College Hospital, but did not reach agreement. Some members wanted to see an immediate increase in funding for the Environmental Health Clinic as a way to reduce wait times and improve access to specialized care while the action plan is initiated. Other members were concerned that approach would simply maintain the status quo and potentially delay the much needed investment in developing a centre of excellence and for the enhanced system of primary care proposed in the report. This underscores the challenge ahead to provide immediate and sustainable health care for people with ME/CFS, FM and ES/MCS.

I. The Health Care Gap

More than 740,000 Ontarians² – six of every 100 people age 12 and older – live with one or more of three complex chronic conditions:

- myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)
- fibromyalgia (FM) and/or
- environmental sensitivities/multiple chemical sensitivity (ES/MCS).

That is more than twice the number of people in the province living with chronic obstructive pulmonary disease (COPD).³ **ME/CFS, FM and ES/MCS are profoundly life altering conditions that have a drastic impact on people's health and quality of life.** In some cases, the symptoms are so severe that people are housebound and even bedbound. In addition, people living with these conditions are more likely to have poorer social and health outcomes.⁴



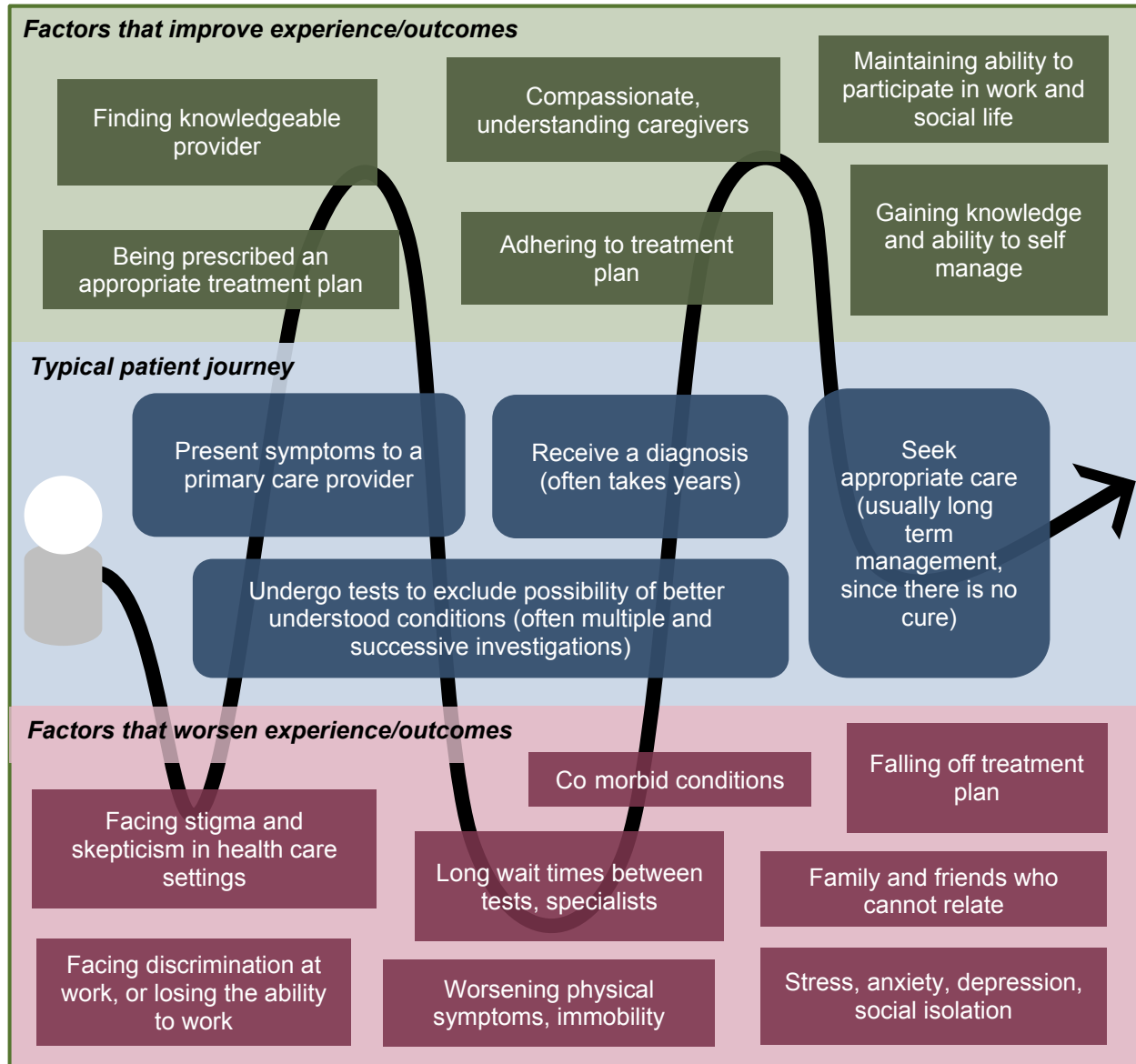
² Includes Ontarians age 12 years of age or older. Source: Canadian Community Health Survey (CCHS), 2016, MOHLTC Share File, Statistics Canada.

³ Statistics Canada. Table 13-10-0096-01 Canadian health characteristics, annual estimates. <https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1310009601>

⁴ Canadian Community Health Survey (CCHS) 2016, MOHLTC Share File, Statistics Canada.

Despite the large number of Ontarians affected, these complex chronic conditions remain under-recognized, under-researched, poorly understood and poorly managed. Care providers lack the knowledge, resources and support they need to serve those affected. More often than not, the care provided does not work for patients and their families.

Patient Experience



In May 2016, to help improve care and health outcomes for people living with ME/CFS, FM and/or ES/MCS, the Minister of Health and Long-Term Care established the Task Force on Environmental Health (task force). Since then, the task force has worked hard over many months to understand the current state of evidence and research on ME/CFS, FM and ES/MCS as well as the current state of care, health provider education and general awareness about these complex chronic conditions. The findings? Throughout the health care system and in society at large, there is:

I can't go to church anymore. Unless they see you faint it's invisible. The aftermath isn't shown. It's like people have to be personally affected to understand. – Bailey (pseudonym)

- little recognition of how serious and severe these conditions are
- a shortage of knowledgeable care providers
- a lack of clinical tools to support and guide care
- a discouraging shortage of services and supports for people living with these conditions
- a dearth of research and leadership to improve the management of these conditions as well as health outcomes for those affected
- a failure to acknowledge the stigma associated with these conditions and its devastating impact on people's lives.

These gaps in knowledge and care have devastating effects on Ontarians struggling with ME/CFS, FM and ES/MCS. In addition to experiencing poor health outcomes, people with these chronic conditions suffer from a lack of access to safe housing and challenges accessing education.

The recommendations in this report and in the task force's Phase 1 report – *Time for Leadership: Recognizing and Improving Care for those with ME/CFS, FM and ES/MCS* (July 2017) – are designed to close those gaps and create a system of care that actively supports patients, families and care providers.

The Conditions and Their Impact

People with **myalgic encephalomyelitis/chronic fatigue syndrome** (ME/CFS) suffer from chronic and disabling fatigue that does not improve when they rest or sleep. The conditions may cause profound weakness and people find it very difficult to complete simple everyday tasks. Minimal physical, mental or cognitive exertion results in a myriad of symptoms, such as soreness and feeling drained or sick. People with ME/CFS also experience varying degrees of sleep disturbances and problems with memory and concentration or symptoms that arise when standing and resolve when lying down (e.g. orthostatic intolerance) and pain. ME/CFS affects multiple systems in the body (e.g. respiratory, nervous, digestive).

People with **fibromyalgia** (FM) suffer from chronic, widespread pain with varying intensity and severity. Patients' pain can fluctuate or change in intensity on a daily or monthly basis, or due to circumstances (e.g. stress, strenuous exercise, prolonged inactivity, weather or temperature changes). Other symptoms include poor sleep, physical exhaustion and problems with memory and concentration. Researchers think that the pain of fibromyalgia is caused by altered pain processing due to atypical brain chemistry and function.

People with **environmental sensitivities/multiple chemical sensitivity** (ES/MCS) suffer from a range of recurrent symptoms, which can be very severe, such as headache, respiratory problems, irritated eyes, nose and throat, and problems thinking or concentrating (e.g. feeling dull/groggy/spacey) as well as increased incidence of fatigue and/or odor hypersensitivity. Symptoms affect multiple organs. Symptoms are triggered by exposure to low levels of chemical, biologic or physical agents in their environments, which they used to tolerate and are tolerated by others.

Although there is a lack of understanding and awareness of these conditions in the medical community, each one is distinct and recognized as real. Their characteristics and symptoms are known but their causes and underlying pathophysiological mechanisms are still unclear.

Although patients with any of these three disorders are often at risk of also experiencing anxiety, depression or other psychiatric conditions, the evidence does not indicate that any of these conditions is mainly psychological. Psychological approaches to care have had very limited success. The stigmatization that patients with these disorders often experience likely contributes to anxiety and depression.

II. About the Task Force

Our Membership

The task force is a highly skilled group of researchers, clinicians with experience caring for people with ME/CFS, FM and ES/MCS, people with lived experience of these conditions, family caregivers, patient advocates and representatives of ministries and other organizations. One-third of its members are people with lived experience. See Appendix A for a list of members.

Our Mandate

The task force's goal was to improve care and the patient experience for Ontarians living with ME/CFS, FM and ES/MCS. Its three-year mandate was to:

- inform guidelines and policies to support patients with these health conditions
- increase public and health care providers' knowledge of these health conditions and reduce stigma
- identify gaps in evidence, knowledge transfer and care for those affected by these conditions
- identify patient-focused actions to improve health outcomes.

Our Approach

The task force's work happened in two phases:

- Phase 1 – assessed the evidence and recommended early steps to enhance awareness and knowledge
- Phase 2 – developed a comprehensive set of recommendations that, when implemented, will increase awareness, enhance access to clinical tools and interdisciplinary care teams, and create a system of care that will improve the diagnosis, treatment and management of ME/CFS, FM and ES/MCS.

To complete its work, the task force formed three working groups: research, care and education. Each group examined the current state of knowledge, identified gaps and opportunities, established priorities and recommended practical approaches to improve care.

Using an approach that integrated health system and clinical evidence, lived experience and clinical experience⁵, the task force gathered evidence, information and key resources from:

- expert members of the task force – scientists, clinicians, people with lived experience and caregivers
- outside clinical experts who made presentations to the task force
- a survey of physician experiences
- research on health system utilization and associated costs
- analysis of existing clinical tools
- work by an expert panel to reach consensus on clinical case definitions
- data and research gathered and analyzed by the task force secretariat.

The task force benefited from its members' extensive expertise. Members would particularly like to acknowledge the critical importance of the knowledge and experience of individuals and families living with these conditions.

The Phase 1 Report

Our Phase 1 report, *Time for Leadership: Recognizing and Improving Care for those with ME/CFS, FM and ES/MCS*⁶, submitted to the then Minister of Health and Long-Term Care on July 9, 2017, confirmed that the poor health outcomes of people with these conditions are the result of gaps, barriers and attitudes in the health system and society at large.

In that report, the task force made eight interim recommendations and we are encouraged that action has already been taken on some of them. Specifically, the ministry:

- issued a supportive public statement in the Health Bulletin (September 29, 2017) recognizing the conditions and committing to ongoing efforts to improve care⁷
- invested up to \$200,000 to support the development of expert consensus on clinical case definitions for ME/CFS, FM and/or ES/MCS, which will help guide primary clinical care in Ontario
- extended the funding for the enhanced skills program in clinical environmental health for 3rd year residents in family medicine at the University of Toronto.

Other recommendations from *Time for Leadership* are elaborated on in this report. See Appendix D for a summary of all eight recommendations. That report serves as the

⁵ Jacobs JA, Jones E, Gabella BA, Spring B, Brownson RC. Tools for Implementing an Evidence-Based Approach in Public Health Practice. *Prev Chronic Dis* 2012; 9:110324.

https://www.cdc.gov/pcd/issues/2012/11_0324.htm

⁶http://www.health.gov.on.ca/en/common/ministry/publications/reports/environmental_health_2017/default.aspx

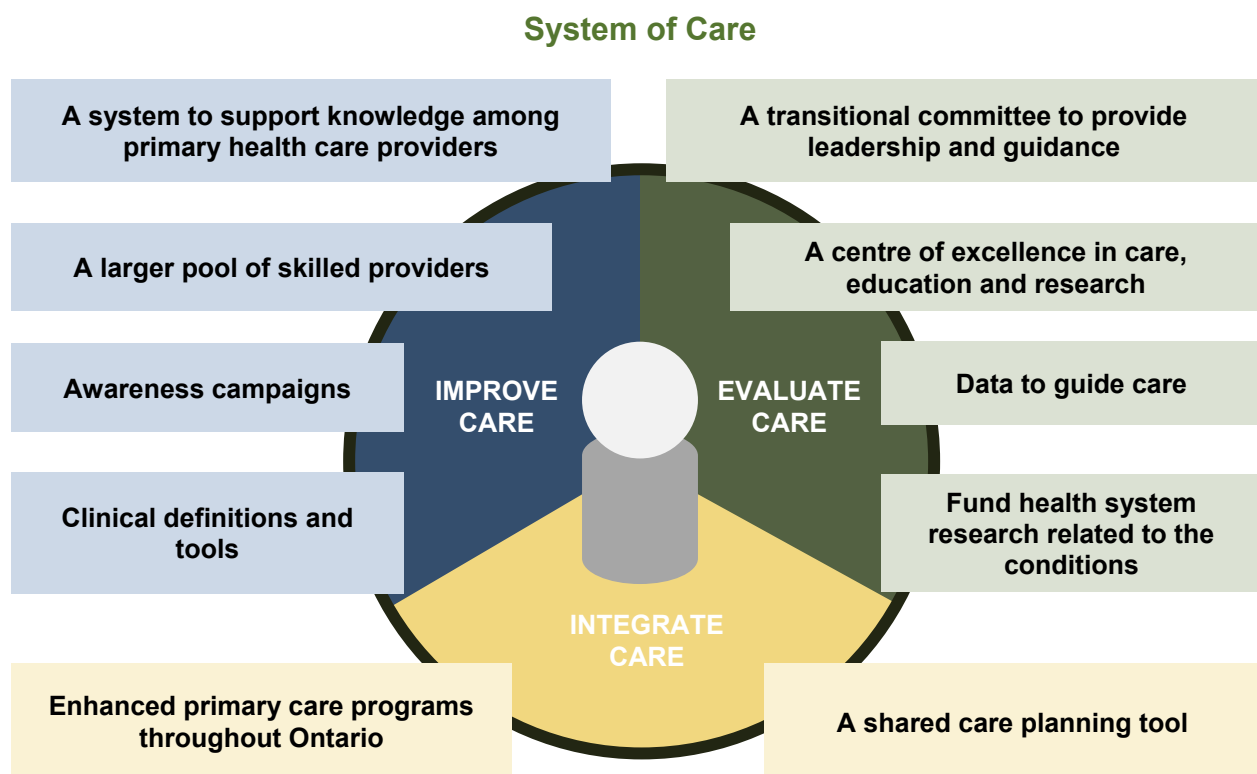
⁷ http://www.health.gov.on.ca/en/news/bulletin/2017/hb_20170929.aspx

foundation for the following action plan for a system of care for ME/CFS, FM and ES/MCS.

III. Action Plan for a System of Care

Based on its extensive research and consultations, the task force has developed an evidence-based, practical and incremental plan for a patient-centered system that will improve care and supports for people living with ME/CFS, FM and ES/MCS and their families. This system of care will give both patients and providers the support they need, while ensuring that the system is flexible enough to adapt to new research and clinical evidence and meet patients' changing needs.

This system of care is organized around three strategic initiatives: improve care, integrate care and evaluate care.



These initiatives are designed to close gaps in care, research and education/awareness, and improve health and social outcomes.

The greatest challenge in improving the health of people with these complex chronic conditions is the lack of clinical and scientific understanding of their causes, cures and best care. Unlike other chronic diseases – such as diabetes, asthma and arthritis – these conditions do not belong to a specific medical specialty nor do they have established standardized diagnostic tools, treatments or cures.

The system of care we propose creates opportunities to use chronic disease management approaches already in place in Ontario to provide appropriate care in the short term, gather data to evaluate these management strategies in real time and, over

time, develop a body of knowledge and skilled providers who are able to help people living with ME/CFS, FM and ES/MCS.

With this proposed action plan, Ontario has the opportunity to become a global leader in the management of ME/CFS, FM and ES/MCS.

Improve Care

Goal: Improve the quality, consistency and accessibility of care for these conditions by raising awareness, developing clinical tools and training more care providers.

The most important action the ministry can take to help people living with ME/CFS, FM and ES/MCS is to improve care now.

Ontario must commit to removing systemic barriers to care by:

- raising awareness of these conditions among the general public and health care providers
- giving health care providers the tools they need to help their patients
- developing more skilled providers who are knowledgeable about these conditions.

1. Raise Awareness, Reduce Stigma

Stigma has a devastating effect on Ontarians living with ME/CFS, FM and ES/MCS and their families:

- Many providers are unaware of these conditions and may question or dismiss patients' symptoms.
- Family caregivers, who often take on a severe caregiving burden, lack access to credible information about the conditions and can struggle to empathize with the patient experience.
- Employers, landlords and others often deny them insurance benefits⁸, social services, accommodations and other supports because they are sceptical about their conditions.

There is an institutionalized bias against ME and ME patients, that has really made life hell for anybody with ME. I've been denigrated ... made to feel that I was wasting doctors' time, the system's time. In talking to ME patients, the one thing that would make them feel better is if physicians said, "I don't know what's wrong with you, but I will help you try to figure it out," versus, "you've got a mood disorder," and dismissing their physical symptoms entirely. – Scott

⁸ Business Case for an Ontario Centre of Excellence in Environmental Health.
<http://recognitioninclusionandequity.org/about-theconditions/community-consultation-and-patient-survey/>

- Individuals themselves are often unaware of these conditions and their symptoms, which undermines their ability to seek appropriate care and advocate with providers, employers and others for the care and accommodation they need.

Stigma is mainly due to lack of awareness about ME/CFS, FM and ES/MCS in society at large and lack of recognition that they are real physical illnesses.

Raising awareness is a critical first step in stopping stigma and the pain it causes, promoting a better understanding of these conditions and significantly improving relationships between patients and health care providers.

Recommendation 1

Develop a one-to-three year awareness campaign that targets:

- the general public – with a special focus on employers and housing providers
- health care facilities and providers – with a special focus on hospitals, long-term care homes and home care providers
- primary care settings – with a special focus on patients and all staff.

For all three targets of the awareness campaign – general public, health care facilities and primary care settings – the purpose is to raise awareness of the conditions and their disabling impact on the people who have them. The key messages that will improve the patient experience are:

- People with ME/CFS, FM and ES/MCS experience profound physical, mental, social and economic impacts as a result of these conditions.
- Families and caregivers need support to understand and help their loved ones.
- Health and other service providers as well as employers can and should accommodate people who have these complex chronic health conditions and abide by the Ontario Human Rights Code and the Accessibility for Ontarians with Disabilities Act.

Because it takes so much energy to get out, I have lost so many friends. Because of my 3-year-old, I have made a few connections at playgrounds, not really friendships though. I don't want to be negative and tell them the truth about how I am. Also, a lot of the time, people don't really understand. They think, she looks good, she looks fine, this disability is invisible. I remember one time I was at a playground with some parents and we were standing and talking when I asked if we could move next to a bench so I could sit down, but they wouldn't. I wanted to stay with them but it is very hard to be on my feet. I cannot stop and talk to a neighbour. I will collapse. Shopping is very hard and the worst is standing at the cashier. I bring a folding stool with me whenever I am even capable of going to get groceries. People don't understand, they just don't get it. You cannot assume that people who look fine are well. If someone asks to be accommodated, you should listen. – Lily

- People living with these conditions deserve to be considered fairly for insurance benefits, safe housing and social services.

Educate the General Public

Recommendation 1.1

Develop awareness materials that target the general public and specifically engage priority groups, starting with employers and landlords.

The task force recommends the ministry support the development of materials that can be widely disseminated to the general public over time. The task force also suggests that the ministry work with government partners to communicate the key messages widely and encourage appropriate accommodation.

People living with ME/CFS, FM and ES/MCS experience stigma in many non-medical contexts – both formal and informal – and this stigma has a significant negative impact on their quality of life. For example, landlords, employers, friends, family or caregivers are often skeptical about the severity and impact of their conditions. An awareness campaign that talks about these conditions, the symptoms and their impact is a fundamental first step in improving the patient experience. We recommend that:

- Messages highlight the severity of these disabling conditions and their impact.
- Messages be visible on ministry-supported mediums such as web sites and social media.
- The ministry work across government with stakeholders at the Ministry of Municipal Affairs and Housing, the Ministry of Labour and the Ministry for Seniors and Accessibility to reach housing providers and employers and provide clear, credible information about the disabling nature of these conditions and the duty to accommodate people with ME/CFS, FM and ES/MCS (see recommendations from the Phase I report in Appendix D).

This disease is very isolating. I used to like to go to live theatre and concerts but because of exposures I've given up ... When I register the smell a headache comes on pretty quickly then my brain turns to mush. I can't think or can't speak. There's been a couple of scary incidents when I was legally impaired, couldn't drive home. My arms were made out of lead. It's unpleasant. It sounds a lot like being poisoned. I'm afraid to get hurt. I'm afraid. There are days when I feel like I'm one step away from being a shut in and it depresses me. – Pat (pseudonym)

Target Health Facilities and Services

Recommendation 1.2

Create materials and tools designed to promote awareness of ME/CFS, FM and ES/MCS and explain how to accommodate patients with these chronic conditions in priority health care settings, starting with hospitals, long-term care homes and key home care providers.

The task force recommends the ministry support the development of materials specifically for health care settings. These materials should focus on the disabling nature of these conditions and the critical importance of accommodation. To do this, the ministry should build on existing work and expertise, particularly that of the Environmental Health Clinic at Women's College Hospital.

The task force also recommends that the ministry actively engage with hospitals, long-term care homes and home care providers to develop education programs for staff and shape practices.

A major barrier for people living with ME/CFS, FM and ES/MCS is a lack of awareness of these conditions on the part of providers and staff in health care settings, which means they are often unwilling to accommodate patients when they seek care. For example, they may not be aware that people with these conditions may be highly sensitive to light, noise and touch.

In many cases, health care providers and administrative staff in hospitals, long-term care homes and community settings want to help but don't know how. As a result, when patients go to health care facilities

I've had to go to the ER a few times from my reactions to exposures. Should have gone more but didn't because of the cleaners they use there. Since a lot of reactions occurred at work, just for documentation I had to go to the hospital, but it also makes me sick. – Chris (pseudonym)

complaining of what are often "invisible" symptoms, they experience stigma, negative interactions, stress as well as adverse reactions to exposures to air, light and noise in those settings and a worsening of their conditions. With the right policies, practices and attitudes, health care facilities can provide patient-specific accommodation designed to prevent reactions, minimize discomfort and build trust with patients and families.

The ministry should leverage its relationships with all parts of the health care sector – particularly hospitals, long-term care homes and home care providers – to raise awareness and establish effective policies and practices.

Awareness materials, such as guidelines, posters and brochures, should be disseminated to all settings. Those materials should be user friendly, easy to use, visible to all staff and the public, and seen as credible throughout the health system.

The key messages should focus on the disabling nature of the conditions, the need to accommodate patients, the impact on family caregivers and practical information and tips on how to help.

I have had a lot of help from my elderly mother but it is very hard on her. Daily she takes care of my kids, does shopping, all sorts of things. She helps me with everything. I am so lucky, I don't know what I would do if I didn't have her help. – Lily

To develop materials and messages, the task force recommends that the ministry:

- build on existing work, such as the Quinte Healthcare Corporation Policy on Multiple Chemical Sensitivities⁹ and the guidance for hospital staff contained in *Environmental health in hospitals: A practical guide for hospital staff* (2001)¹⁰
- seek guidance from the Environmental Health Clinic at Women's College Hospital.

The second part of this recommendation – the call for the ministry to work directly with health settings to shape practices – recognizes that patients with ME/CFS and FM¹¹ have complex health needs and, as a result, use more health services than other patients of similar age, sex and geography. They have more interactions with a health care system that largely does not recognize or understand the effect the conditions have on their lives. When visiting a hospital for any reason, such as day surgery, cancer care or another illness, patients can find themselves explaining what they need over and over. The task force has heard anecdotal accounts of patients, particularly those with ES/MCS, avoiding hospitals even when they need them. Patients in long-term care struggle to get accommodation to avoid the problems they experience from poor indoor air quality or painful stimulation from touch, light and noise. Although patients with ME/CFS and FM utilize home care services at a greater rate than others of similar age, sex and geography,¹² we have heard anecdotally that case managers have a variable understanding of the conditions and their functional limitations.

We understand that, in Ontario's large and decentralized health system, it can be difficult to promote and enforce accommodation strategies. In pursuit of a collaborative approach to improving accommodation, the task force recommends the ministry engage

⁹ Quinte Health Care (2010). Multiple Chemical Sensitivities. *Policy no: 232*. <http://www.qhc.on.ca/multiple-chemical-sensitivities--p279.php>

¹⁰ Marshall, LM and Maclennan JG. (2001). "Part I Pollution prevention" and "Part II Environment-sensitive care," in *Environmental health in hospital: A practical guide for hospital staff*. Canadian Society for Environmental Medicine.

¹¹ Note: These findings are based on analysis that did not include ES/MCS

¹² Health care utilization and costs among Ontarians with Chronic Fatigue Syndrome or Fibromyalgia. Institute for Clinical Evaluate Sciences (2018, September 21): p. 11.

with key partners in the health system through its appropriate liaison branches, focusing particularly on hospitals, long-term care homes and home care providers. The objectives should be to:

- endorse the guidelines and tools the ministry has created
- shape policies and practices in health care facilities
- promote changes in staff awareness and attitudes.

Recommendation 1.3

Increase awareness of ME/CFS, FM and ES/MCS, clinical tools and information, and the need for accommodation, in all primary care settings in Ontario.

The task force recommends that the ministry support the development and dissemination of a package of materials that promotes awareness and accommodation to all clinicians, staff and patients in primary care settings. The package should include case definitions and clinical tools as well as information for patients.

Engage Primary Care

Compared to others in Ontario, people with these conditions are significantly more likely to have one or more additional chronic conditions (71% versus 38%), and to state that their health status is fair or poor (42% versus 10%).¹³ These health differences may explain why patients with CFS and/or FM use physician services more frequently.¹⁴

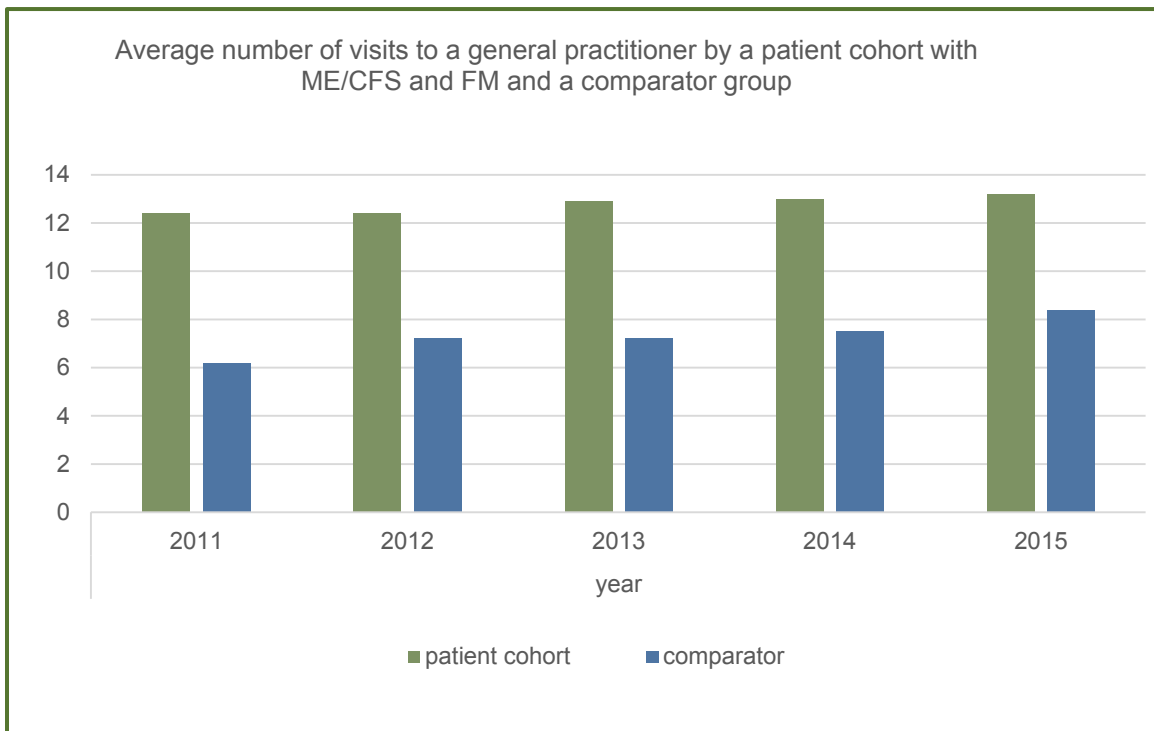
Because people with these conditions see primary care providers frequently, it's critically important that those providers be knowledgeable about their health needs. The task force recommends that the ministry support a comprehensive awareness campaign targeted to all primary care settings that provides key information for physicians, other clinic staff, patients and visitors.

¹³ Refers to the chronic conditions: asthma, arthritis, COPD, diabetes, hypertension, heart disease, cancer or stroke. Source: Canadian Community Health Survey (CCHS) 2016, MOHLTC Share File, Statistics Canada.

¹⁴ Compared to others of a similar age, sex and geography, a greater proportion of patients with ME/CFS and FM had 1+ visit to their general practitioner (GP) and visited their GP more frequently per year. Source: Health care utilization and costs among Ontarians with Chronic Fatigue Syndrome or Fibromyalgia. Institute for Clinical Evaluative Sciences (2018, September 21): p.7.

This campaign should include:

- general awareness messages that can be made visible to all staff and visitors
- the Ontario Consensus on Clinical Case Definitions for each of the conditions and references to any clinical tools and other resources for primary care providers
- a ministry-endorsed, patient-specific resource that provides high level information about the conditions.



Source: Institute for Clinical Evaluative Sciences (2018, September 21). Health care utilization and costs among Ontarians with Chronic Fatigue Syndrome or Fibromyalgia. *Response to a Ministry of Health and Long-Term Care Applied Health research Question*

How to Build an Effective Awareness Campaign

To help guide the development of an effective awareness campaign, the task force examined studies of campaigns related to other stigmatized illnesses, such as HIV/AIDS, obesity, and mental health and addictions. Effective campaigns incorporate the following key elements:

- The information is seen as conclusive and is promoted by people who have a reputation for being reliable and credible.¹ The campaign messaging should include the most up-to-date, credible information available. The campaign should be endorsed or presented by credible, trustworthy sources.
- People can relate to the experience of the stigmatized group.² For example, the effect of the message can be increased by aligning it with the idea that people with disabilities deserve a good quality of life, which is something people can relate to.³
- The messages are able to reach a diverse audience that, in this case, would include those who have these conditions, their caregivers, those who have important interactions with people with these conditions, such as employers and landlords, and the general public.
- The approach addresses both public (individual) and structural (organizational) stigma.⁴
- The campaign is well researched, planned and funded over time, and uses multiple ways to deliver its message(s).⁵
- The causes of the illness(es) have been identified and cures developed. While great progress has been made in understanding ME/CFS, FM and ES/MCS, new developments are emerging all the time. The campaign materials should be easy to update to reflect new evidence as it emerges. However, even before we have all the evidence, messaging should emphasize that it is possible to manage these conditions.⁶
- The campaign uses a variety of formats – posters, brochures, web-based, social media – to communicate messages consistently and broadly.
- Progress in proactively changing social views is monitored and measured over time.

¹ Clair, Mathew, Caitlin Daniel, and Michele Lamont (2016, March 15), "Destigmatization and health: cultural constructions and the long-term reduction of stigma," *Social Science and Medicine*, 165: 223-232.

² Clair et al., (2016) *Social Science and Medicine*.

³ Clair et al., (2016) *Social Science and Medicine*.

⁴ Committee on the Science of Changing Behavioral Social Norms (2016).

⁵ Committee on the Science of Changing Behavioral Social Norms (2016).

⁶ Committee on the Science of Changing Behavioral Social Norms (2016), "Ending discrimination against people with mental and substance use disorders: the evidence for stigma change," *Washington DC: National Academy Press*. <https://www.nap.edu/read/23442/chapter/1>

2. Develop and Disseminate Clinical Tools

In response to the task force's recommendations in its Phase 1 report, the ministry took steps to develop clinical case definitions and tools. In late 2017, the ministry contracted with the Centre for Effective Practice to conduct a consensus process to develop the Ontario Consensus on Clinical Case Definitions for each of the conditions (Appendix G). The second part of this recommendation, the development of clinical tools based on these definitions, still needs to be completed.

We considered the possibility of it being CFS for a while, but my family doctor wanted to make sure we weren't missing anything. – Ali

These two pieces of work are critical to improving care. Analysis conducted by Ipsos for the task force clearly indicated that many physicians in Ontario have patients with the conditions and would like more information to help them provide better care.¹⁵

Recommendation 2

Develop and disseminate clinical tools and information that support evidence-informed treatment and management.

New approaches to treatment and management – including the Ontario definitions and clinical tools for diagnosis, treatment and management – should be developed and disseminated to all primary care settings through established channels. Knowledge translation efforts should reflect proven, effective approaches for reaching clinicians and changing clinical practice.

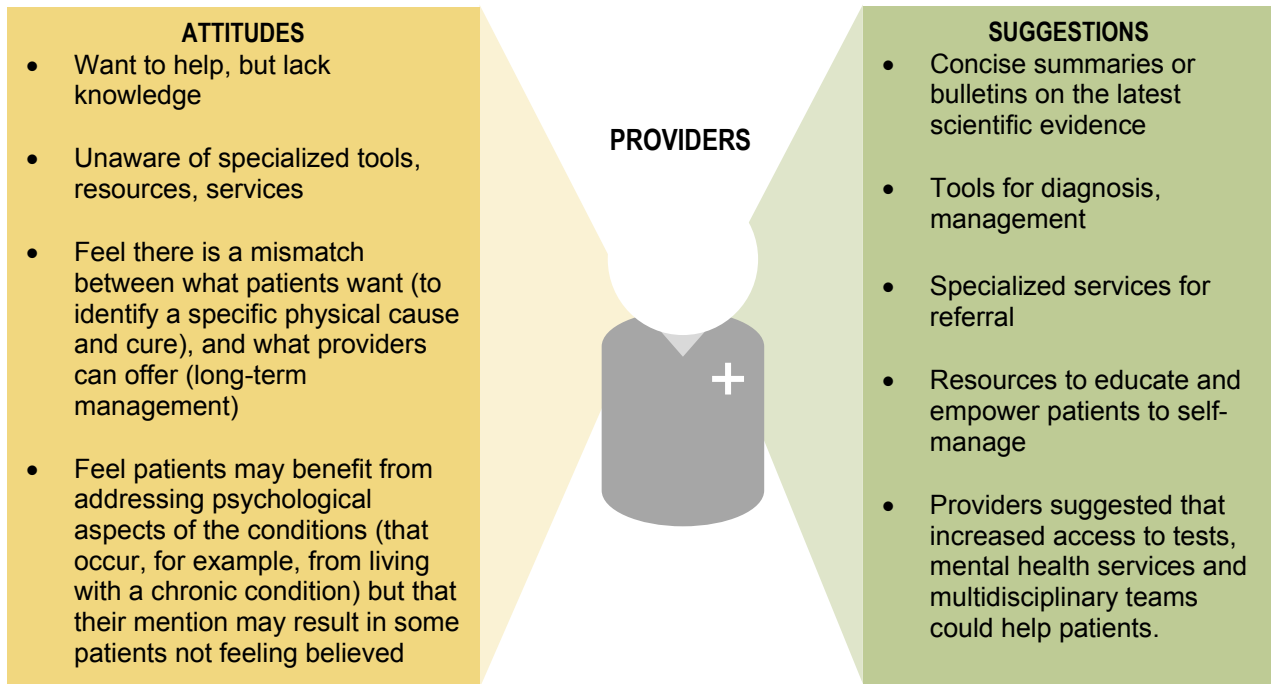
We recommend the ministry develop and disseminate clinical tools that primary care providers can access at the point of care to improve diagnosis, treatment and management of ME/CFS, FM and ES/MCS, including: syntheses, summaries, critically-appraised topics and articles, evidence-based practice resources, guidelines, differential diagnosis tools and calculators.

These tools should be disseminated using approaches that reflect current research into clinical knowledge translation and proven, effective approaches for reaching clinicians and changing clinical practice.¹⁶ The tools should be developed using credible sources and content, and leverage the work of the Environmental Health Centre at Women's College Hospital.

¹⁵ Ipsos Public Affairs (2018, January). Ministry of Health and Long-Term Care Health Practitioner Consultation: Qualitative Report for the Task Force on Environmental Health. Prepared by Ipsos Public Affairs.

¹⁶ Communicating With Physicians to Influence Practice: A Rapid Review Update, Sharon Lobo, Physician Outreach Specialist, Peel Public Health, February 2017.

Provider Attitudes and Suggestions



Source: Ipsos Public Affairs (2018, January). Ministry of Health and Long-Term Care Health Practitioner Consultation: Qualitative Report for the Task Force on Environmental Health. Prepared by Ipsos Public Affairs.

3. Develop a Skilled, Knowledgeable Health Workforce

Recommendation 3

Establish a system to develop and support a cadre of primary health care and specialized providers skilled in managing ME/CFS, FM and ES/MCS

The task force recommends that the ministry establish the type of training and other supports required to develop a knowledgeable workforce of both primary care providers and specialists skilled in the diagnosis, treatment and management of these complex chronic conditions.

Interested providers should be recruited through a variety of channels.

To improve care for people with ME/CFS, FM and ES/MCS, the health care system must develop a knowledgeable health workforce. The goal should be to enhance the skills of both primary care and more specialized providers.

It is challenging to build new clinical knowledge in health professions at all levels of education and practice. Schools face many competing demands so it is difficult to get

new material into the curriculum. At the undergraduate level, accredited medical/nursing programs in Canada establish curriculum requirements for educational programs independent of government. At the individual school level, each school designs its own curriculum and there is no central way for the ministry to influence that process. Engaging directly with individual medical and nursing schools is one way to influence curricula, but it is time consuming and the outcome is uncertain.

It is also challenging to get content into continuing education programs for health care providers already in practice. The Ontario College of Family Physicians offers accredited education programs for physicians on the conditions, air quality and health; however, demand for the course is low so it is not offered regularly.¹⁷

I got sick very abruptly in 1999 and saw my family doctor and tried so many things, but it took 11 years of suffering to get the diagnosis. I eventually got diagnosed with FM. I was also diagnosed with ME and I experience symptoms of ES/MCS as I react very strongly to many substances, including medication. – Lily

Given these challenges, the most effective approach to provider education is likely to be one that is highly targeted to providers with an interest in these conditions.

Support Primary Care Providers

Recommendation 3.1

Establish a community of practice to provide training and support the network of primary care clinics that will provide chronic disease management for people with ME/CFS, FM and ES/MCS across the province.

The task force recommends that the ministry support the development of a community of practice in ME/CFS, FM and ES/MCS that, over time, will evolve into an Extensions for Community Healthcare Outcomes (ECHO) program that can train and support primary care clinicians in local communities and link them with expert specialist teams at an academic hub.

While all primary care providers should be aware of these conditions and their impact, only a select number are likely to be interested in developing advanced expertise in managing them. The task force recommends that, to maximize the return on investment, the ministry identify/recruit interested primary health care providers across the province and target the advanced training to them. As providers become aware of these conditions and trustworthy, credible clinical tools are developed, we anticipate

¹⁷ <http://ocfp.on.ca/cpd/credit-login/cfpc-certification-exam-workshop/offerings/environmental-health>

that more clinicians will be interested in learning about how to manage these conditions more effectively.

To provide that training, the task force recommends that the ministry support the creation of a distributed “community of practice” (CoP): a group of health professionals who work together to identify and leverage best practices and standards. Through a CoP, professionals share information and experiences, learn from each other and have an opportunity to develop both personally and professionally.¹⁸ This community also provides opportunities to access formal training.

The task force recommends that the ministry promote the CoP by initially supporting a monthly teleconference/webinar where experts speak to specific topics and take questions from health care providers. This process, which can be led and organized by the Environmental Health Clinic at Women’s College Hospital, will require:

- identifying and contracting with appropriate experts
- promoting and administering the community of practice
- monitoring topics and responding to questions.

The experts hosting the CoP should receive honoraria or other forms of compensation. In addition, adequate resources should be allocated to cover administrative and promotion costs.

Through the CoP, primary care providers will be engaged in activities and opportunities that address their specific needs and skills. Knowledge sharing tools should provide opportunities that include: being able to ask individual questions; participating in enhanced care delivery; and being a knowledge expert who shares expertise with other providers.

Eventually the CoP group should become more robust and evolve into an Extensions for Community Healthcare Outcomes (ECHO) program.¹⁹ The ECHO model effectively and efficiently provides training for primary care clinicians in local communities and links them with expert specialist teams at an academic hub. Primary care clinicians become part of a learning community, where they receive mentoring and feedback from specialists.²⁰ The task force recommends that, in tandem with developing a CoP, work should begin as soon as possible to identify the necessary expertise and network required to create a robust ECHO program in ME/CFS, FM and ES/MCS.

¹⁸ Li, Linda C; Grimshaw, Jeremy M; Nielsen, Camilla; Judd, Maria; Coyte, Peter C; Graham, Ian D (17 May 2009). "Use of communities of practice in business and health care sectors: A systematic review". *Implementation Science*. **4** (1). doi:10.1186/1748-5908-4-27.

¹⁹ There are several ECHO programs in Ontario, including ones for chronic pain and opioids, mental health and addictions, and rheumatology.

²⁰ ECHO Ontario <https://www.echoontario.ca/>

Train More Specialized Providers

Recommendation 3.2

Fund a comprehensive strategy to increase the pool of skilled, specialized providers to reflect the high demand for interdisciplinary care.

The task force recommends that the ministry explore options to increase the pool of specialized providers with the expertise to provide interdisciplinary care for patients with ME/CFS, FM and ES/MCS, including the University of Toronto Enhanced Skills Program.

In Ontario, there are very few secondary or specialized care providers who have a special interest or expertise in ME/CFS, FM and ES/MCS and most either work or have trained at the Environmental Health Clinic at Women's College Hospital in Toronto. There is no formal medical specialization or certification for expertise in these conditions. Historically, physicians have gained expertise through self-study, peer-to-peer learning and experience treating patients.

Since 2014, the Environmental Health Clinic has supported a one-year residency for family physicians offered through the University of Toronto Enhanced Skills Program. This residency is currently the only formal way for physicians in Ontario to gain expertise in managing these conditions. Based on patient demand for services at the Environmental Health Clinic, there is clearly a need for more specialized providers. In our Phase 1 report, we recommended that the ministry continue to fund this program, which it has done. However, more must be done to increase the pool of specialists in Ontario.

The Enhanced Skills Program in Clinical Environmental Health, funded by the ministry – referred to as the “fellowship” or PGY3 – is a one-year full-time program for third-year family medicine residents. It has also been extended to practicing family physicians.

I waited over a year to be seen at the EHC. My life changed significantly with the EHC experience three years ago. I've been sick for fourteen years. They were able to tell me exactly what this was. No cleaning products in your house, everything natural. I've had to change my life completely. – Chris (pseudonym)

The program, which offers two different courses – one on the conditions and one on exposures – provides curriculum-based clinical teaching focused on addressing the needs of patient populations. It is designed to enhance primary care providers' knowledge and awareness of environmental health conditions. Graduates practice comprehensive family medicine and act as a resource to patients and colleagues in their area of enhanced training. Trainees in the program build diagnostic skills while working with patients to:

- develop a detailed family health history as well as a chronological history of environmental exposures
- identify practical, systematic ways to address a range of factors that might improve patients' health status and quality of life.

In April 2014, the ministry provided funding to the University of Toronto to support two positions a year for three years. In March 2018, the ministry extended the funding for another three years (to 2021) for up to four candidates.

While the program offers access to training otherwise unavailable anywhere in Ontario, it has not always been able to attract enough applicants to fill all the funded positions. This is due to a number of factors, including:

- The program requires participants to be in Toronto for a year, which often means relocating and leaving their current practice.
- New family physician graduates are not aware of these conditions.
- The program may be more suited to established family physicians who may have patients with the conditions, but the PGY3 is primarily marketed to 3rd year family medicine residents.
- The program, which is delivered by the Department of Family and Community Medicine, is limited to family physicians/residents and not open to nurse practitioners or other types of physicians.
- The program does not offer a certification or degree, and has no research component, so it may not be an attractive educational investment for physicians.

Even when all the available spots in the program are filled, the pool of providers will grow very slowly. For this reason, we recommend the ministry see this program as only part of a broader strategy to build a pool of specialized multidisciplinary care providers.

Specifically, the task force recommends exploring opportunities to: provide shorter (i.e. three months instead of a year) or more spread out, less intensive learning opportunities that allow physicians to stay in their communities while learning; and create education opportunities for other providers on the multidisciplinary team, such as nurses, social workers and allied health professionals. We also encourage the ministry to explore options to partner with a master's degree granting program.

The task force also discussed in detail another recommendation on additional funding for the Environmental Health Clinic but did not reach agreement. Some members wanted to see an immediate increase in funding for the Environmental Health Clinic as a way to reduce wait times and improve access to specialized care while the action plan is initiated. Other members were concerned that approach would simply maintain the status quo and potentially delay the much needed investment in developing a centre of excellence and for the enhanced system of primary care proposed in the report.

Integrate Care

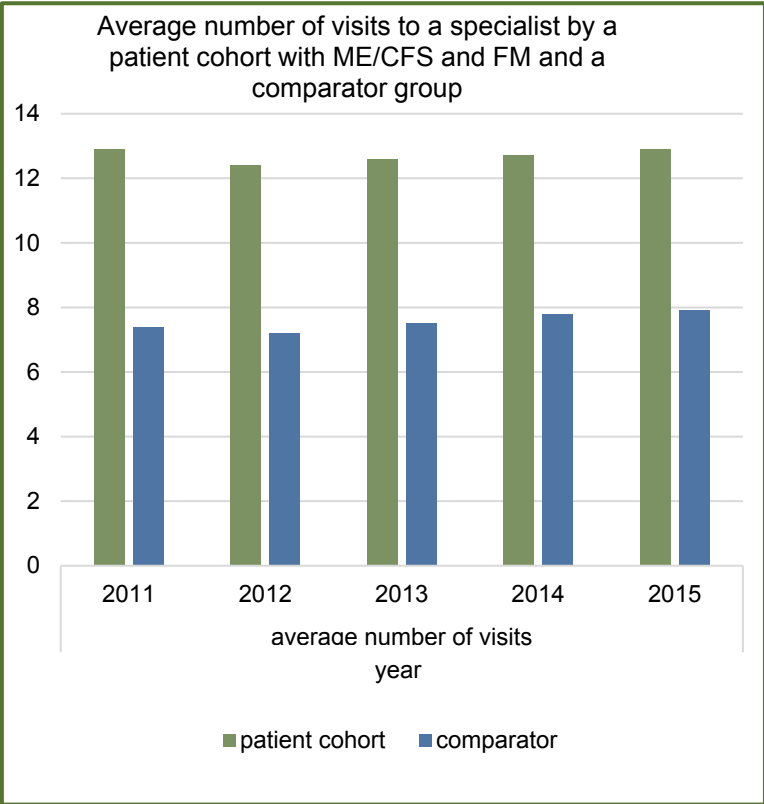
Goal: Develop a system of care for people living with ME/CFS, FM and ES/MCS based on the Ontario Chronic Disease Prevention and Management Framework.

People living with ME/CFS, FM and ES/MCS experience a range of poor health, social and economic outcomes, which have important implications for care. Like people with other chronic conditions, they need “whole person” care that helps them live as well as possible. Their care should be managed by primary care providers who have access to specialized expertise and services – such as those provided by the Environmental Health Clinic at Women’s College Hospital in Toronto – as needed.

The goal is to create an integrated, appropriate, sustainable system of care for Ontarians across the province. The objective is to use the health system efficiently (minimize duplication and preventable costs) while providing the type of care needed to manage these complex chronic conditions. Compared to people of comparable age and sex, patients with ME/CFS and FM have significantly more specialist visits. If we could provide more care within primary care settings, we could bring down specialist visits and decrease costs dramatically.

The health care system in Ontario has historically been more focused on acute care – immediate care for short-term health problems – rather than chronic care.²¹ Appointments with physicians are usually for a single, identifiable problem, which is not adequate for people with complex chronic conditions like ME/CFS, FM and ES/MCS.

To identify a way to help people manage all their



Source: Institute for Clinical Evaluative Sciences (2018, September 21). Health care utilization and costs among Ontarians with Chronic Fatigue Syndrome or Fibromyalgia. *Response to a Ministry of Health and Long-Term care Applied Health research Question*

²¹ Ministry of Health and Long-Term Care (2007). Preventing and Managing Chronic Disease: Ontario’s Framework. *Ontario*, p. 6. http://www.health.gov.on.ca/en/pro/programs/cdpm/pdf/framework_full.pdf

symptoms over time, we mapped the issues and needs as well as the services, tools and initiatives that could address them. We then mapped these solutions to Ontario's Chronic Diseases Prevention and Management (CDPM) Framework, which is based on widely applied and proven approaches in chronic care delivery,²² and outlines important considerations for the

I don't have good days. I have bad days and worse days. What really helps me is what they call pacing – really not over exerting – not walking up two flights of stairs in a row, not walking more than 15 minutes, not showering two days in a row. – Scott

delivery of care. This framework was ideal for our work in that it promotes a patient-centered, proactive, integrated and interdisciplinary model of care.²³ It includes four key elements:

1. **Self-management support** to help patients become active managers of their own health.
2. **Delivery system design** to restructure care teams so that they can efficiently use the interdisciplinary health care providers required to provide diagnosis and treatment of chronic illness across the continuum of care, and in an integrated manner.
3. **Decision support** through integrating clinical practice guidelines and tools into daily practice and enhancing access to specialists.
4. **Clinical information systems** to help with planning, integration, building evidence and information sharing.²⁴

To identify other ideas for system innovations, we analyzed two models designed for these and similar conditions: the Complex Chronic Care Program in British Columbia, and the Integrated Chronic Care Service in Nova Scotia (see Appendix H for more information). These models both draw on the CDPM and:

- use coordinated, interdisciplinary teams to provide care that focuses on the whole patient and address multi-morbidity (as opposed to individual diseases)
- recognize that long-term management is necessary for chronic conditions such as ME/CFS, FM and ES/MCS
- place an emphasis on integrating services with primary care through outreach, education and coordination initiatives

²² Ibid p.8-9

²³ Ibid. p. 14.

²⁴ Ibid. p.14-29.

- empower patients to be active partners in care.^{25,26,27}

4. Develop a Network of Primary Care Programs

Recommendation 4

Create and support a network of enhanced primary care programs throughout Ontario.

Develop and support interdisciplinary primary care teams with a special interest in ME/CFS, FM and ES/MCS. These sites will have the expertise to diagnose these conditions and provide integrated, multidisciplinary treatment and management plans. They will form a provincial network that will support data collection and education.

Right now, Ontario is highly reliant on a single specialized clinic – the Environmental Health Clinic at Women’s College Hospital in Toronto – to provide expert care. One site with this kind of expertise is not sufficient. Patients face extremely long wait times to access services at the resource-constrained clinic and are limited to three visits, primarily for diagnosis. The clinic then sends care plans and information to the patient’s primary care providers, many of whom do not have the knowledge or capacity to support and monitor the person’s care over time.

Instead, we recommend that the ministry create a network of enhanced primary care programs for these conditions by investing in existing primary care sites that already use interdisciplinary teams for chronic care and have an interest in working with

patients to manage these conditions. This network of enhanced primary care programs would be supported in the short term by the ministry-funded Environmental Health Clinic as a referral site for severe cases.

One thing that would be beneficial for young people especially would be talking about the mental health impacts that can come from having a life-changing condition – having better supports out there for how to manage once you’re diagnosed with a life changing illness, and a chronic illness that realistically probably won’t go away. – Ali

²⁵ Sampali, Tara, Robert Dickson, Jill Hayden, Lynn Edwards and Arun Salunkhe (2016). Meeting the needs of a complex population: a functional health-and patient centered approach to managing multiborbidity. *Journal of Comorbidity* 6 (2): p. 77-79. DOI: 10.15256/joc.2016.6.83

²⁶ Nova Scotia Health Authority (2017). Integrated Chronic Care Service. *Webpage*. <http://www.nshealth.ca/content/integrated-chronic-care-service-iccs>

²⁷ Provincial Health Services Authority (2018). Complex Chronic Disease Program (CCDP). *BC Women’s Hospital + Health centre Webpage*. <http://www.bcwomens.ca/our-services/specialized-services/complex-chronic-diseases-program>

We recognize that not every primary care provider has the knowledge, skill or interest to diagnose or provide the level of care often required by patients with these complex chronic conditions. A more effective and efficient approach would be to identify and support primary care sites that already use an interdisciplinary primary care (IPC) model and who have the interest and capacity to develop expertise and become a referral site for patients with these conditions.

The task force discussed with the Ministry of Health and Long-term Care the potential to use this approach to manage ME/CFS, FM and

ES/MCS. The ministry has experience in funding these kinds of services and could support a process to seek out/identify interested primary care sites. These sites could be any qualified community health centre, family health team or other primary care setting. In partnership with their local health integration network (LHIN), successful primary care sites would need to demonstrate:

- the need for services in their area
- clinical understanding of the three conditions
- access to an interdisciplinary care team qualified to manage chronic conditions
- an environmentally safe clinic space
- the ability to deliver care by telemedicine or other distance modalities to ensure isolated, homebound patients have access to care.

The task force expects there will be several waves of site development, with up to six sites identified and supported in the first phase. The goal is to increase access to integrated, appropriate care that is close to home, which will reduce the distances people have to travel for care and improve their quality of life. To that end, the ministry should ensure that the initial sites are located across the province and outside Toronto.

The request for application process should be clear and simple, and allow plenty of time for clinics to respond. The ministry should ensure that interested sites receive adequate support and funding to apply (i.e. sites may need resources to conduct needs

An IPC team is a group of professionals from different disciplines who communicate and work together to care for patients in primary care settings. The Conference Board of Canada notes that “optimizing IPC teams can help mitigate the economic burden of chronic conditions and comorbidities and improve the sustainability of the health care system.”¹ An interdisciplinary approach to primary care has been shown to improve the patient experience, timely access to care and chronic disease management.² In Ontario, team-based primary care practices are already acting as regional anchors for coordinating care for complex patients, managing low back and other chronic conditions.

1 The Conference Board of Canada (2012). Briefing 1—Current Knowledge About Interprofessional Teams in Canada. *Improving Primary Health Care Through Collaboration*, p. 2.

<https://www.conferenceboard.ca/e-Library/abstract.aspx?did=5157>

2 Saint-Pierre, Cecilia, Valeria Herskovic and Marcos Sepulveda (2017, September 16). Multidisciplinary collaboration in primary care: A systematic review. *Family Practice*, Volume 35 (2): p. 132-141.

assessments and determine whether they have a large enough patient population to warrant a specialized program). Funding should also be adequate to provide continued support and resources after the initial implementation of these specialized primary care programs.

These sites will form a network that will support the community of practice, data collection, research and other initiatives recommended in this report. All sites will use a standardized evaluation framework to demonstrate how care is working.

5. Develop a Shared Care Planning Tool

Recommendation 5

Develop a shared care planning tool.

To support integrated care, the ministry should support the development and ongoing maintenance of an online shared care planning tool focused on managing chronic disease, engaging patients in their care and encouraging efficient communication across the care team. The tool should be developed with patient input.

The complexity and chronicity of these conditions, and the fact that many people with ME/CFS, FM and ES/MCS are also likely to be ill with other chronic conditions, can make it extremely difficult to navigate the health system. Shared care plans – accessible by health care providers and patients and available online – are a proven way to help patients and their caregivers communicate, coordinate their needs and navigate the system. They are also a transparent way to integrate care between patients and health care providers with different skills and in a variety of locations.²⁸

Shared care plans help engage patients and enable them to be active partners in their care.²⁹ They give patients a tool to learn about and practice self-management. The plan is updated as patients interact with their providers. It effectively becomes a living, breathing view of the patient's care status.

The task force recommends that – to help engage patients and make communication more efficient across the entire care team, including family members and home-based care givers – the ministry develop a shared care planning tool focused on managing these chronic complex conditions. Such a tool would facilitate communication between patients and health care professionals and support more effective care for patients with

²⁸ Dykes, Patricia C. et al. (2014). A patient-centered longitudinal care plan: vision versus reality. *Journal of American Medical Informatics Association* 21 (6): 1082-1090.

²⁹ Chunchu, K et al. (2012). A patient centered care plan in the HER: improving collaboration and engagement. *Family, Systems and health: The Journal of Collaborative Family Healthcare* 30 (3): 199-209.

chronic illnesses.^{30,31} This tool, which puts patients at the centre of all care planning, should provide:

- opportunities for patient and interdisciplinary provider input
- standardized assessments and questionnaires
- support for communication across the care team
- access to current and credible literature/updates on the conditions relating to treatment and management
- strategies and approaches for self-management
- online access (web and mobile phone) and be printable.

³⁰Institute for Healthcare Improvement (2018). My Shared Care Plan. *Online tool/template found on the Institute for Healthcare Improvement's Website.*

<http://www.ihl.org/resources/Pages/Tools/MySharedCarePlan.aspx>

³¹Went West (2017). LinkedEHR. *Digital Health page of the Sydney, Australia-based primary health care network's website.* <https://www.wentwest.com.au/phn/programs/digital-health>

Evaluate Care

Goal: Take a comprehensive, systematic approach to filling the ME/CFS, FM and ES/MCS knowledge gap, including collecting data, supporting research and evaluating all programs and services.

Relatively little is known about the causes and cures of these complex chronic conditions or about their prevalence and severity. The data we do have suggest that individuals with these conditions are very ill and use the health system more than most people.

Given the complexity of creating a system of care for diseases where not enough is known about their cause, diagnosis and treatment, it is especially important that the ministry monitor and evaluate all its investments in the proposed system of care. It is also extremely important to create and adopt new knowledge, and to monitor the impact of programs, services and initiatives over time – to ensure they improve the patient experience, making it more efficient, cost-effective and positive.

The task force’s recommendations related to data, research and monitoring and evaluation are designed to enhance the credibility and legitimacy of these conditions within the health system and medical-scientific community. They will also ensure leadership and continuity as Ontario develops the proposed system of care.

6. Use OHIP Fee Codes to Help Fill Data Gaps

Recommendation 6

Modernize the K037 fee code to include all three conditions and use it to help gather data on their prevalence.

The task force recommends that the ministry re-initiate the process to modernize the Ontario Health Insurance Program (OHIP) fee code K037 – in collaboration with physician and patient experts – to ensure it recognizes all three conditions.

The ministry should then use the administrative data provided by those codes to enhance understanding of the prevalence of these conditions and how people with these conditions use the health care system.

We believe that the lack of specific reference to these conditions in the OHIP Schedule of Benefits is one reason that ME/CFS, FM and ES/MCS are not widely recognized in health care settings and the data on these conditions are limited.

While an OHIP fee code does exist for CFS and FM (K037), it does not include ES/MCS or specifically mention ME. Of the 740,000 Ontarians with one or more of the conditions,

404,200 have ES/MCS; however, it is not clear if individuals with ES/MCS use the health system differently than those with ME/CFS and/or FM.³²

As our Phase I report recommended, having a billing code that explicitly includes ME/CFS, FM and ES/MCS would improve recognition and understanding of these difficult-to-diagnose-and-treat conditions.

The task force acknowledges that the purpose of OHIP fee codes is not primarily to support data collection or research. However, we are aware that administrative datasets derived from fee codes have been extremely helpful in understanding trends in diseases over time. Therefore, we recommend that the ministry actively pursue opportunities to update OHIP fee codes to ensure they accurately reflect current definitions of these conditions, as well as the health care needs of patients who suffer from them.

7. Support Research

Recommendation 7

Support research to fill critical gaps in knowledge about the pathogenesis, prevention and treatment of ME/CFS, FM and ES/MCS.

The ministry should commit to funding a targeted priority research call that grows our understanding of how these conditions affect Ontarians and the steps the health system can take to mitigate their impact.

The task force was asked to recommend a research agenda. As we noted in our Phase 1 report, progress in understanding the causes of these conditions and identifying effective treatments is hindered by a lack of evidence. There are huge gaps in our knowledge of these conditions and their impact on patients, families and society. We need research to: identify the underlying causes of these conditions; understand their physical, mental, economic and social impacts; guide clinical practice; and improve treatment and support.³³ We also need epidemiological and bench research that explores the biological mechanisms behind these illnesses.

To fill the knowledge gap, research should focus on four questions:

- What is the impact of these conditions in Ontario – both on individual patients and their families, as well as on society more broadly?
- What treatment and management strategies work?
- How can the health system provide access to appropriate care for all Ontarians in need?
- What can be done to improve access to safe housing and employment?

³² Canadian Community Health Survey (CCHS) 2016, MOHLTC Share File, Statistics Canada.

³³ Task Force on Environmental Health (2017), *Time for Leadership: recognizing and Improving Care for those with ME/CFS, FM and ES/MCS*. Ontario.

We recommend that the ministry provide the funding to make these conditions a “priority area” for research. Once funding is approved, the ministry branch responsible for administering the funds can develop the details of the targeted research call. The ministry should also support applied clinical research as part of its investments in care and leverage other research investments.

Leverage the Health System Research Fund

Recommendation 7.1

Leverage the Health System Research Fund (HSRF) to fund priority research into patients’ experience with the health system and improve care and efficiency.

The ministry should ensure that research funding programs, such as the HSRF, include research on ME/CFS, FM and ES/MCS in their priorities and calls.

The ministry’s Health System Research Fund (HSRF) can provide opportunities for researchers across the province. HSRF projects must show how an investment by the ministry would benefit the Ontario health system and how they are addressing ministry-identified strategic priorities. An HSRF research call can request proposals for projects that have the potential to close knowledge gaps and support evidence-based decision making across the health system.

I woke up that day feeling like I had never felt before. I wasn’t just fatigued - I am very familiar with what fatigue feels like being a triathlete - this was qualitatively different. I remember thinking, there is something very wrong with me. That was the day my life changed. – Scott

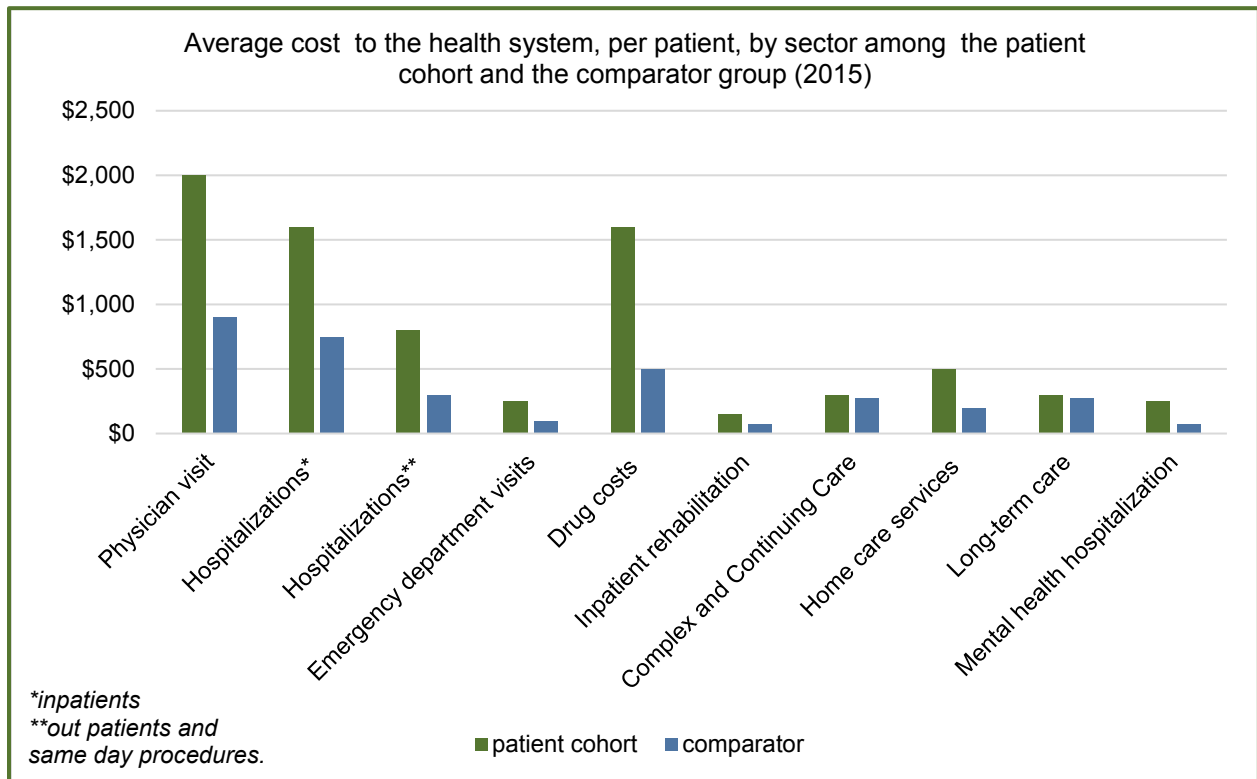
The HSRF also requires that all ministry-funded research organizations/programs/projects respond to applied health research questions (AHRQs).³⁴ As part of its work, the task force secretariat submitted the following AHRQ question to the Institute of Clinical and Evaluative Sciences (ICES): *How do individuals with ES/MCS, ME/CFS, and FM currently use the health care system?* In response, ICES was able to conduct a study of health care utilization and costs among Ontarians with CFS or FM³⁵ (but not

³⁴ An “AHRQ is question posed by a health system policy maker or provider in order to obtain research evidence to inform planning, policy and program development that will benefit the entire Ontario health system.”

Source: <http://www.health.gov.on.ca/en/pro/ministry/research/ahrq.aspx>

³⁵ The study was not able to create a patient cohort that included Ontarians living with ES/MCS, while also meeting methodological requirements (to use a cohort definition with a high predictive value).

ES/MCS because, as noted earlier, there is no diagnostic code or billing code for ES/MCS). Findings showed that, compared to a similar group of patients who do not have the conditions, patients with CFS and FM use more health services overall and incur higher health care costs.



Source: Institute for Clinical Evaluative Sciences (2018, September 21). Health care utilization and costs among Ontarians with Chronic Fatigue Syndrome or Fibromyalgia. *Response to a Ministry of Health and Long-Term Care Applied Health Research Question*

This exploratory research was very valuable and we recommend that the ministry continue to use the AHRQ process to help understand health system utilization and create efficient, effective care pathways.

Source: Health care utilization and costs among Ontarians with Chronic Fatigue Syndrome or Fibromyalgia. Institute for Clinical Evaluative Sciences (2018, September 21): p.15.

Recommendation 7.2

Work with funding organizations such as the Canadian Institutes of Health Research (CIHR) and the US National Institutes of Health (NIH) to support funding research projects that explore questions related to the pathogenesis and prevention of ME/CFS, FM and ES/MCS.

The ministry should collaborate with other research funding partners to increase the amount of rigorous research being done on these condition and to use the findings to improve diagnosis, treatment and management.

We recognize that the ministry is not solely responsible for filling the research gap. Scientific research institutions and networks such as the Canadian Institutes of Health Research (CIHR) as well as other governments within and outside Canada also play a significant role in identifying and funding key research priorities.

For the task force, the priority is to encourage and support research that will develop and sustain an effective system of care for ME/CFS, FM and ES/MCS in Ontario.

Now, I am unable to work or do anything social. Some days are better than others but I never know how I will feel and it varies throughout the day as well. Some days I can barely get out of bed and other days I have mobility. I have tried to figure out what is causing it. I know some of the things that make me feel worse. But I don't know what makes me feel better. – Lily

8. Create a Centre of Excellence

Recommendation 8

Create a centre of excellence in ME/CFS, FM and ES/MCS care, education and research in Ontario.

The task force recommends that the ministry support the development of a centre of excellence for care, education and research in Ontario to provide specialized care, especially for people with severe cases of ME/CFS, FM and ES/MCS, educate providers and conduct research. This centre will be a key part of the proposed system of care, providing leadership and support to the network of primary care sites as well as the broader health system.

The specialized centre of excellence in care, education and research will support the system of care by attracting a critical mass of clinical and research experts who can

provide clinical care for those who are the most ill as well as education and support for the network of enhanced primary care sites.

Currently, the Environmental Health Clinic at Toronto's Women's College Hospital is the only specialized centre for these conditions in Ontario. Established by the ministry and in operation since 1996, it provides a much needed service for patients unable to find care through their primary care providers. It also plays a central role in training health care providers and has the potential to expand and to leverage the experience and expertise of its care providers.

However, in its current form, it doesn't have the resources or capacity to support the system of care recommended by the task force. Currently, the Environmental Health Clinic uses nearly all its limited funding and capacity to assess patients, provide diagnoses and develop care plans to guide ongoing care. Given the high demand for these clinical services in Ontario (the average wait is >1 year), the clinic has little time for research, education, care coordination and awareness building.

In the task force's vision of the system of ME/CFS, FM and ES/MCS care, the enhanced primary care sites will be responsible for most of the diagnoses, treatment and management of these conditions. The centre of excellence in care, education and research will play a distinct role that includes:

Because of brain fog from constant exposures I couldn't follow what someone was saying. I couldn't fill out the disability forms for over a year because I couldn't concentrate. – Amari (pseudonym)

- providing care only for people with the most severe and complicated cases
- monitoring, collecting, endorsing and disseminating on-going research on the conditions from around Ontario, Canada and internationally.³⁶

³⁶ Current promising research initiatives include: The National Institutes of Health (NIH) initiative (announced in 2017), to establish a consortium of centres that will work to collaboratively define the cause(s) of, and discover improved treatments for ME/CFS; The European Network on ME/CFS (EUROMENE), which coordinates research groups across Europe, and is developing strategies to collect population-based data on the prevalence of ME/CFS; The National Health and Medical Research Council in Australia (NHMRC) has established an ME/CFS Advisory Committee that will consider and advise the NHMRC on current research needs and clinical guidance for diagnosis and treatment for ME/CFS; a U.S. study showing that glial cells - the central nervous system's immune cells - are activated in the brains of patients with fibromyalgia, a finding which may open the way for new therapies. Sources:

- National Institute of Neurological Disorders and Stroke (2017, September 17). NIH announces centres for myalgic encephalomyelitis/chronic fatigue syndrome research. *NINDS Press Release*.
- European Network on Myalgic Encephalomyelitis/Chronic fatigue Syndrome Website (2016).
- National Health and Medical Research Council (2018, October). "Myalgic Encephalomyelitis and Chronic Fatigue Syndrome." *NHMRC Website, Government of Australia*.
- Lindberg, Felicia (2018, September 26). "People with fibromyalgia have inflammation of the brain." *Karolinska Institutet Website*.

- facilitating and working in partnership with other research institutions such as CIHR to support applied clinical research throughout the network of enhanced primary care sites
- translating clinical and biomedical research into clinical tools and knowledge that can be disseminated throughout the system of care
- developing education and awareness tools or initiatives
- providing leadership to the rest of the system of care by:
 - establishing evaluation measures and working with health system partners to develop and support quality standards and drive continuous improvement
 - providing credible and authoritative direction to the rest of the health system that health care providers trust and are confident in following
 - providing credible information to decision makers across the health system to inform policy related to the conditions.

To fulfill these functions, we believe that this centre of excellence should be located within an academic health sciences centre that makes a formal commitment to being an active and supportive partner in ME/CFS, FM and ES/MCS care, education and research.

We recommend that the ministry work with the transitional implementation committee (see below) to develop detailed specifications for the centre of excellence and then solicit proposals to meet those specifications. The successful proposal should meet all the criteria listed here. Once the centre of excellence is established, it should be able to take on any ongoing functions of the time-limited transitional implementation committee.

9. Establish a Transitional Implementation Committee

Recommendation 9

Establish a transitional implementation committee to provide the leadership in the initial phases of putting this plan into action.

The task force recommends that the ministry support a small group of key stakeholders to oversee the initial implementation of this action plan. This group would exist only as long as it takes to create the centre of excellence.

The task force strongly encourages the ministry to demonstrate leadership by immediately establishing a transitional implementation committee responsible for putting the plan into action. This small, dedicated group of about six people would have the support and resources to provide advice on the steps required to implement the recommendations in this report.

In terms of membership, the transitional implementation committee should include representation from patients, families, providers experienced in caring for people with these conditions, primary care, hospitals, long-term care and research/academia.

Members should be well positioned in the health care sector to establish the partnerships and alliances required for the action plan to succeed. The ministry would provide secretariat support.

One of the committee's key functions will be to help plan for enhanced primary care and select the network of sites. It will also provide advice and expertise to the ministry as it considers future investments in the system of care and works to ensure a proactive and patient-centered approach to care. The committee would also develop standardized outcome measures across all clinical care sites and begin collecting data specific to this patient population – using scientific theories and clinical experience to provide accurate and verifiable knowledge about the effects of interventions, diagnostic procedures and therapeutic treatments.³⁷ We recommend that the transitional implementation committee use a similar approach as the Integrated Chronic Care Services in Nova Scotia to address the current lack of measures and tests that would typically be used to establish a baseline and monitor progress. That group developed an evaluative method that uses objective functional health measures, subjective measures of patient satisfaction as well as process and economic outcomes³⁸ to establish a standardized approach to collecting data and assessing impact.

The transitional implementation committee should be temporary. It should exist long enough to support action on the task force recommendations and establish a stable foundation for the proposed system of care. Once the centre of excellence is established, the transitional implementation committee will no longer be required. A fully operational centre of excellence will provide ongoing leadership for the entire system of care, guide education and research initiatives, and provide tertiary care for people with the most complex and severe cases of these conditions.

³⁷ <https://www.ntnu.edu/mh/akf/forskning>

³⁸ Sampali, Tara, Robert Dickson, Jill Hayden, Lynn Edwards and Arun Salunkhe (2016). Meeting the needs of a complex population: a functional health-and patient centered approach to managing multiborbidity. *Journal of Comorbidity* 6 (2): p. 81. DOI: 10.15256/joc.2016.6.83

10. Provide Regular Progress Reports

Recommendation 10
Provide regular updates and progress reports on the implementation of the proposed action plan.

The task force recommends that the ministry provide regular updates and reports on the progress in implementing the proposed action plan – both for public accountability and to continue to engage people and organizations who have a role to play in the proposed system of care.

Many people and organizations will be intensely interested in the progress made in implementing the recommendations in this report. Regular progress reports will make people aware of the progress. They will also raise the profile of these conditions, help reduce stigma and make people aware of the ministry’s commitment to improve care, integrate care and evaluate care.

Appendices

[Appendix A - Task Force members](#)

[Appendix B - Number of Ontarians with FM, CFS, and MCS: Findings from the 2016 CCHS](#)

[Appendix C - Profile of Ontarians with FM, CFS, and MCS: Findings from the 2016 CCHS](#)

[Appendix D - Summary of all phase 1 report recommendations](#)

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[Appendix H - Report on Nova Scotia and British Columbia clinics](#)

Appendix A - Task Force on Environmental Health Membership

Appendix A - Task Force on Environmental Health Membership

Name	Biography
Ray Copes (Chair)	Dr. Ray Copes received his MD and MSc from McGill University. Afterwards he completed training in family medicine at Victoria Hospital in London, ON and in occupational and environmental medicine at St. Michael's Hospital and the University of Toronto. Since 1990, Dr. Copes' work has centred around research, teaching and practice in environmental health. He holds appointments as an Associate Professor at the University of Toronto and as a Clinical Professor at the University of British Columbia. He is currently the Chief of Environmental and Occupational Health at Public Health Ontario. Prior to that he was the Medical Director of Environmental Health Services at the BC Centre for Disease Control and the founding Scientific Director of the National Collaborating Centre for Environmental Health.
Neil Stuart (Vice-Chair)	Neil served for many years as a partner and practice leader in the Canadian health care consulting practices of Price Waterhouse, PricewaterhouseCoopers and then IBM. Neil was a founding member of Patients Canada and serves on its board. And he is an active board member of Health Standards Organization, and the Ontario Neurotrauma Foundation. He recently served on the boards of Cancer Care Ontario, VON Canada, The Change Foundation, the Ontario Hospital Association and Toronto East General Hospital. Neil taught for several years in the University of Ottawa's Masters of Health Administration program and he currently has an adjunct appointment at the University of Toronto in its Institute of Health Policy Management and Evaluation. He received his PhD in health policy from Brandeis University where he was a fellow in the University's Health Policy Center.
Howard Hu (Chair for Phase 1)	Dr. Howard Hu, M.D. (Albert Einstein); M.P.H., Sc.D. (Harvard) is Professor of Environmental and Occupational Health Sciences at the University of Washington School of Public Health. During 2012-2018, he was Professor of Environmental Health, Epidemiology, Global Health and Medicine, the Founding Dean of the Dalla Lana School of Public Health at the University of Toronto, and a member of the Canadian Academy of Health Sciences. He is a physician-scientist with board certifications in Internal Medicine and Occupational Medicine. As a clinician, he has also evaluated and managed over 300 patients with ES/MCS, ME/CFS and FM in the academic occupational and environmental medicine clinics at Harvard (1985-2006) and the University of Michigan (2006-2012).

Name	Biography
Christine Oliver	<p>Dr. Christine Oliver received her M.D. degree at the University of North Carolina Chapel Hill and her MPH and MS degrees from the Harvard School of Public Health. Board certified in the US in preventive (occupational) medicine and internal medicine, Dr. Oliver’s primary specialty is occupational and environmental medicine. She cared for patients, did research, and taught in the area of occupational and environmental medicine at the Massachusetts General Hospital and Harvard Medical School in Boston. In 2017 she re-located to Toronto, where she holds an appointment as Adjunct Professor at the Dalla Lana School of Public Health, University of Toronto, in the Division of Occupational and Environmental Health. Dr. Oliver’s clinical practice included patients with multiple chemical sensitivity (ES/MCS). She has advocated on their behalf and taught colleagues and students about the disease. She worked closely with the Massachusetts Association for the Chemically Injured (MACI) and others to find solutions to everyday problems that plague those with this condition, including health care and housing.</p>
Cornelia Baines	<p>Dr. Cornelia Baines is a Professor Emerita at the Dalla Lana School of Public Health, University of Toronto. Cornelia was co-principle investigator and deputy director of the Canadian National Breast Screening Study, and has also engaged in silicone breast implant and Multiple Chemical Sensitivity research. Her current interests include the efficacy of breast cancer screening, the influence of conflicts of interest on health policy, and the effect on health of wind turbines.</p>
Denise Magi	<p>Denise Magi is President of the Myalgic Encephalomyelitis Association of Ontario (MEAO), an organization that provides information, support and awareness for Ontarians living with ME/CFS, FM, and ES/MCS. In the public sector, she has long and extensive work experience as a legal assistant and in the library sciences. Denise has been on various steering committees, including the initial steering committee that developed the business case proposal for the Ontario Centre of Excellence in Environmental Health. She has been diagnosed with ME/CFS, FM and ES/MCS and is a long-standing health advocate and volunteer for health based organizations.</p>
Izzat Jiwani	<p>Izzat Jiwani has a Ph.D. and has been a post-doctoral fellow with Research Chair in Governance and Transformations of Health Care Organizations and Systems (University of Montreal). She is a health and social policy analyst with broad experience in the public sector including the Ontario Ministry of Health and Long</p>

Name	Biography
	Term Care in Strategic Health Policy division for the development of chronic disease prevention and management strategy. Her extensive volunteer work also includes qualitative research on the status of palliative care in AKDN hospitals in six developing countries. Izzat and her husband have had an agonizing experience as caregivers of their daughter who has debilitating ME and MCS, and have witnessed how a young professional with much to contribute to society is severely hampered by lack of knowledgeable medical care professionals and supportive social care systems. Izzat herself is a lived experience person.
Joanne Plaxton	Joanne Plaxton is the Director of the Health Equity Branch in the Ontario Ministry of Health and Long-Term Care. Since joining the public service 2002, Joanne has held senior leadership roles across a range of ministries, specializing in bringing evidence into policy discussions, creating effective partnerships, and fostering innovation. Joanne and her team led the ministry work to create the Task Force. She holds a Masters of Economics and Social Sciences from the University of Manchester (UK) which she attended as a Commonwealth Scholar.
John Molot	Dr. John Molot has practiced environmental medicine for over 30 years and has assessed and advised more than 12,000 patients with environmentally-linked conditions. He has developed and provided workshops for both the Canadian and Ontario Colleges of Family Physicians regarding chronic fatigue syndrome, fibromyalgia, multiple chemical sensitivity, and the relationship of common chronic illnesses and the environment. Presently, John is a staff physician at the University of Toronto affiliated Environmental Health Clinic at Women's College Hospital in Toronto. He has taught medical students from a range of universities.
Julie Schroeder	Julie Schroeder has worked for the Ministry of the Environment, Conservation and Parks for 18 years in the Environmental Sciences and Standards Division. Julie has been involved in a number of environmental health initiatives. Her current role is as the Technical Assessment and Standards Development Branch's manager of Human Toxicology and Air Standards Section. Julie's academic history includes a B.Sc. in biology and a M.Sc. and Ph.D. in aquatic toxicology from the University of Waterloo.
Maureen MacQuarrie	Maureen MacQuarrie is a lawyer and policy advisor who was forced to stop working in 2001 due to ME/CFS. Maureen is the editor of Eleanor Stein MD's self-management manual "Let your light shine through: Strategies for living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Fibromyalgia and

Name	Biography
	<p>Multiple Chemical Sensitivity” and a collaborator on Valerie Free’s "Lighting up a Hidden World: CFS and ME." Maureen is also member of the National ME/FM Action Network, MEAO and Action CIND, and is an Associate member of the International Association for ME/CFS (IACFS/ME), a professional organization dedicated to advancing CFS, ME and fibromyalgia research, patient care and treatment.</p>
<p>Mike Ford</p>	<p>Mike Ford is a Toronto-based bilingual professional songwriter, musician, and educator with 25 years of experience in the entertainment industry, as well as 15 years of experience creating and delivering artistic, socially-focused educational programs across Ontario. As a caregiver, he has seen the incredible difficulties and obstacles that MCS presents, in terms of physical pain and debilitation, housing, day-to-day functioning, threat of exposures, health care challenges, financial hardship, and legal ordeals. Mike has repeatedly seen how vastly short society falls in terms of providing understanding, guidance, help, and healing to those suffering from the effects of toxic environmental exposure.</p>
<p>Nancy Sikich</p>	<p>Nancy Sikich is the Director of Health Technology Assessment at Health Quality Ontario in Toronto, Ontario. She has been working in the area of Health Technology Assessment for 14 years developing evidence to support health policy recommendations. She is also a Registered Nurse and Clinical Epidemiologist.</p>
<p>Sharron Ellis</p>	<p>Sharron Ellis is located in Ottawa and was formerly a Director General in the federal government. She was a patient of Dr. John Molot, and has been treated for multiple environmentally-linked conditions using an evidence-based, multidiscipline, multimodal treatment model. Sharron has fibromyalgia and MCS, and had chronic fatigue as a result of fibromyalgia.</p>

Alternate Members	
Bev Agar	Bev Agar was forced to retire early from her teaching position and move out of Toronto due to a lack of accommodation for serious ES/FM/ME. She has fought long and hard for accessibility and accommodation. She uses her skills to empower others and to assist in legal and advocacy efforts. She has also worked to raise awareness in a number of organizations, convincing them to make policy changes. Bev is optimistic that positive change will occur so that everyone can reach their full potential and live barrier-free lives, free of discrimination.
Diane Meitz	Diane is a Registered Nurse who was a volunteer board member/nurse with MEAO for many years. She continues to support those with ME/FM/MCS and is a strong advocate for the ME/FM/MCS community in Ontario.
Mary-Lou VandenBroek	Mary-Lou VandenBroek has been diagnosed with the illnesses ME/CFS, FM, and ES/MCS. She is a retired Registered Nurse and lives in Toronto. She has encountered many problems and discrimination while trying to find family doctors and specialists to provide ongoing treatment for these illnesses. Mary-Lou has experienced severe reactions to the air quality and chemicals in her homes. A case with the Ontario Human Rights Tribunal resulted in new housing policy.
Previous Task Force Members	
Bill Manson (stepped down October 2017)	Bill Manson was Vice President, Quality, Performance and Accountability of the Toronto Central Local Health Integration Network (LHIN). With an Executive MBA from Richard Ivey School of Business and a Bachelor of Science in Pharmacy, Bill has held several executive level positions. During a 30+ year career in academic and community hospital settings, Bill has been an active participant on various local and regional task forces as well as steering committees which include the Toronto District Health Council. He was also Vice-Chair of the Board of Directors at Casey House.

<p style="text-align: center;">Dona Bowers (stepped down May 2017)</p>	<p>Dr. Dona Bowers, a family physician, was the Director of Primary Health Care at Somerset West Community Health Centre in Ottawa. In this capacity she was responsible for program development and management of an innovative and creative inter-professional team of over 30 health professionals. Dona was also involved in the steering committee that developed the proposal for the Ontario Centre of Excellence for Environmental Health, an educational experience which illuminated the need for services for those with environmental sensitivities as well as ME, CFS and fibromyalgia.</p>
<p style="text-align: center;">Varda Burstyn (stepped down February 2017)</p>	<p>Varda Burstyn has been working for the last five years with non-profits and the Ontario government to meet the health and social service needs of the 550,000+ Ontario residents with chronic, co-morbid, environmentally-linked illnesses. Since May 2012, she has been the lead consultant developing a strategy to improve the quality of care and support for those living with these conditions, and assisted with a business case proposal for the Ontario Centre of Excellence in Environmental Health. Varda has been involved in environmental movement for 40 years and has written for 30 years on health and environmental health subjects.</p>

Appendix B - Number of Ontarians with FM, CFS, and MCS: Findings from the 2016 CCHS

Number of Ontarians with fibromyalgia, chronic fatigue syndrome, and multiple chemical sensitivities: Findings from the 2016 Canadian Community Health Survey
Prepared by the Health Equity Policy Unit, Ministry of Health and Long-Term Care
December 2018

Part 1: Introduction

- This document contains updated information on the number and per cent of Ontarians with fibromyalgia, chronic fatigue syndrome, and multiple chemical sensitivities using data from the 2016 Canadian Community Health Survey (CCHS).
- The Task Force has previously reported this information using data from the 2010, 2014, and 2015 CCHS cycles.
- The 2016 results can be compared with the 2015 results. However, the 2016 and 2015 results **should not** be compared to previous releases of the CCHS because of the recent survey redesign (more details are provided in the Appendix of this document).
- The figures presented in this document can be used in all Task Force materials going forward.

Part 2: Results and interpretation

2.1 Number and per cent of the population age 12 and older with fibromyalgia, chronic fatigue syndrome, and multiple chemical sensitivities (age 12 and older)

Table 1: Number and per cent of Ontarians age 12 and older who have fibromyalgia, chronic fatigue syndrome, or multiple chemical sensitivities OR one or more of the conditions (2015 and 2016)						
Condition	2016			2015		
	#	%	95% Confidence Interval	#	%	95% Confidence Interval
Fibromyalgia	236,297	2.0	1.7 - 2.3	194,405	1.6	1.3 - 2.0
Chronic fatigue syndrome	249,461	2.1	1.7 - 2.5	226,838	1.9	1.6 - 2.3
Multiple chemical sensitivities	404,207	3.4	2.9 - 3.9	383,006	3.2	2.8 - 3.7
One or more of these conditions	740,370	6.2	5.6 - 6.8	674,125	5.7	5.1 - 6.3
Sources: Canadian Community Health Survey (CCHS) 2016, MOHLTC Share File, Statistics Canada. Canadian Community Health Survey (CCHS) 2015, MOHLTC Share File, Statistics Canada.						

Interpretation

- Table 1 shows that there are 740,370 (6.2%) Ontarians age 12 and older with one or more of the conditions.
- Between 2015 and 2016, the per cent of the Ontario population age 12 and older with one or more of the conditions increased slightly (5.7% to 6.2%), however this increase is not statistically significant (based on the 95% confidence intervals).

- The 2016 data show that:
 - 6.2% of the Ontario population age 12 and older have one or more of these three conditions.
 - 2.0% of the Ontario population age 12 and older have fibromyalgia.
 - 2.1% of the Ontario population age 12 and older have chronic fatigue syndrome.
 - 3.4% of the Ontario population age 12 and older have multiple chemical sensitivities.

2.2 Number and per cent of the population age 12 and older with fibromyalgia, chronic fatigue syndrome, and multiple chemical sensitivities (age 12 and older), by sex

Table 2: Number and per cent of Ontarians age 12 and older who have fibromyalgia, chronic fatigue syndrome, multiple chemical sensitivities OR one more of these conditions following, by sex (2015 and 2016)							
Condition	Sex	2016			2015		
		#	%	95% Confidence Interval	#	%	95% Confidence Interval
Fibromyalgia	Male	52,796*	0.9	0.6 - 1.2	39,576*	0.7	0.3 - 1.1
	Female	183,501	3.0	2.4 - 3.6	154,829	2.6	2.1 - 3.0
	All	236,297	2.0	1.7 - 2.3	194,405	1.6	1.3 - 2.0
Chronic fatigue syndrome	Male	87,471	1.5	1.1 - 2.0	75,536*	1.3	0.8 - 1.8
	Female	161,990	2.7	2.0 - 3.3	151,302	2.5	2.0 - 3.0
	All	249,461	2.1	1.7 - 2.5	226,838	1.9	1.6 - 2.3
Multiple chemical sensitivities	Male	110,246	1.9	1.4 - 2.4	108,739	1.9	1.4 - 2.4
	Female	293,961	4.8	4.0 - 5.7	274,267	4.5	3.8 - 5.3
	All	404,207	3.4	2.9 - 3.9	383,006	3.2	2.8 - 3.7
One or more of these conditions	Male	228,607	3.9	3.2 - 4.7	198,879	3.4	2.8 - 4.1
	Female	511,764	8.4	7.4 - 9.4	475,247	7.9	6.9 - 8.8
	All	740,370	6.2	5.6 - 6.8	674,125	5.7	5.1 - 6.3
*Estimate should be used with caution due to high sampling variability.							
Sources:							
Canadian Community Health Survey (CCHS) 2016, MOHLTC Share File, Statistics Canada.							
Canadian Community Health Survey (CCHS) 2015, MOHLTC Share File, Statistics Canada.							

Interpretation

- Females are significantly more likely than males to have fibromyalgia, chronic fatigue syndrome, multiple chemical sensitivities, or one or more of these three conditions (based on assessment of the 95% confidence intervals).
- Please note that for both 2015 and 2016, the results for males with fibromyalgia must be treated with caution due to high sampling variability. For 2015, the results for males with chronic fatigue syndrome must be also treated with caution due to high sampling variability.

2.3 Number and per cent of the population age 12 and older with fibromyalgia, chronic fatigue syndrome, and multiple chemical sensitivities (age 12 and older), by age group

Table 3: Number and per cent of Ontarians age 12 and older who have fibromyalgia, chronic fatigue syndrome, multiple chemical sensitivities OR one or more of these conditions following, by age group (2015 and 2016)							
Condition	Age Group	2016			2015		
		#	%	95% Confidence Interval	#	%	95% Confidence Interval
Fibromyalgia	12-49	63,470*	0.9	0.6 - 1.3	59,139*	0.9	0.5 - 1.2
	50+	172,827	3.4	2.8 - 4.0	135,266	2.7	2.2 - 3.2
	All	236,297	2.0	1.7 - 2.3	194,405	1.6	1.3 - 2.0
Chronic fatigue syndrome	12-49	100,830	1.5	1.1 - 1.8	84,221*	1.2	0.8 - 1.7
	50+	148,631	2.9	2.2 - 3.6	142,617	2.9	2.3 - 3.4
	All	249,461	2.1	1.7 - 2.5	226,838	1.9	1.6 - 2.3
Multiple chemical sensitivities	12-49	163,853	2.4	1.8 - 3.0	164,960	2.4	1.8 - 3.0
	50+	240,354	4.7	3.9 - 5.5	218,046	4.4	3.7 - 5.0
	All	404,207	3.4	2.9 - 3.9	383,006	3.2	2.8 - 3.7
One or more of these conditions	12-49	285,976	4.2	3.4 - 5.0	268,524	3.9	3.2 - 4.7
	50+	454,394	8.9	7.8 - 9.9	405,601	8.1	7.2 - 9.0
	All	740,370	6.2	5.6 - 6.8	674,125	5.7	5.1 - 6.3
*Estimate should be used with caution due to high sampling variability.							
Sources: Canadian Community Health Survey (CCHS) 2016, MOHLTC Share File, Statistics Canada. Canadian Community Health Survey (CCHS) 2015, MOHLTC Share File, Statistics Canada.							

Interpretation

- Ontarians age 50 and older are significantly more likely than Ontarians age 12-49 to have fibromyalgia, chronic fatigue syndrome, multiple chemical sensitivities, or one or more of these three conditions (based on the 95% confidence intervals).
- Please note that for both 2015 and 2016, the results for the number and per cent of Ontarians age 12-49 with fibromyalgia must be treated with caution due to high sampling variability. For 2015, the results for Ontarians age 12-49 with chronic fatigue syndrome must also be treated with caution due to high sampling variability.

Part 3: Analytical notes

- The results presented in this document were obtained from the Canadian Community Health Survey (CCHS) 2016 and 2015 MOHLTC Share File.
- Percentages are presented for those aged 12 and older. Denominators exclude those who were categorized as 'don't know', 'refused', 'not stated' or 'not applicable'.

- The analysis was conducted by the ministry's Health Analytics Branch and was conducted in accordance with Statistics Canada's guidelines:
 - All results are based on weighted analysis using sampling weights supplied by Statistics Canada.
 - Confidence intervals (95%) and coefficients of variation (CV)³⁹ were calculated for all estimates. Confidence intervals and CVs indicate the reliability of the estimates.
 - Total weighted numbers are rounded to the nearest 100 unit.
 - Percentages and 95% confidence intervals are presented to one decimal place.
 - Statistics Canada release guidelines dictate that estimates can only be released if sampling variability (as defined by Coefficient of Variation [CV]) is within acceptable guidelines. The quality of the indicator must also be noted as follows:
 - A: $CV \leq 0.05$: Acceptable (Unrestricted release)
 - B: $0.05 < CV \leq 0.15$ Acceptable (Unrestricted release)
 - C: $0.15 < CV \leq 0.25$ Marginal (Use with caution-high sampling variability)
 - D: $0.25 < CV \leq 0.35$ Marginal (Use with caution-high sampling variability)
 - E: $CV > 0.35$ Unacceptable (Not reportable (NR)-Unacceptable variability)

Methodological changes in the CCHS – background information and future changes⁴⁰

- 2015 methodological changes
 - In 2012, Statistics Canada began a major redesign project that was completed and implemented for the 2015 cycle of the CCHS. The objectives of the redesign were to review the sampling methodology, adopt a new sample frame, modernize the content, and review the target population.
 - Consultations were held with federal, provincial and territorial share partners, health region authorities, and academics.
 - As a result, the 2015 CCHS has a new collection strategy; is drawing the sample from two different frames; and has undergone major content revisions. Therefore, caution should be taken when comparing 2015 data to earlier cycles of data.
 - The 2015 and 2016 data can be compared.
- 2017 methodological changes
 - CCHS response rates have been steadily declining since the survey began in 2000.⁴¹ Therefore, beginning in 2017, to counter the declining response rates, the CCHS became a mandatory survey for adults age 18 and older (it will remain voluntary for youth age 12-17). Consequently, sensitive modules were removed and the survey was shortened to be 45 minutes (maximum).
 - The questions used to measure the number of Ontarians with fibromyalgia, chronic fatigue syndrome, and multiple chemical sensitivities were not included on the 2017 and 2018

³⁹ Please note – coefficients of variation (CVs) are not presented in this document.

⁴⁰ Canadian Community Health Survey - Annual Component (CCHS). Retrieved August 10, 2017 from: <http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3226>

⁴¹ The early years of the CCHS had response rates of 80% or higher. Response rates dipped below 60% for the first time in 2015, which had a significant impact on the quality of the estimates particularly at the health region level. In early 2016, Statistics Canada conducted a test to determine if rates increased if they made the survey mandatory and managed to increase the rates to 78.2%.

surveys. Fibromyalgia and chronic fatigue syndrome will be on the 2019 and 2020 surveys, but multiple chemical sensitivities will not appear until the 2021 survey.

Appendix C - Profile of Ontarians with FM, CFS, and MCS: Findings from the 2016 CCHS

Profile of Ontarians with fibromyalgia, chronic fatigue syndrome, and multiple chemical sensitivities: Findings from the 2016 Canadian Community Health Survey
Prepared by the Health Equity Policy Unit, Ministry of Health and Long-Term Care
December 2018

Part 1: Introduction

- The purpose of this document is to:
 - Present a profile of the Ontario population age 12 and older with fibromyalgia, chronic fatigue syndrome or multiple chemical sensitivities using demographic and health measures.
 - Compare this population with the Ontario population age 12 and older who do not have these conditions.
- All data were obtained from the 2016 Canadian Community Health Survey (CCHS).⁴² Statistical significance is based on the 95% confidence intervals.
- **Please note:** The CCHS is a cross-sectional survey that collects information about health status. The results presented indicate whether there is an association between the conditions and the health and demographic measures. However, they do not speak to the nature of the relationship or infer causality.

Part 2: Key Findings

- Compared to the Ontario population without any of the conditions, the population with these conditions:
 - Has a significantly higher proportion of females – 69% of this population are female and 31% are male. In the Ontario population without these conditions, the proportion of males and females is 50%.
 - Is significantly older - 61% of this population is age 50 and older while 41% of the population without these conditions is age 50 and older.
- Compared to the Ontario population without these conditions, this population is significantly more likely to:
 - Be in the lowest income category (31% versus 14%).
 - Have one or more additional chronic conditions⁴³ (71% versus 38%).
 - State that their self-perceived health is fair or poor (42% versus 10%).
 - State that their self-perceived mental health is fair or poor (21% versus 7%).
 - Report life stress (36% versus 21%).
 - Indicate that they are physically inactive (41% versus 30%).
 - Report that their sense of belonging to the local community is weak (39% versus 28%).
 - Report that they did not work in the last year (51% versus 24%).

⁴² Canadian Community Health Survey (CCHS) 2016, MOHLTC Share File, Statistics Canada.

⁴³ Refers to select chronic conditions including: asthma, arthritis, COPD, diabetes, hypertension, heart disease, cancer, or stroke.

Table 1: Profile of Ontarians age 12 and older with Fibromyalgia, Chronic Fatigue Syndrome, or Multiple Chemical Sensitivities (2016)

Variables		1 or more condition(s)		No conditions	
		%	95% Confidence Interval	%	95% Confidence Interval
Sex	Male	30.9	26.2 - 35.5	50.0	49.7 - 50.3
	Female	69.1	64.5 - 73.8	50.0	49.7 - 50.3
Age	Aged 12-49	38.6	33.6 - 43.7	58.6	58.2 - 58.9
	Aged 50+	61.4	56.3 - 66.4	41.4	41.1 - 41.8
Marital status	Have a partner	56.9	51.7 - 62.1	57.2	56.0 - 58.4
	No partner	43.1	37.9 - 48.3	42.8	41.6 - 44.0
Self-perceived Health	Fair/Poor	42.4	37.1 - 47.7	9.6	8.7 - 10.4
	Excellent/Very Good/Good	57.6	52.3 - 62.9	90.4	89.6 - 91.3
Life Stress	No	64.5	59.5 - 69.5	78.9	77.8 - 80.1
	Yes	35.5	30.5 - 40.5	21.1	19.9 - 22.2
Sense of belonging	Strong	61.2	56.0 - 66.4	71.9	70.6 - 73.2
	Weak	38.8	33.6 - 44.0	28.1	26.8 - 29.4
Perceived mental health	Fair/Poor	21.3	16.6 - 26.1	6.6	5.9 - 7.3
	Excellent/Very Good/Good	78.7	73.9 - 83.4	93.4	92.7 - 94.1
Income	\$0-\$39,999	31.1	26.0 - 36.1	14.1	13.1 - 15.1
	\$40,000-\$79,999	38.3	33.1 - 43.5	32.8	31.5 - 34.2
	\$80,000 +	30.6	26.2 - 35.0	53.1	51.6 - 54.6
One of 8 chronic conditions	No	28.9	24.4 - 33.4	62.1	61.0 - 63.2
	Yes	71.1	66.6 - 75.6	37.9	36.8 - 39.0
Working status (last week)	No	56.5	51.3 - 61.8	31.8	30.5 - 33.1
	Yes	43.5	38.2 - 48.7	68.2	66.9 - 69.5
Working status (last 12 months)	No	50.6	45.0 - 56.2	23.7	22.5 - 24.9
	Yes	49.4	43.8 - 55.0	76.3	75.1 - 77.5
Highest level of education	High school or less	49.2	44.2 - 54.3	40.7	39.4 - 42.0
	More than high school	50.8	45.7 - 55.8	59.3	58.0 - 60.6
Physical activity	Active	58.7	53.0 - 64.4	70.2	68.9 - 71.6
	Inactive	41.3	35.6 - 47.0	29.8	28.4 - 31.1
Notes:					
<ul style="list-style-type: none"> • Unmet healthcare needs were not included in the CCHS 2016. • One of 8 chronic conditions: asthma, arthritis, COPD, diabetes, hypertension, heart disease, cancer and stroke. 					

Part 3: Definitions of variables

Category	Variable Name	Question	Categories	Age Limit
1. Sex	DHH_SEX		<ul style="list-style-type: none"> • Male • Female 	12+
2. Age group	DHH_AGE		<ul style="list-style-type: none"> • Under 50 • 50+ 	12+
3. Marital status	DHH_MS	What is your marital status? Are you married, living common-law, widowed, separated, divorced, or single, never married?	<ul style="list-style-type: none"> • Partner (Married, Common-law) • No Partner (Single, Separated, Never Married, Divorced) 	12+
4. General health status	GENDVHDI	Derived variable: Based on self-perceived health variable (GEN_01) - In general, would you say your health is... ?	<ul style="list-style-type: none"> • Excellent, Very good, Good • Fair, Poor 	12+
5. Have you worked at job in past 12 months?	MAC_010	Have you worked at a job or business at any time in the past 12 months?	<ul style="list-style-type: none"> • Yes • No 	15 to 75
6. Life stress	GEN_020	Thinking about the amount of stress in your life, would you say that most days are...?	<ul style="list-style-type: none"> • Extremely and Quite a bit • Not at all, Not very, A bit stressful 	12+
7. Working status last week	LBFDVWSS	Derived variable: Based on Labour Force questions	<ul style="list-style-type: none"> • Yes (had a job - at work last week or had a job - absent from work last week) • No (did not have a job last week or permanently unable to work) 	14 to 75
8. Sense of belonging to your local community	GEN_030	How would you describe your sense of belonging to your local community? Would you say it is...?	<ul style="list-style-type: none"> • Very Strong, Somewhat Strong • Somewhat Weak, Very Weak 	12+
9. Household income	INC_020	Derived variable: Total household income before taxes	<ul style="list-style-type: none"> • Less than \$40,000 • \$40,000-\$79,999 • \$80,000+ 	12+
10. Highest level of education	EHG2DVR3	Derived variable: Highest level of education achieved	<ul style="list-style-type: none"> • High school or less • More than high school 	12+
11. Have other chronic conditions (yes/no)	CCC_015, CCC_030, CCC_085, CCC_050, CCC_090,	Derived variable: Based on 8 chronic conditions: Asthma, Arthritis, COPD, Diabetes, Hypertension,	<ul style="list-style-type: none"> • One of these 8 conditions • None of these 8 conditions 	12+, except for Arthritis (14+) and COPD (35+)

	CCC_095, CCC_130, CCC_065	Heart Disease, Cancer and Stroke		
12. Perceived Mental Health	GENDVMHI	Derived variable: Based on self-perceived mental health variable GEN_02B	<ul style="list-style-type: none"> • Excellent, Very Good, Good • Fair, Poor 	12+
13. Physical activity	PAADVAC2	Derived variable: Based on PACDEE	<ul style="list-style-type: none"> • Active, moderately active • Inactive 	12+

Appendix D - Status Update TFEH Phase 1 Report Recommendations

Task Force on Environmental Health Phase 1 Recommendations	Current Status
<p>Make a Formal public statement recognizing ME/CFS, FM and ES/MCS.</p> <p>The task force recommends the Minister of Health and Long-Term Care make a statement recognizing ME/CFS, FM and ES/MCS. The statement should reinforce the serious debilitating nature of these conditions and dispel the misperception that they are psychological. It should also include a commitment to improve care and education, develop a system of care for people living with ME/CFS, FM and ES/MCS, and provide support for caregivers.</p>	<p>The Phase 1 report was released online with a Health Bulletin. This release included a supportive public statement from the then Minister of Health and Long-Term Care, Eric Hoskins.</p>
<p>Establish academic chairs focused on ME/CFS, FM and ES/MCS.</p> <p>The task force recommends that the Ministry of Health and Long-Term Care (ministry) fund academic chair positions in clinical environmental health focused specifically on ME/CFS, FM and ES/MCS. The chairs should be located at three different academic health science centres across the province. A key criterion in selecting/awarding these chairs should be a demonstrated commitment to champion improved care for those affected by these conditions.</p>	<p>There is no ministry mechanism to fund research chairs.</p>
<p>Modernize the K037 fee code to include all three conditions</p> <p>The task force recommends that the ministry re-initiate the process to modernize the Ontario Health Insurance Program (OHIP) fee code K037 – in collaboration with physician and patient experts – to ensure it recognizes all three conditions.</p>	<p>This recommendation is addressed in final report (Recommendation 6)</p>

Task Force on Environmental Health Phase 1 Recommendations	Current Status
<p>Develop clinical case definitions and clinical practice guidelines to support standardized, high-quality, patient-centred care.</p> <p>The task force recommends that the ministry establish an expert panel to reach consensus on clinical case definitions and clinical practice guidelines for each of the three conditions. The expert panel, which should include people with lived experience as well as input from expert advisors outside Ontario, should meet periodically to review updates in the science on each condition, evaluate the evidence and assess progress in managing the three conditions.</p>	<p>The ministry funded the development of an expert consensus on clinical case definitions. This work was completed July 2017. See Appendix G in final report.</p> <p>A second procurement process would be required to develop clinical tools based on the consensus definitions. This recommendation is addressed in final report (Recommendation 2)</p>
<p>Establish detailed clinical care pathways to support the development of an evidence-based system of care.</p> <p>The task force recommends that the ministry provide funds to support the development of clinical care pathways for people with ME/CFS, FM and ES/MCS and map out an appropriate patient-centred system of care for Ontario.</p>	<p>This recommendation was further developed in the final report.</p>
<p>Make hospitals safe for people with ME/CFS, FM and/or ES/MCS.</p> <p>The task force recommends that the ministry work with its partners and with expert patients, caregivers and physicians to ensure hospitals comply, as quickly as possible, with relevant accessibility and accommodation legislation.</p> <p>As a starting point, the ministry should work with the Ontario Hospitals Association (OHA) to build on relevant prior work, including the Quinte Healthcare Corporation policy on Multiple Chemical Sensitivities and the guidance for hospital staff contained in <i>Marshall, LM, MacLennan JG. Environmental health in hospital: A practical guide for hospital staff. Part I Pollution prevention, Part II Environment-sensitive care (2001).</i></p>	<p>This recommendation is further developed in the final report (Recommendation 3.2)</p>

Task Force on Environmental Health Phase 1 Recommendations	Current Status
<p>Make long-term care homes safe for people with ME/CFS, FM and/or ES/MCS.</p> <p>The task force recommends that the ministry work with its partners and with expert patients, caregivers and physicians to ensure long-term care homes comply, as quickly as possible, with relevant accessibility and accommodation legislation.</p> <p>The ministry should work with long-term care provider associations to build on opportunities within the long-term care home renewal process to improve accessibility and accommodation in existing homes and in the homes of the future.</p>	<p>This recommendation is addressed in final report (Recommendation 3.2)</p>
<p>Continue to fund the fellowship Enhanced Skills Program for 3rd Year Residents in Clinical Environmental Health.</p> <p>The task force recommends that the ministry continue to fund this program until the task force makes further recommendations for advanced education specializing in ME/CFS, FM and ES/MCS.</p>	<p>The ministry extended funding for this program for an additional four spots from July 2018 to June 2021.</p>

Appendix E - ICES report / analysis

Health care utilization and costs among Ontarians with Chronic Fatigue Syndrome or Fibromyalgia

Prepared By
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*Response to an Ontario Ministry of Health and
Long-Term Care Applied Health Research Question*

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Exhibits

- 0.0 Data sources used to identify Ontarians with health care utilization for ME/CFS or FM.
- 1.0 Cohort selection.
- 2.0 Visits to a general practitioner among the patient cohort and the comparator group.
- 2.1 Visits to a specialist physician among the patient cohort and the comparator group.
- 2.2 Visits to multiple specialist physicians among the patient cohort and the comparator group during fiscal year 2015.
- 2.3 Hospitalizations, emergency department visits and same day surgery/procedures among the patient cohort and the comparator group.
- 2.4 Home care services, complex continuing care hospitalizations and rehabilitation hospitalizations among the patient cohort and the comparator group.
- 2.5 Home care services, complex continuing care hospitalizations and rehabilitation hospitalizations among the patient cohort and the comparator group.
- 3.0 Health care system cost per patient by sector of the patient cohort and the comparator group.
- 3.1 Total health care system costs per patient of the patient cohort and the comparator group.

Background

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a condition characterized by chronic fatigue and other debilitating symptoms that limit a person's ability to carry out usual activities of daily living (Littlejohn, 2015). Various biological, genetic, infectious, and psychological mechanisms have been proposed as potential causes of ME/CFS, but ultimately its cause is unknown (Clauw, 2014; Häuser et al., 2015). Because many medical conditions can cause chronic fatigue and there's no definitive test for ME/CFS (Brurberg, Fønhus, Larun, Flottorp, & Malterud, 2014), other potential causes of the symptoms, such as hypothyroidism, anemia, diabetes and mood disorders, must be ruled out before a diagnosis of ME/CFS can be given. This is why a diagnosis of ME/CFS is known as a diagnosis of exclusion (Häuser et al., 2015).

Fibromyalgia (FM), which frequently co-occurs with ME/CFS, is a condition characterized by chronic, widespread pain and a heightened pain response to pressure (Clauw, 2014; Häuser et al., 2015). Like ME/CFS, the differential diagnosis of FM is one of exclusion through careful evaluation of the patient's medical history, physical exam, and laboratory investigations, with particular attention to a range of potential systemic, inflammatory conditions, such as lupus, ankylosing spondylitis, polymyalgia rheumatica and rheumatoid arthritis (Häuser et al., 2015).

Due at least partially to the challenges of diagnosing ME/CFS and FM, little is known about the prevalence of these conditions in Canada (Task Force on Environmental Health, 2017). The problem is further exacerbated by a combination of non-specific diagnosis coding for outpatient care and the absence of a validated case definition for identifying patients with ME/CFS and FM in administrative data. Fortunately, in 2006 the Ontario Ministry of Health and Long-Term Care introduced a specific fee code for use by family doctors when providing care related to ME/CFS and FM. Care for both of these conditions is captured in the system by this single fee code, K037, which we will refer to as "FM/CFS" in this report. Ontario hospitals and emergency departments also have a specific diagnosis code that may be used to identify patients whose care is influenced by FM.

The purposes of this study were to address the following research questions:

- 1) Can we identify Ontarians living with these conditions in ICES data?
- 2) Do these patients use health services differently than those without such conditions, after controlling for age, sex, and where they live (Local Health Integration Network (LHIN))?

Methods

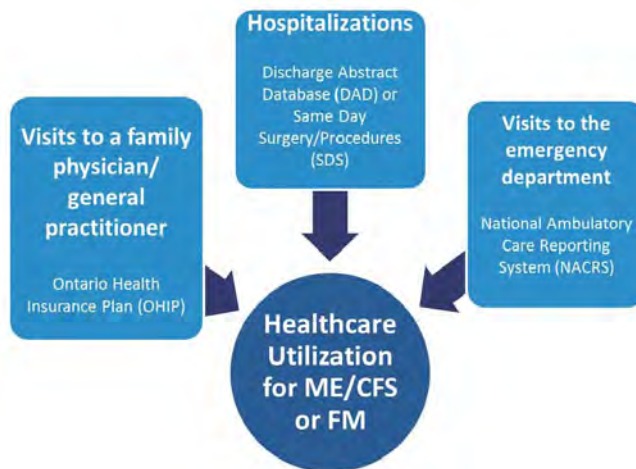
Data Sources

We used the administrative health care records of all Ontarians with a valid health insurance number, linked and analyzed at ICES. The patient cohort was identified from (Figure 1):

- 1) Hospitalization records (Discharge Abstract Database and Same Day Surgery)
- 2) Emergency department visits (National Ambulatory Care Reporting System)
- 3) Physician visits (Ontario Health Insurance Plan database)

For health care utilization and costing, additional data holdings at ICES were used (Appendix A, Table 1).

Exhibit 0.0 Data sources used to identify Ontarians with health care utilization for ME/CFS or FM.



Study Period

We started with anyone in Ontario who had contact with a health care provider or service from April 1, 2011 to March 31, 2015.

Patient Cohort and Comparators

The cohort of patients with health care utilization for ME/CFS or FM from March 31, 2009 to March 31, 2011 was obtained using the following definition:

- 1 hospitalization or visit to an emergency department with an ICD-10-CA diagnosis code for FM (M797); or
- 2 or more family physician visits associated with a specific fee code for FM/CFS-related care (K037).

We chose to require at least two physician visits for FM/CFS to improve the predictive accuracy of the case definition. Although the formal validation of the case definition has not been performed, the consultation fee code is specific for FM/CFS. Further, case definitions of other conditions cared for by family doctors that have specific diagnosis codes, such as hypertension, have been shown to have sensitivities, specificities, and positive predictive values in the range of 84%, 95% and 87% (Tu, Campbell, Chen, Cauch-dudek, & Finlay, 2007).

Patients were excluded if they lived out of province, had died before or were not eligible for OHIP one year prior to the beginning of the study period (March 31, 2011).

The patient cohort was matched 1:1 to population based controls without ME/CFS or FM (using the definition above), based on age, sex and area of residence (LHIN). Thus, age, sex and area of residence were equally distributed between the patient cohort and comparators utilized in the following analyses.

Analysis

Part 1: Demographics

In part 1, the patient cohort and comparator group were compared on key demographics (age, sex, neighbourhood income, rurality, LHIN of residence, time since diagnosis and Charlson comorbidity score) prior to the start of the observation window (March 31, 2011). The number of individuals and the proportion (%) of the total were computed for each demographic variable of interest. Significance testing was not done for this report.

Part 2: Health Care Utilization

In part 2, the health care utilization of the patient cohort and the comparator group was compared per fiscal year of the follow up period (April 1, 2011 to March 31, 2016). Health care utilization across multiple sectors was defined as one or more visits or use of services within each sector. The number of patients in each cohort (n) and the proportion of the total cohort (%)

with 1 or more visits/uses within each sector were calculated. Mean or average number of visits was also calculated using only patients with 1 or more visits during that year.

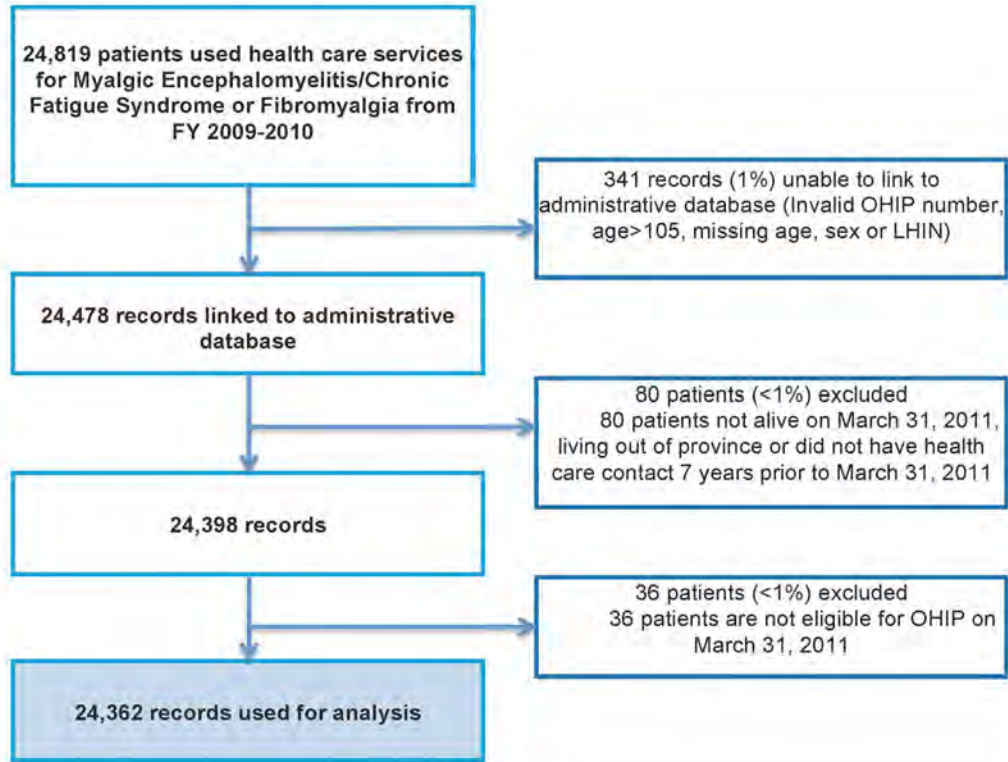
Part 3: Health Care Costs

In part 3, the health care costs of the patient cohort and comparator group were compared per fiscal year of the follow up period (April 1, 2011 to March 31, 2016). The costing methodology at ICES utilizes the total provincial health care budget and allocates it to individual patients by assigning a price based on their use of health care services. Depending on the health care sector of interest, this price may be based on the fee paid to a physician for their services or determined using an algorithm that considers length of stay, the intensity of resources utilized by a typical patient and the main condition of the patient. Thus, health care costs include total system costs (i.e. all health care used by the people we identified) not costs attributed to a specific health condition.

Total health care costs include the sum of 1) physician payments, 2) OHIP lab claims, 3) OHIP non-physician claims, 4) inpatient hospitalizations, 5) outpatient hospitalizations, 6) same day surgeries or procedures, 7) Ontario Drug Benefit costs, 8) inpatient rehabilitation, 9) home care services, 10) complex continuing care, 11) long term care, and 12) inpatient mental health hospitalizations. The total cost across all sectors for all patients in the patient cohort was divided by the total number of patients to obtain the average health care costs per patient. Possible additional health care costs incurred by the patient that are not included in the reported costs include: copayments, caregiver costs, private insurance, overheads and capital expenditures and community-level services (i.e. outreach programs, public health).

Exhibits and Findings

Exhibit 1 Cohort selection



Part 1: Demographics of patient cohort

- Over 80% of patients are included into the patient cohort from multiple physician visits for ME/CFS or FM within 2 years.
- Approximately half of patients are 50-65 years of age.
- Females make up the majority of the patient cohort (85%).

Part 2: Health Care Utilization

Overall Findings

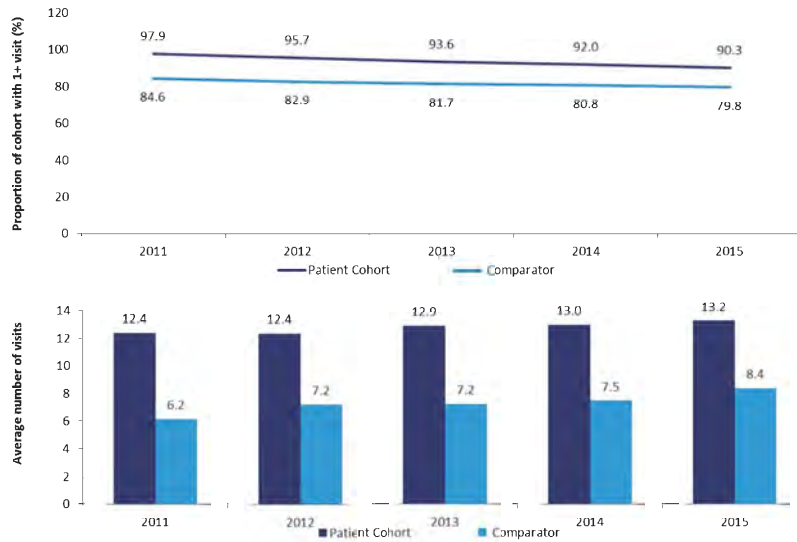
- Health care utilization is different between the patient cohort and the comparator group.
- The patient cohort uses more health care resources across most sectors.

A greater proportion of the patient cohort:

- uses physician services yearly and at a greater frequency.
- uses acute care services (hospitalizations, ED visits) and have a longer length of stay when hospitalized.
- uses home care services and at a greater frequency.
- are dispensed prescription drugs per year (over 65 only) and prescriptions often include pain related medication (opiate agonists).

General Practitioner and Specialist Physician

Exhibit 2.0 Visits to a general practitioner among the patient cohort and the comparator group.



Data sources: OHIP

Key Findings:

A greater proportion of the patient cohort had 1+ visit to their general practitioner (GP) and visited their GP more frequently per year.

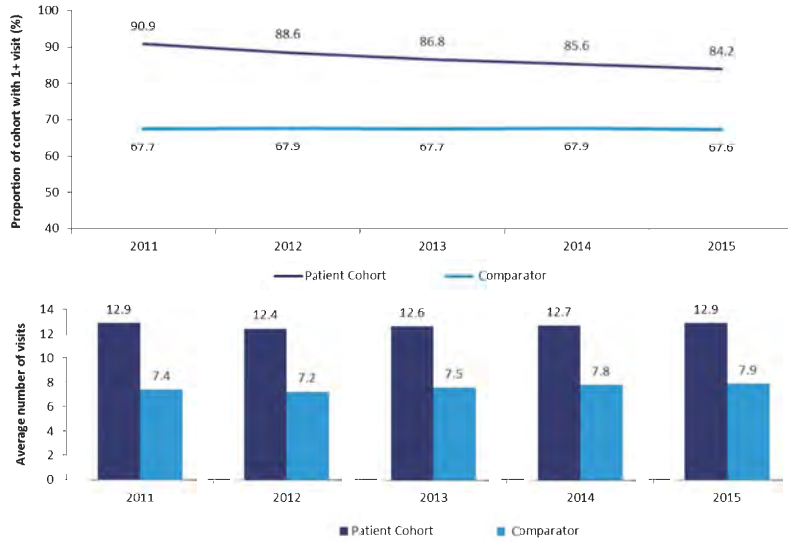
The *top diagnoses* for the patient cohort in 2011 were:

- 1) Without diagnosis (i.e. vaccination or other procedure that does not require a diagnosis) (38.9%)
- 2) Anxiety neurosis, hysteria, or reactive depression (30.8%)
- 3) Fibrosis, myositis, or muscular rheumatism (28.8%)

The *top diagnoses* for the comparator group in 2011 were:

- 1) Without diagnosis (i.e. vaccination or other procedure that does not require a diagnosis) (31.9%)
- 2) Annual health examination (21.2%)
- 3) Hypertension (17.46%)

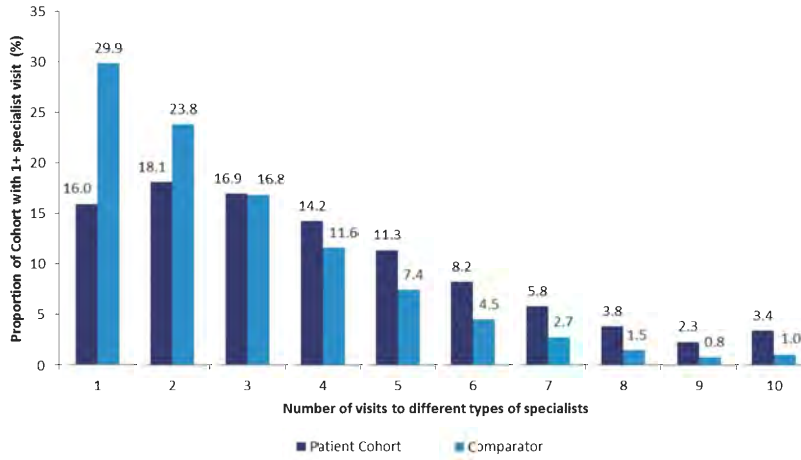
Exhibit 2.1 Visits to a specialist physician among the patient cohort and the comparator group.



Data sources: OHIP

Key Findings:
 A greater proportion of the patient cohort had 1+ visit to a specialist physician and visited a specialist physician more frequently per year.

Exhibit 2.2 Visits to multiple specialist physicians among the patient cohort and the comparator group during fiscal year 2015.



Data sources: OHIP

Key Findings:

A greater proportion of the patient cohort saw 4 or more different types of specialist physicians in 2015.

On average, the patient cohort saw 3.9 different types of specialist physicians whereas the comparator group saw 2.9 different specialist physicians in 2015*.

Diagnostic medicine (86%, 79%), internal medicine (44%, 31%) and surgical specialists (44%, 31%) were the most common specialist physicians visited by both the patient cohort and the comparator group respectively*.

*Results not shown on graph

Acute Care Services

Exhibit 2.3 Hospitalizations, emergency department visits and same day surgery/procedures among the patient cohort and the comparator group.



Data sources: DAD, NACRS, SDS

Key Findings:

A greater proportion of the patient cohort had 1+ hospitalization, 1+ ED visit or 1+ same day surgery/procedure across all years.

Exhibit 2.4 Home care services, complex continuing care hospitalizations and rehabilitation hospitalizations among the patient cohort and the comparator group.



Data sources: HCD, CCRS, NRS

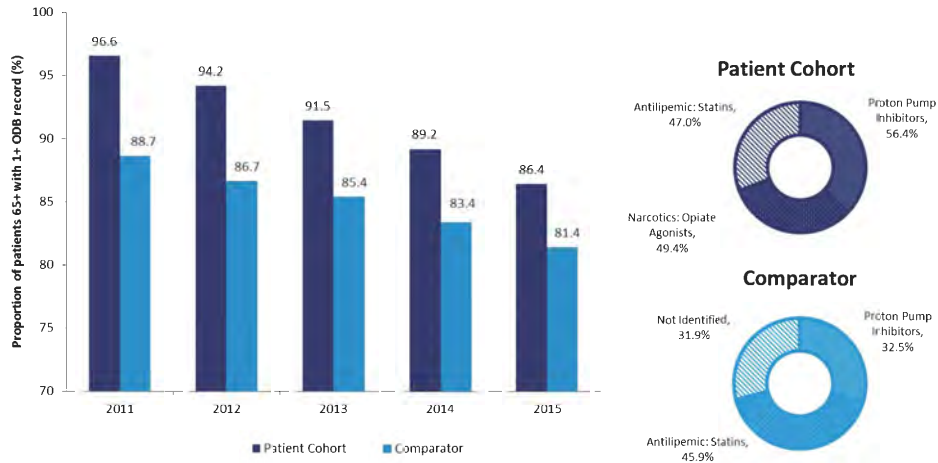
Key Findings:

A greater proportion of the patient cohort had 1+ home care visits

The top three home care sectors utilized by both the patient cohort and comparators are: 1) Case management, 2) Nursing, 3) Combined personal and homemaking services.

Prescription Drugs

Exhibit 2.5 Home care services, complex continuing care hospitalizations and rehabilitation hospitalizations among the patient cohort and the comparator group. Top 3 prescription drugs in 2015 for the patient cohort and the comparator group.



Data sources: ODB, DIN

Key Findings:

Prescription drug use differed between the patient cohort and the comparator group across all years.

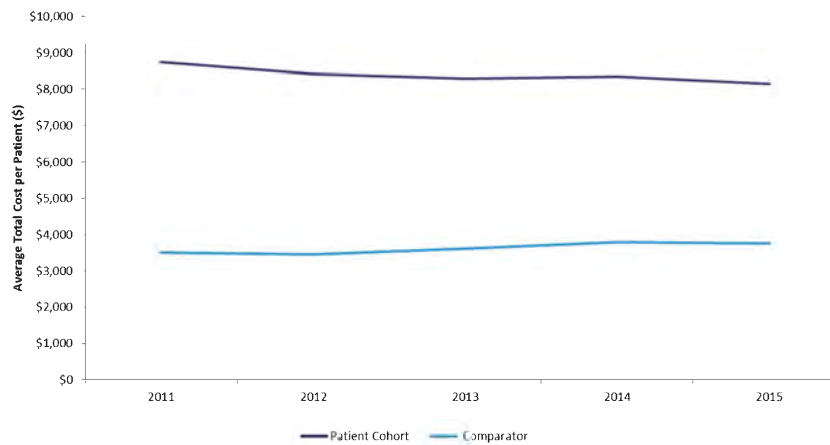
Part 3: Health Care Costs

Overall Costing Conclusion

- The relative costs are different between the patient cohort and the comparator group.
- Patients with health care utilization for ME/CFS or FM cost more to the health care system.

Total Health Care System Costs

Exhibit 3.0 Total health care system costs per patient among the patient cohort and the comparator group.



Data sources: DAD, SDS, NACRS, OHIP, CCRS, HCD, NRS, ODB, OMHRS, CAPE

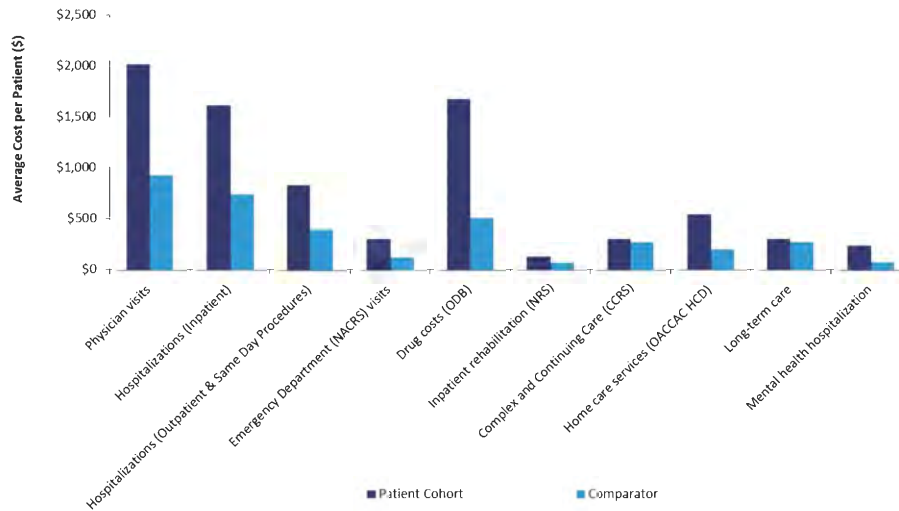
Key Findings:

Total health care costs are higher for the patient cohort across all 5 years of follow up.

Total health care cost for the patient cohort was \$213,361,405 compared to \$85,401,133 in 2011 and \$199,207,8770 compared to \$91,667,869 in 2015, for the patient cohort and comparison cohort respectively.

Sector Specific Costs

Exhibit 3.1 Health care system cost per patient by sector among the patient cohort and the comparator group.



Data sources: DAD, SDS, NACRS, OHIP, CCRS, HCD, NRS, ODB, OMHRS, CAPE

Key Findings:

The patient cohort had higher costs in all sectors, with the largest differences seen in physician visits, drugs and hospitalizations.

Part 4: Discussion

Conclusions

We have identified that people in our patient cohort use more health care services overall and incur greater health care costs than our matched comparator group. Thus, these patients represent high health care users compared to the comparator group. In addition, patterns of health care use differ between our patient cohort and the comparator group.

However, this study does not capture the level of overall need or unmet need that Ontarians living with ME/CFS and FM experience. Further, we have not identified how this patient cohort compares to patients who experience chronic conditions similar to ME/CFS and FM. Finally, it is possible that some of individuals in the comparator cohort do have ME/CFS as there is a possibility of misdiagnosis or error in recording the ICD-10-CA or fee codes attributed to ME/CFS and FM. To that end, it is challenging to understand the true experience of patients with ME/CFS and FM throughout the health care system. Unfortunately, it is not possible to identify, improve or recommend patient-centered pathways and models of care most appropriate for individuals with these conditions.

Alternative Definitions

To create the patient cohort definition used in this study, we considered multiple options including alternative definitions for the same conditions and definitions that incorporated additional conditions of interest. We did not have the ability to formally validate any of these definitions. Instead, ICES scientists with expertise in creating disease cohort definitions using administrative data, vetted the various definitions being considered, and helped us settle on the patient cohort definition used in this work, which has high predictive value.

The alternative definitions we considered were:

1. Environmental Sensitivities/Multiple Chemical Sensitivity (N=45,002)

2+ physician visits or 2+ hospitalizations or same day procedures/emergency department visits or 1+ physician visit & 1+ hospitalization/emergency department visits for:

- a. Adverse effects, not elsewhere classified (Hypersensitivity, Idiosyncrasy, NOS)
- b. Adverse effects of other chemicals

2. Environmental Sensitivities/Multiple Chemical Sensitivity and ME/CFS & Fibromyalgia (N=347)

People who were flagged in our patient cohort (ME/CFS and FM) and in the environmental sensitivities/multiple chemical sensitivity cohort.

3. ME/CFS & Fibromyalgia (additional inclusions for ME/CFS) (N=29,532)

People who were included in our patient cohort and also people with hospitalizations or emergency department visits for:

- c. Malaise and Fatigue (2 visits in 2 years)
- d. Exhaustion due to excess exertion (2 visits in 2 years)
- e. Post-viral fatigue syndrome (2 visits in 2 years)

Limitations and Future Directions

The findings of this study should be interpreted with the following limitations in mind. The patient cohort definition utilized in this report has not yet been validated. Thus, we do not know what fraction of the patients included in the patient cohort truly have these conditions, or how many Ontarians with these conditions are missing from the patient cohort. Further, utilizing administrative data alone only allows for the detection of ME/CFS and FM patients who are actively using the health care system for these conditions, thus, possibly underestimating the true prevalence of Ontarians living with these conditions. Further, investigation into a validated definition of patients living with these conditions using administrative health records is required. One approach may be to develop a cohort of patients with diagnoses of the specific diseases by way of a recruitment study, and analyze their utilization of the health care system. With that in mind however, it will be prudent to identify an appropriate comparator cohort to draw meaningful and impactful conclusions. Given the limitations of administrative data however, understanding the patient experience firsthand may be an initial step in better identifying how these conditions are treated throughout the system.

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Appendix A

Table A.1 ICES data holdings utilized to measure service utilization and health care system costs of the patient cohort and comparator group.

Concept	ICES Data Holding
Physician Visits and Lab Claims	Ontario Health Insurance Plan (OHIP) Client Agency Program Enrolment (CAPE)
Inpatient Hospitalizations	Discharge Abstract Database (DAD)
Outpatient Hospital Clinics	Discharge Abstract Database (DAD)
Emergency Department visits	National Ambulatory Care Reporting System (NACRS)
Same Day Surgery	Same Day Surgery Database (SDS)
Prescription Drugs	Ontario Drug Benefit Claims (ODB) Drugs from the ODB Formulary (DIN)
Inpatient Rehabilitation	National Rehabilitation Reporting System (NRS)
Home Care Services	Home Care Database (HCD)
Complex and Continuing Care	Continuing Care Reporting System (CCRS)
Patient Demographics (age, sex, date of death etc.)	Registered Persons Database files (RPDB)
Mental Health Hospitalizations	Ontario Mental Health Reporting System (OMHRS)

Appendix B

Table B.1 Disease code definitions of CFS/FM and other environmental sensitivities.

Cohort Type	Sources	Disease algorithm and Disuse codes
Primary Analysis		
FM/CFS	DAD, SDS, NACRS	1 hospitalization, same day procedure or emergency department visits with ICD-10 code M797 or; 2 physician visits with OHIP feecode K037 recorded anytime during the previous 2 years from March 31, 2009 to March 31, 2011
	OHIP	
Additional ways to define the cohort		
Environmental Sensitivities & FM/CFS	DAD, SDS, NACRS	Two of the below events within 2 years: 1 hospitalization, same day procedure or emergency department visits with ICD-10-CA code T78 or; 1 physician visit with OHIP dxcode 989 <i>and</i> membership in the primary cohort
	OHIP	
Environmental Sensitivities	DAD, SDS, NACRS	Two of the following events from March 31, 2009 to March 31, 2011: 1 hospitalization, same day procedure or emergency department visits with ICD-10-CA code T78 or; 1 physician visit with OHIP dxcode 989
	OHIP	
FM/CFS	DAD, SDS, NACRS	One or two of the following events from March 31, 2009 to March 31, 2011: 1 hospitalization, same day procedure or emergency department visits with ICD-10-CA code M797 or; 2 hospitalizations, same day procedure or emergency department visits with ICD-10-CA code R53, T733, G933 or; 2 physician visits with OHIP dxcode K037
	OHIP	

Appendix F - Ipsos report / analysis



Ministry of Health and Long-Term Care **Healthcare Practitioner Consultation**

Qualitative Report for the Task Force on Environmental Health
January 2018

Prepared by: Ipsos Public Affairs
www.ipsos.ca



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Executive Summary

Introduction

Ipsos was commissioned by the Ministry of Health and Long-Term Care (MOHLTC), on behalf of the Task Force on Environmental Health, to conduct qualitative research with physicians. The objectives were to understand physicians’:

- awareness, knowledge and opinion on the etiology of ES/MCS, ME/CFS and FM
- current approach to diagnosis and management of patients with ES/MCS, ME/CFS and FM (including any specialized supports, systematic, or multidisciplinary approaches used)
- opinions on what supports should be provided in the future for physicians or patients

Fifteen in-depth qualitative interviews were conducted between November – December 2017. Only physicians based in Ontario who had treated, in the past year, patients affected by at least one of three conditions were eligible to participate in the research.

Key findings

There was broad consensus among all participants that the fundamental challenge with all the conditions of interest to this study is that there are many unknowns:

- all three conditions are “ill defined” and “nebulous” in that they encompass a broad spectrum of patient complaints with varying degrees of impact on patients’ quality of life
- there are no “measurable” or “observable” physiological changes to demonstrate the presence or the cause of any of the three conditions or a reliable test to confirm their presence
- there are a very limited number of scientifically proven treatment options and the options that are available pertain to management as opposed to curing

These challenges did not lead to participants saying outright that they do not believe in the existence of these conditions. Rather, belief in these conditions was more often discussed in reference to the fact that patients affected by these conditions often also present “psychological disorders” which participants felt should be addressed. Mention of mental health issues can result in patients feeling that participants do not believe in them.

All participants try to help their patients but in many cases acknowledged that this can be a frustrating process for both themselves and patients, given the limitations of our understanding of these conditions:

You desperately try to find an explanation for this individual’s fatigue, and [...] something that will resolve and give them back that quality of life [...] And when you keep hitting dead ends in everything, [...] you’re getting to the point of saying, [it] is chronic fatigue. [...] Then you get into the long treatment process where you try to change their behaviour, you try to encourage them to be active beyond their physical comfort levels. You get into the cognitive behavioural therapy to help them understand that, [...] I know you’re suffering with it. But this is how you have to learn how to live with it [...]



Inevitably, you'll get to that point but they'll come back week after week, month after month, year after year desperately saying is there anything you can do? You've gotta do something, you've gotta try something else, and they're already on antidepressants and everything else. [...] You just try to put [out] little fires that erupt in their condition.

Family physician – group practice, 10+ years

The lack of tests for any of the three conditions means that participants relied on a “diagnosis of exclusion” where they attempted to eliminate the presence of other, better understood conditions for which there are reliable tests. With the exception of the rheumatology guidelines on pain points for FM and the Environmental Health Clinic at the Women’s College Hospital in Toronto, participants were unaware of any other specialised supports available to them or their patients. Still, it was evident that many had developed their own approaches to dealing with ME/CFS and FM.

There were mixed feelings and reactions to a diagnosis of ES/MCS, ME/CFS or FM. On the one hand, participants can tell patients that they are not affected by the “more serious”, “terminal” or “debilitating” conditions that have been excluded. At the same time, being able to confirm what patients do not have combined with the inability to pinpoint a specific physical cause or offer a cure may be “hard” for patients to accept. Indeed, it was felt that there is a “disjoint” between what patients want and what participants can offer them.

The lack of proven treatment means that a variety of options are offered to patients with some participants adopting an attitude of willing to try anything as long as it is “not harmful” or “non-evasive”. Further, some stressed the importance of “empowering”, “educating”, “motivating” and “encouraging” patients to become “proactive” in the management of their conditions, since many of the management strategies available relate to lifestyle changes. Specific management options suggested by participants to their patients included more exercise, avoiding triggers, physical therapies, medication and mental health services.

Looking to the future, there was interest in more resources and tools for both physicians and patients.

The main suggestions made were:

- Concise summaries or bulletins on the latest scientific evidence on these conditions for physicians.
- Evidence-based guidelines and toolkits on all three conditions that include diagnostic criteria and the most appropriate testing that should be conducted; proven management and treatment options; local referral pathways for management options; a tool that physicians can use to track patients’ progress over time (such as that for ADHD); and patient handouts to empower patients by helping them understand their conditions and how they can manage their condition.
- Patient access to multidisciplinary teams comprising relevant specialities in the diagnosis and management of the conditions (rheumatologists, psychologists, CBT therapists etc.)
- Better patient access to tests and management options by addressing the waitlists for tests and mental health services as well as more OHIP funding for physical therapies.



1 Introduction

1.1 Research Objectives

Approximately 670,000 Ontarians are living with one or more of the following chronic conditions: Environmental Sensitivities (ES) / Multiple Chemical Sensitivity (MCS); Myalgic Encephalomyelitis (ME) / Chronic Fatigue Syndrome (CFS); and Fibromyalgia (FM).

The Ministry of Health and Long-Term Care (MOHLTC) has appointed a Task Force on Environmental Health (TFEH). The Task Force is an advisory body with a three-year mandate to provide MOHLTC with recommendations on improving support for people living with the aforementioned conditions and on the design of an education and research agenda.

Ipsos was commissioned by MOHLTC, on behalf of the Task Force on Environmental Health, to conduct qualitative research with physicians. The objectives were to understand physicians’:

- awareness, knowledge and opinion on the etiology of ES/MCS, ME/CFS and FM
- current approach to diagnosis and management of patients with ES/MCS, ME/CFS and FM (including any specialized supports, systematic, or multidisciplinary approaches used)
- opinions on what supports should be provided in the future for physicians and patients

1.2 Methodology

Fifteen in-depth qualitative interviews were conducted between November and December 2017. Interviews lasted between 30 and 45 minutes.

Participants for the study were recruited by:

- ‘cold calling’ physicians based in Ontario using the MD Select Directory (This is a paid subscription directory that contains details of all physicians in Canada. It lists their graduation year, address, specialty and contact details.)
- contacting physicians based in Ontario who have taken part in past market and social research studies (this includes studies conducted by other organisations, not just Ipsos) and agreed to be re-contacted regarding future studies of this nature

A recruitment screener was developed by Ipsos with input from MOHLTC and select members from the Task Force. This was developed to ensure that those who took part met the agreed participant profile for the study. Only physicians based in Ontario who had treated, in the past year, patients affected by at least one of three conditions (ES/MCS; ME/CFS; and FM) were eligible to participate in the research. Quotas on physician type and self-reported knowledge of the conditions were also set. The table below shows the profile of the achieved sample.



Profile of final sample

Variable	No. of Interviews
Physician type	
Family Physician (mainly in group practices, some solo practices and 1 Family Health Team)	10
Specialist (Cardiologist, Gastroenterologist, Hematologist/Oncologist, Neurologist, Psychiatrist)	5
Self-reported knowledge of the conditions (personal rating of knowledge on each condition on a 1-10 scale)	
Self-reported higher level of knowledge (average score of 5 or more)	10
Self-reported lower level of knowledge (average score of 4 or less)	5
Years of practice	
10 years or less	6
More than 10 years	9
Location	
GTA	8
Ottawa	2
Sudbury	1
Hamilton	1
Elizabethtown (near Brockville)	1
Owen Sound	1
Heidelberg (near Kitchener)	1

A discussion guide was developed based around the objectives of the study. A copy has been provided in the appendix.

1.3 Interpretation of findings

The findings presented in this report are qualitative in nature. The value of qualitative research is that it allows for the in-depth exploration of factors that shape attitudes and behaviours on certain issues. The intention is not to produce results that are statistically representative of the population at large. This should be borne in mind when interpreting and making inferences from the findings.

The small number of interviews typically involved in qualitative research preclude a detailed analysis by subgroups. In this study, there was a high degree of consistency in the views expressed by all physicians who took part, despite the varied profile of the final sample (see table above). Thus, findings have been reported on an aggregate basis to tell the overall 'story' that emerged. The few notable differences that emerged have been highlighted where appropriate.

Finally, it worth noting that this report intends to capture the knowledge, opinion and approaches of Ontario physicians as they are, and in a neutral manner. The interview data presented in this report is therefore not necessarily consistent with the most current literature, or medical and scientific consensus regarding the causes, diagnosis or treatment of these conditions.



2. Physicians' awareness, knowledge and opinion on the etiology of ES/MCS, ME/CFS and FM

2.1 The state of the scientific evidence

There was broad consensus among all participants that the fundamental challenge with all the conditions of interest to this study is that there are many unknowns. Three main points were made time and time again throughout the interviews.

Firstly, all three conditions were described as “ill defined” and “nebulous”, particularly in the case of ES/MCS and ME/CFS, in that they encompass a broad spectrum of patient complaints with varying degrees of impact on patients' quality of life. In the case of ES/MCS for example, participants gave examples of potential sensitivities ranging from food stuff (gluten) to chemicals (pesticides, perfumes, detergents, radon) and things in the environment (pollen, dander). Further, there was a view that the labels, and CFS in particular, were unhelpful because they grouped patients with very different symptoms into “a pot”.

*Very difficult, very nebulous conditions. Each one of those conditions has a broad spectrum of presentation, everything from extremely mild and subtle to severely disabling and debilitating [...]. All of these conditions [...] remain quite controversial and there's a lot of debate as to whether they're true conditions. **Family doctor – group practice, 10+ years***

*I'm a believer in the symptoms. Diagnosis is hard. I think that as time progresses we're going to be able to start treating out different subsets, but right now those diagnoses are mainly a clustering of we don't know what to do with those patients so we put them into a pot. [...] Patients are classified with these diagnoses but experience very different symptoms. I don't think they're all the same. **Family doctor – group practice, 10 or less years***

Secondly, participants commented that all three conditions are “poorly understood” from a scientific standpoint in that: there are no “measurable” or “observable” physiological changes to demonstrate the presence or the cause of these conditions; nor studies showing a causal link of environmental factors to physiological changes in the case of ES/MCS. As such, there are no tests to confirm the existence of any of these conditions.

*It's interesting because usually for 90% of medical conditions, we either have straightforward guidelines, [...] criteria that meet the diagnosis, but for what we're discussing [...] there isn't one perfect test that clearly identifies that this exists. **Family doctor – solo practice, 10+ years***

Chronic fatigue syndrome and fibromyalgia, there's a lot of overlap in symptoms, something that's not typically well understood at this point, at least from a conventional medicine point of view, and it's very difficult and challenging for patients to manage, because often their



needs are not addressed and often the treatment that we can offer is quite limited. **Family physician – group practice, 10+ years**

Finally, there are a very limited number of scientifically proven treatment options; and the options that are available pertain to management as opposed to curing. This creates the difficulty of managing a chronic condition with a somewhat lacking “toolbox”.

Unlike diabetes where we have hard numbers to target for, cholesterol, etcetera, it's not so clear how to treat these patients. What is better, what is worse, there's no markers to use. Medications, they're suggestions but there's no algorithms, so it's kind of a DIY type of thing.

Family physician – group practice, 10 years or less

Very difficult to treat, in any one particular fashion. It requires the art of medicine in terms of the complexity of the different sorts of treatment modalities [...]. It needs to be managed over time [...] So we fall into the area of chronic treatment [and] we haven't got a definitive treatment for it either. Across the board it's a difficult thing to manage and to work with.

Specialist – psychiatrist, 10 or less years

2.2. Attitudes towards the legitimacy of the conditions

Participants acknowledged that the lack of definitive scientific evidence on the conditions' etiology, physical presentation and treatment led to believability or “legitimacy” issues. Two main viewpoints emerged in this regard.

Firstly, participants were aware of the fact that some physicians in the wider physician population dismiss these conditions outright due to the lack of scientific evidence. Indeed, one participant brought up the fact that ES/MCS is not recognised the by the American Allergy and Asthma Association, the California Medical Association nor the American Medical (it was this participant's perception that these are relevant medical associations from which equivalent Canadian associations may currently be taking direction). Related to this view, participants were aware that some physicians believe that patients “fabricate” these conditions in order to take advantage of disability benefits.

Overall, these views however were not personally held by participants who took part in the research. Just one participant admitted that he was skeptical about the existence of ES/MCS. For FM, the same participant had been a sceptic in the past but has changed his mind in light of new scientific studies conducted on brain activity. His position on ME/CFS was in between ES/MCS and FM.

It's hard because there's no specific physical findings or laboratory test to confirm that kind of complaint, and it's - to be perfectly honest - not scientifically logical. It's not something that I would readily accept as valid, from a medical science point of view. Individuals who claim, for example, to have a sensitivity to an extraordinarily wide variety of things that one would find in the environment don't actually demonstrate measurable physical features.

Specialist – neurologist, 10+ years

The condition is not recognized by the American Allergy and Asthma Association. It's not recognized by the California Medical Association, which tends to be very keen on - because I think of the type of population they have there - on allergies. It's not recognized and



*considered a valid clinical entity by the American Medical Association, so there isn't a lot of [...] board-level support or scientific support for the condition over and beyond what an individual complains of. **Family physician – group practice, 10+ years***

As noted above, all but one participant did not subscribe to these views but were aware of their existence in the wider physician community; some had come across patients who had seen a “skeptical” physician in the past. Participants believed that their patients were genuinely experiencing and affected by their complaints and proceed with investigating accordingly (see section 3 for more details on diagnosis approach). A small number admitted that they had been skeptical in the past, but had changed their opinion and attitudes in light of new scientific literature and years of personal experience treating patients affected by these conditions.

*I do understand with things like fibromyalgia [...] some physicians don't seem to quote unquote believe in them, but I do understand as far as I know, it's a legitimate condition, and I have had some patients who had to talk to their family doctors, the rheumatologist for example diagnoses that, but the family doctor quote unquote doesn't believe in it. I've heard some stories of that nature. **Family physician – group practice, 10 or less years***

*There's been a lot of controversy in the past that people are basically fabricating this. I've heard people go so far as to say these conditions are a convenient way by which someone can access disability benefits, because they're very difficult to measure and objectify. In the cases I've seen - and I've seen a number that span the spectrum of not only ages but socioeconomic classes, patients that span the spectrum of motivation and self-purported tendencies, and I will say that I have seen quite a few cases where these individuals are legitimately affected by their condition and don't want the condition. They have absolutely no secondary gain in mind. It's something they struggle with and they try to overcome to the best of their ability with varying degrees of success. **Family physician – group practice, 10+ years***

*I started off as a skeptic; I now am a 70% believer. The vast amount of literature, basically, changed my way of thinking. So I'm much more sympathetic, as well as much more rigorous, from an academic [...] therapeutic and diagnostic standpoint in looking at these patients. **Specialist – cardiologist, 10+ years***

Secondly, and more commonly, the issue of believability emerged around the view that patients affected by ES/MCS, ME/CFS or FM often also display “psychological disorders”. On the one hand, it was noted that anxiety and depression are likely a result of living with the chronic nature of the conditions. On the other hand, there was a belief that the conditions are manifestations of underlying psychological disorders. In either of these interpretations, participants felt that patients would benefit from addressing the psychological component: as a means to cope with living with a chronic condition or, to help with managing the physical complaints. In some cases, participants felt that the mention of psychological conditions can result in some patients feeling that participants do not believe them. This in turn leads to patients repeatedly returning to participants for more tests or for more suggestions of what to do, or these patients may turn to other practitioners for help. In other cases, patients may be unwilling to



accept counselling or a referral to a psychologist because they do not believe that this type of support would help them.

*Patients who suffer with it when they've been diagnosed have been suffering for a long time and have built up a lot of frustrations and maybe anger, and are very anxious about their problem and that presents as anxiety to the physician. So the dominant symptom that's being seen is the anxiety, so therefore when discussing the symptoms with the patient, there's the anger, the anxiety, and frustration that comes of a psychological concern, because there's nothing physical defined. **Family physician – solo practice, 10+ years***

*I think there's a big connect between mental health and physical health symptoms. So often physical health presents as a manifestation of mental health issues, there is a connect, I don't think they're two separate health systems. **Family physician – group practice, 10+ years***

*My understanding of fibromyalgia is that it has to do with people having more sensitive nerves than people who do not have fibromyalgia. So something that wouldn't be painful to me would be painful to them because their nerves are more sensitive than mine. But I think most people who I've ever met that have fibromyalgia have some sort of stressor in their life or some form of trauma or a history of anxiety or depression, often that's gone undertreated or undiagnosed, and that can manifest with chronic pain disorders. **Family physician – group practice, 10 or less years***

*The majority of [multiple environmental sensitivities] patients, [...] Close to 70% of these patients have a very measurable psychiatric or psychological disorder if one delves into their history or takes an appropriate history [...] Not to say that we should push those things aside; they're very legitimate problems that need to be addressed. But the focus should be the underlying psychological disorder and not the perception that there's something medically more worrisome. **Specialist – neurologist, 10+ years***

2.3 Emotions experienced when dealing with these conditions

Given the challenges described above and those discussed in more detail in subsequent sections, participants, family physicians in particular, admitted to personally feeling “at a loss” with what to do due to the lack of clear guidelines for these conditions or even broader acknowledgement from the scientific community that these conditions exist.

*Environmental sensitivity, I only have three patients in my practice. There are some specialists in the city of Toronto that have a special interest in that, so they've actually helped me because I was at a loss. **Family physician – solo practice, 10+ years***

*It's a real dilemma because if you've got a patient in front of you who you know well and know has no reason to be complaining of these things if they didn't exist.[...] Yet the scientific community out there says no, it's not a condition, it doesn't exist [...] How do you tell a patient [...] I appreciate and understand and sympathize with what you're telling me and I believe what you say is valid, but the scientific body out there says it doesn't exist. That's a real tough problem. **Family physician – group practice, 10+ years***



The research also found feelings of frustration at the inability to pin point a cause; the limited “treatment” options physicians can offer their patients; the “frequent flyer” patients who are unwilling to make the necessary lifestyle changes to help manage their conditions.

*You desperately try to find an explanation for this individual's fatigue, and [...] something that will resolve and give them back that quality of life [...] And when you keep hitting dead ends in everything, [...] you're getting to the point of saying, [it] is chronic fatigue. [...] Then you get into the long treatment process where you try to change their behaviour, you try to encourage them to be active beyond their physical comfort levels. You get into the cognitive behavioural therapy to help them understand that, [...] I know you're suffering with it. But this is how you have to learn how to live with it [...] Inevitably, you'll get to that point but they'll come back week after week, month after month, year after year desperately saying is there anything you can do? You've gotta do something, you've gotta try something else, and they're already on antidepressants and everything else. [...] You just try to put [out] little fires that erupt in their condition. **Family physician – group practice, 10+ years***

*I think sometimes the frustration is when patients [...] just want to fix their physical issue without addressing anything that might be triggering it in [...] their own lifestyle. So often there are some [...] patients who don't take any responsibility for their health, [...] [they] keep coming back and keep coming back and haven't tried anything that anyone suggested to them. **Family physician – group practice, 10+ years***

*It's about engaging them in lifestyle things. So if you can't, then it does become quite difficult as to what else you could do, I don't know how else to then follow these patients up, what else you can offer them after this. Often what I find is a lot of these patients end up on analgesics or antidepressants, those are the other things that are somewhat effective. **Family physician – group practice, 10+ years***

At the same time, there was appreciation that patients themselves may feel somewhat “let down by the system” stemming from a “disjoint” between what they want and what physicians can offer them.

*I think their frustration is that there's not a huge amount that's been offered to them, [...] talking to them about a graded exercise, well initially they would just say they're too tired to do that anyway. So they just think that that's a completely useless suggestion. So I think they feel a little bit let down by the system. because they have no answer to their issue. **Family physician – group practice, 10+ years***

*Patients can also be quite frustrating because they want answers that I can't necessarily give, so there's a disjoint between patients and what we're able to provide in a lot of cases. **Family physician – group practice, 10 years or less***



3. Physicians' approach to diagnosing ES/MCS, ME/CFS and FM

3.1 "A Diagnosis of Exclusion"

There was a desire among all to help their patients. In a couple of interviews, participants admitted that they had to be "convinced" first by looking at a variety of measures (e.g. how long the patient experienced their complaints, the impact of the complaint on their quality of life) or, they required patients whom they wouldn't expect to display those symptoms to "go out of their way to prove their case".

*My measure of how far to take things in terms of investigations is, how does a condition affect a person's quality of life? And if I get the sense after maybe a couple of encounters with an individual who complains of these things, and they're not episodic [...] So it's not like I had a bad spell for a week or so but it's gone [...] Once I'm convinced it's probably more of a longstanding thing – [...] in existence for at least six months; that's what I qualify to my measure of a chronic situation. **Family physician – group practice, 10+ years***

Virtually all of the family physicians interviewed conducted a "diagnosis of exclusion," where they attempted to eliminate the presence of other, better understood conditions for which there are reliable tests. Participants often referred to these other conditions as "structural" or "more worrisome" which in this context can be taken to mean conditions for which there are clear tests and which, if left untreated can lead to serious complications for patients.

*I think for the most part, these diagnoses are often labeled or diagnosed on the basis of exclusion. Where a number of other things have been ruled out and they've been exhaustively investigated, no other underlying cause for the individual's spectrum of symptoms and findings exist, and so by exclusion they're given one of these three labels, depending on the presentation. **Family physician – group practice, 10+ years***

*Fatigue isn't really a disease, it's a symptom. There are probably dozens of serious conditions that can lead to fatigue, and of course it has to be looked at individually, because fatigue in an 18 year old is not the same as fatigue in an 80 year old. So by exclusion, I have to think about what would an 18 year old be suffering from medically that has to be ruled out. So you do your focused investigations and you go through your spectrum of things that are more worrisome. Obviously an older person with fatigue, you have to worry about serious life-threatening conditions. **Family physician – solo practice, 10+ years***

Let's say your patient presents to you with muscle aches and so on and you make the diagnosis and you don't do any further work and you start treating them as a typical patient with fibromyalgia. You miss the opportunity of diagnosing an important medical condition, which is inflammatory in nature, and if left untreated, almost one in five of these individuals



can develop a very debilitating condition, in which they can go blind. So unfortunately missing a diagnosis as important as that is very bad for patient care. **Specialist – hematologist / oncologist, 10 or less years**

3.2 Approach to ES/MCS

Participants who took part in the research tended to have the least experience dealing with ES/MCS cases. Indeed, a small number were somewhat unfamiliar with the terminology itself and several admitted at being less confident in making a diagnosis than in the case of ME/CFS and FM.

*I don't come across that many patients with environmental health sensitivities, since I've been here I've had two. **Family physician – group practice, 10+ years***

*Not many. Of the three conditions, in my experience, ES/MCS represents the significant minority of the three conditions in total. And I would say for the most part, the ones I have encountered, have been on the mild end of the spectrum. A person may say, you know, I really have trouble when I go into a crowded waiting room or a shopping mall or a store or something, and people are wearing perfume. It really bothers me, or I seem to have a heightened sense of smell. I notice things that other people don't notice and it kind of bothers me. As opposed to the other end of the spectrum where individuals have measurable respiratory, perhaps some rash associations, etcetera. I don't really see that. **Family physician – group practice, 10+ years***

Much of the specific types of testing conducted in relation to ES/MCS were:

- allergy testing or referrals to allergists and gastroenterologists
- “common” tests for lead, asbestos and mercury
- checking for respiratory conditions

There was some awareness of specialist support available at the Environmental Health Clinic at the Women's College Hospital in Toronto, but this was not universal. One participant only found out about it after sending a patient to a general allergist who then referred the patient on to the Environmental Health Clinic. Beyond these items, participants were unaware of any other tools, supports or guidelines that are available for ES/MCS.

*If you're looking to help the patient who presents those symptoms, it's very close to having allergies, but it's not specific to one allergy that I can pinpoint. And [...] there may be work-related sensitivities because of the environment [...] then I have an obligation to make sure that there are no workplace incidents, because that's a reportable issue for safety. [...] I'm not quite certain how to approach [them]. There aren't many tests I can order [...] except for the common ones like lead and asbestos and mercury. There aren't any other specific tests that I'm familiar with, but it can be quite a devastating condition for people who suffer from it, so I don't want to ignore it. **Family physician – solo practice, 10+ years***

I didn't know about the multiple chemical sensitivity program downtown. [I had] an interesting situation. She was a really healthy, 40-ish year old woman with a family and



worked as a teacher in an elementary school, and she was having issues with chemicals in the school library, which had just been renovated. [...] I didn't know quite how to approach it. So truthfully I didn't end up doing all that much for her. I probably ordered routine blood work, [...] I suggested trying to avoid those situations as much as she could, and I referred her to an allergist. [...] I think that [...] the general allergist I sent her to [...] ended up sending her to another allergist who specializes in multiple chemical sensitivities, and then I think they thought that she had multiple chemical sensitivities. **Family physician – group practice, 10 years or less**

There's an Environmental Health Clinic at the Women's College Hospital that deals with these questions, and there are also allergists who test for specific metals and other types of things, but that's a limited set of tests. Really it's [the] Environmental Health Clinic overall. **Family physician – group practice, 10 years or less**

3.3 Approach to ME/CFS and FM

Among family physicians who took part in the research, most had more experience seeing patients with ME/CFS or FM than patients with ES/MCS. There was a view that there was a lot of overlap between ME/CFS and FM in that patients affected by the former are likely also affected by the latter. In much of the discussions, participants spoke about CFS and FM specifically and a couple of participants said that they had never heard of ME before.

Chronic fatigue and FM, I'm quite comfortable making the diagnosis and I have about 15 patients that I see on a regular basis who have those diagnoses. So it's certainly [...] not uncommon in my practice. **Family physician – solo practice, 10+ years**

I haven't actually heard of Myalgic Encephalomyelitis, but I guess it's connected somehow to chronic fatigue? [...] Chronic fatigue and fibromyalgia I feel often go hand-in-hand and I have a number of patients who have those diagnoses. A lot of people who have the diagnosis of fibromyalgia also have the diagnosis of chronic fatigue syndrome. **Family physician – group practice, 10 or less years**

The specific types of tests physicians conducted for ME/CFS and FM as part of their “diagnosis of exclusion” included:

- in the case of ME/CFS, bloodwork, imaging and referrals to internists or hematologists to rule out anaemia, kidney failure, diabetes, or metabolic problems
- in the case of FM, bloodwork or referrals to a rheumatologist to rule out inflammatory joint conditions or autoimmune joint conditions

I go with blood tests. Obviously you want to make sure that they're not anaemic, or kidney failure, or diabetic, things like that. **Family physician – group practice, 10+ years**

Not so much tools or guidelines that will direct you to the diagnosis initially. [...] Fatigue can be caused by an enormous number of [...] causes. So really, the onus is on one to rule out all of the other causes - be it anemia, be it thyroid problems, be it metabolic problems such as



electrolyte or sugar abnormalities. Psychological issues, different forms of depression, anxiety, somatoform disorders. You have to go through the whole gamut, because there is no single test that says oh, if you have these results, that's chronic fatigue. **Family physician – group practice, 10+ years**

Most of these people [...] generally don't have any underlying medical cause, and that's when we attribute [them] to one of these ill-defined syndromes. But when you see these initially, you want to find out any structural cause[s], whether it's through blood work or imaging. **Specialist – hematologist / oncologist, 10 or less years**

In fibromyalgia, obviously you want to rule out that there is an inflammatory joint condition going on, so you can do antibody testing, you can do inflammatory markers, you can do imaging. [These are] quite good in ruling out some of the [...] autoimmune joint conditions. **Family physician – group practice, 10+ years**

There was awareness of the rheumatological guidelines on the “18 pressure points” to diagnose FM, although some noted that these have changed in recent times. Participants were unaware of any other diagnostic supports available. It was evident that many had developed their own approaches from their years of experience and a number went on to say that they felt very comfortable in conducting a diagnosis. Still, they saw the value in referring to a specialist for a second opinion and in case they “missed something”. One participant also felt that referring to a specialist was an important element in the patient journey; it shows patients that their concerns are being truly listened to and investigated.

There are the pressure points for fibromyalgia, specifically, the 18 points. And you see if people are tender in those spots, it's a match. **Family physician – group practice, 10 or less years**

I'm not following a specific set of diagnostic criteria. It's [...] more looking at my side of the equation [and] excluding of a disorder with which I'm much more familiar; a neurologic disorder. **Specialist – neurologist, 10+ years**

Over the years, we all get into patterns of practice and what to look for, so I have my own approach that I think is common in terms of what tests to order and what things to be concerned about. **Family physician – solo practice, 10+ years**

Most of the people I have referred onto rheumatology, with the [diagnosis] that it is chronic fatigue syndrome, have come back with the diagnosis of chronic fatigue syndrome. I merely do it, it's mostly as a confirmation and to help the patient. [...] If they're seeing another doctor I think psychologically it makes a big difference to them to know that they're seen by a specialist [...] There isn't a huge amount you can offer [...]. I think seeing a few doctors [...] that is quite a good therapeutic tool. **Family physician – group practice, 10+ years**

In addition to the types of testing and referrals discussed above, a number of participants stressed the importance of spending time with patients to obtain a detailed personal history and for some, it is in these types of consultations that they identify mental health issues. There was a view that devoting time



to this can be a challenge for family physicians and recognition that this in turn may lead to “defaulting to an anxiety diagnosis” or “dismiss[ing] patients as pain medication seekers”.

*For CFS, [...] the blood test it more often than not will come back normal, so I think taking a really detailed and full history is the key. So, looking into really when it started, what the situations around that, what their social circumstances are, what their support network is like, what their occupation is, and their mental health, doing a full mental health investigation into their mood. So I think the history is the most important part of the whole thing. **Family physician – group practice, 10+ years***

*We know that people are not feeling well, but it’s-- sometimes I think it’s our fault that we don’t have enough time in the day to inquire. Sometimes it’s the careful history and time that helps, and in my busy day, it’s easier to default to an anxiety diagnosis and try to delve into the workplace situation. **Family physician – solo practice, 10+ years***

*Family physicians are extremely busy - I respect them, don’t get me wrong. But just because of the patient load that they carry on, and the number of people they can see, it’s not uncommon to see that things may be dismissed as just a pain medication seeker. **Specialist – hematologist / oncologist, 10 or less years***

3.4 Reactions to a diagnosis

There were mixed feelings and reactions to a diagnosis of ES/MCS, ME/CFS or FM. On the one hand, physicians can tell patients that they are not affected by the “more serious”, “terminal” or “debilitating” conditions that have been excluded. Some participants felt that in cases where the condition is having a less drastic impact on the quality of life of patients, for example in the milder cases of ES/MCS, patients are often content with this diagnosis.

*The quality of life measures are quite different, at least in my experience [...]. There are certainly fibromyalgia patients, I have some who cannot work. [Whereas in the environmental sensitivities], they’re not feeling well and want to know why and what can be done about it, so I think once they’re satisfied-- the concern is that it’s not going to cause a terminal or fatal health condition. **Family physician – solo practice, 10+ years***

*It’s sort of a mixed blessing. They’re relieved on one hand that they don’t have cancer [...] leukemia, [...] a brain tumor, [...] all kinds of things that could be really bad and give you these symptoms. That’s one thing. But they’re equally frustrated with I can’t go on with this. **Family physician – group practice, 10+ years***

*Some people are very happy to hear that. “Gee, I don’t have a major heart problem. I can live with my chronic fatigue; I don’t have a major heart problem.” And other people get very frustrated, and they say, “Come on. You’ve got to be able to find something. ...Don’t brush me off as having one of these funny syndromes.” **Specialist – cardiologist, 10+ years***

At the same time, being able to confirm what patients do not have combined with the inability to pinpoint a specific physical cause or offer a cure may be “hard” for patients to accept. Some participants



felt that the mention of mental health issues at this stage may result in patients feeling that the physician does not believe them or there is an unwillingness to accept any link to mental health, as discussed in the previous section. Thus, some were cognisant of the language they used to explain the diagnosis to patients – e.g., “I don’t say that there’s nothing wrong with them”, “I always reinforce to patients that even though we can’t see the pain or feel their pain, that the pain they’re experiencing is real” – and through sensitive language, some have success in securing buy-in from patients on the mental health piece.

*For [other] patients, they know because I have an X-ray or a blood test to show them that’s what they have. For my FM and my chronic fatigue patients, basically I say well I know what you don’t have. It’s not the same answer, and it’s hard for patients. It’s easier to accept when [you] can show something to somebody and say this is what you have. **Family physician – solo practice, 10+ years***

*Often you get patients who have got fairly good insight and they know that if they’re stressed they can develop headaches, or if they are stressed they can develop stomach issues, so some of them completely can see that [...] There are also some who [...] don’t ever want to entertain any idea that their mental health plays a part in how their physical health manifests, and those are the more challenging ones. [...] They often end up with more and more tests, and they go for CT scans and MRIs, and EDs and things like this. **Family physician – group practice, 10+ years***

*I try to play my role pretty straight as a neurologist, so as a consultant I focus on telling the patient that, you know, I can’t find anything worrisome; I cannot find any evidence that they have a more debilitating neurologic disorder. So I can reassure them that I don’t find any signs of nerve damage or muscle disease. [...] The CFS people, I would probably have to broach the fact that a lot of such patients may have an underlying depression. [...] but almost invariably it’s rejected and, you know, it’s sort of a negative interaction that, “You don’t believe me. You don’t think that I suffer from this condition.” And there’s all kinds of things on the internet that they will use to bolster this, and there’s all kinds of people that are quasi-medical such as naturopaths and all kinds of people willing to... I would say take advantage of that, and support them in this perception. **Specialist – neurologist, 10+ years***

*So even if I’m unable to find any particular etiology, I don’t say that there’s nothing wrong with them. I simply always tell them that if their symptoms continue to change, [...] they should either be seen by their family physician, and certainly if my services are needed based on new developments. **Specialist – hematologist / oncologist, 10 or less years***

*I try to always reinforce to patients that even though we can’t see the pain or feel their pain, that the pain they’re experiencing is real, even if the X-rays and blood is coming back normal. I can’t think of any of my patients who have chronic pain who would deny any form of depression, anxiety, trauma. I think almost all of them, if it’s brought up sensitively, will endorse something mental health related. **Family physician – group practice, 10 or less years***



3.5 ES/MCS and workplace safety issues

The issue of worker and workplace safety with ES/MCS was raised in a handful of interviews. Some physicians had instances of patients not wishing to take matters further out of fear of losing their job and then not being able to claim disability or worker's compensation benefits. There was a perception that these conditions are often denied by WSIB. In another case, a physician would prefer to refer back to a company's occupational health department as they would have better knowledge of the different types of chemical exposures and hazards in the workplace.

*The person may need to go on disability, which means there's going to be forms to be completed. There's going to be more stress for the patient because they may not be able to qualify for the disability and worker's compensation as well. I've found a couple times in the past, when I have considered it, the patient has declined to do any further work on it, because they don't want to get in trouble with their manager or boss, so there's a fear that they may lose their job. **Family physician – solo practice, 10+ years***

*When a patient comes into my office, talk about the potential exposures that they're seeing at their workplace, that I might not be best equipped to assess those exposures because I don't know exactly what they're being exposed to in their workplace [...] So if they have an occupational health department, I much prefer that they speak to [...] the doctor that is connected with their company, to make sure that we're not missing anything. **Family physician – family health team, 10 or less years***



4. Physicians' approach to helping patients manage ES/MCS, ME/CFS and FM

4.1 Responsibility for management of ES/MCS, ME/CFS and FM

Once there is a diagnosis the focus shifts to management of the conditions. This role will generally fall on family physicians; the role of specialists often ends once results from testing are available.

*First of all, I don't find specialists have a special interest in wanting to follow these people because they're not doing any treatment. [...] It's not like a diabetic patient who has to see the endocrinologist continually. For the three conditions mentioned, 95% of the time, these patients will go for a consult, maybe one or two sessions, and then they're referred back to me with suggestions for management. **Family physician – solo practice, 10+ years***

*I think family doctors have a pretty good handle on that [...] Whereas my field, neurology, still adopts the approach [...] you exclude anything else of concern and then, quite honestly, the approach will be, "Well okay, it's not *my* problem now." Although I'm inclined to [...] suggest strategies to the patient - just, that's my nature. But, say, yes, you can try this medicine for pain, and yes I'm a big fan of fitness and exercise and so on. **Specialist – neurologist, 10 or less years***

4.2 The range of management options offered to patients

The lack of proven treatment means that a variety of options are offered to patients with participants adopting an attitude of willing to try anything as long as it is "not harmful" or "non-evasive". It was acknowledged that some patients turn to "alternative care" options which led to one participant feeling uncomfortable when asked by her patients for her opinion on these alternative options.

*I think the alternative care practitioners add a few other little levels that improve patient management. And if the patient's willing to pay for them, that's none of our concern. I mean, as long as no one's doing harm. **Family physician – solo practice, 10+ years***

*People talk about doing infusions like an oxygen chamber, vitamin C, and things not in the realm of Western medicine. Maybe it will be one day, but a lot of people, out of frustration, go outside our standard Western medicine system because we don't have a lot of options, and I don't blame them for that. But they come back to me wanting to know my opinion, wanting to know treatment management, and that's frustrating. Other people have other toolboxes and I don't necessarily know what's in their toolbox. **Family physician – group practice, 10 or less years***

Others stressed the importance of "empowering", "educating", "motivating" and "encouraging" patients to become "proactive" in the management of their conditions, since many of the management strategies available relate to lifestyle changes.



Educate them in the understanding of what's going on, the options that are available. And help them become proactive individuals with [...] their own condition. That helps a lot, because if it's passive, being pushed around from one physician to another, being prescribed one medication after another, I'd think that it might foster a sense of added dependency. [...] My goal is often to help them better understand that it's going to be likely a life long management issue, and [...] some of the symptoms will get better [...]. But be prepared for [...] life adaptation [...]. Most often a degree of stabilization can take place, of the effects. Their understanding of it, their ability to kind of join with the management with it, helps them to help understand what's going on and help them to reduce the amount of social stress and family stress, and they encounter. **Specialist – psychiatrist, 10+ years**

The range of management options participants offered to their patients include:

- lifestyle changes for ME/CFS and FM – more exercise or physical activity (yoga was mentioned several times), avoiding stimulants close to bedtime, weight management
- lifestyle changes for ES/MCS – avoiding triggers, antihistamines or cortisol creams, testing their houses for chemicals, changing jobs
- referral to physical therapy for FM – physiotherapist, acupuncture, chiropractor, physiatrist
- prescription medications for ME/CFS and FM: Lyrica and Gabapentin proven to help with FM in past, anti-depressants to help with sleep
- referrals to mental health services for coping with chronic conditions or mental health issues for ME/CFS and FM – psychotherapist, psychiatrist, counsellor, or cognitive behavioural therapist

Oftentimes I tend to emphasize that if they are taking alcoholic beverages, to cut it down to the minimum. They shouldn't take caffeinated products close to bed. They should rest adequately[...] Exercise is an important one. And plus stretch exercises. This is not publicly funded, but [...] I tell them to maybe go to some yoga. **Specialist – hematologist / oncologist, 10 or less years**

In terms of guidelines, a lot of it has to do with lifestyles, so eating well and sleeping well and exercise, those being the basics. Encouraging people to do things like yoga and any activity that will keep them moving and active and engaged. Then medication. **Family physician – group practice, 10 or less years**

The follow-up care falls on the family doctor. It's supportive therapy in addition to, again, re-emphasis on lifestyle management. Smoking cessation; walking 30 minutes three times a week minimally, or other types of exercise; dietary management if they're overweight, reducing carbohydrates, reducing fried foods, fatty foods, red meats. **Family physician – solo practice, 10+ years**

If it [is] related to chemicals, some sort of exposure to some kind of product that they come into contact with, their skin, often I'll recommend trying to figure out what it is that might be the trigger. I'll recommend bland skin care, and trying to avoid products that have fragrances and additives that they're probably not benefitting from, and if it's quite severe, then trying different cortisone creams, or antihistamines if they're itchy, and again, refer them to potentially an allergist to see whether or not they would benefit from some kind of patch



testing to see if they could identify what chemical they might be sensitive to. **Family physician – family health team, 10 or less years**

It's quite frustrating because there's no answers. I'll reiterate what the environmental clinic did and sometimes they'll have recommendations to get lead tested in the pipes in their house, check their house for asbestos, for other types of chemical sensitivities make sure you're using organic solvents, dishwashing detergents. **Family physician – group practice, 10 or less years**

I think FM patients do well with some kind of physiotherapy and chiropractic treatments. [...] I also use part of the aqua therapy. So I use Toronto Rehab quite often for these patients as a referral to get a consult, and I also [suggest] a physiatrist [...] to offer some specific techniques if they show scoliosis symptoms. And acupuncture - I try everything. **Family physician – solo practice, 10+ years**

I find that in fibromyalgia there's often a sleep disorder associated. That's not to say it's the cause, but sometimes if we can find ways of managing and providing better restored sleep through the use of tricyclic antidepressants or [...] one of the other antidepressants with pain-modulating properties, that often goes a long way. Sometimes they need that psychological treatment support to encourage them, to motivate them, to convince them that it's not in their heads - that this is a real condition. **Family physician – group practice, 10+ years**



5. Future ES/MCS, ME/CFS and FM supports for physicians and patients

While most appeared to have developed their own approaches to diagnosing and managing patients with the three conditions, there was still appreciation for more resources and tools that could be provided in the future. This section outlines the suggestions made across all the interviews.

5.1 Updates on latest scientific studies

Participants would welcome concise summaries or bulletins on the latest scientific evidence on these conditions. Physicians wished to stay current on conditions that are related to their specialty or those that affect their patients. More information on latest scientific evidence was seen by the more skeptical participants as important in legitimising patients' complaints in the eyes of "rank and file medical healthcare professionals".

*Nobody wants to receive a research paper that's 15 pages long and filled with statistics. But if the Ministry was to be more proactive, [they can] disseminate quality research, summarize information from places like the Mayo Clinic and other recognized institutions and research facilities, [in order to] heighten one's educational level and [to] the fact that there is some evidence to support the legitimacy of these conditions and the approach to them. **Family physician – group practice, 10+ years***

*I would want a broader education, a broader availability of [...] scientific information, and to see it repeated or validated or quantified so that if that is indeed the case. Can we legitimize that scientific hypothesis that pain modulation is indeed responsible? Then it gives legitimacy to the patient's complaints and it's more broadly accepted by the rank and file of medical healthcare professionals. **Specialist – neurologist, 10+ years***

While all had e-mail and felt that this would be an effective way to disseminate information, it was pointed that they receive a lot e-mails from numerous medical organisations which means that not all is read. For some including the information with the MOHLTC updates on the flu shot would be helpful while another suggestion was disseminating information via the various professional medical associations.

*Email is a good way to get in touch with me but I get so many that I can't read them all. [...] They're all medical organizations that are emailing me, so whether it's one or the other, it doesn't really make a difference. Or if it's like a journal versus an organization. I don't know. Every now and then something will catch my eye and I'll read it. **Family physician – group practice, 10 or less years***

More broadly, it was pointed out that additional research studies or specialised research institutes focusing on these conditions were required to improve our current body of knowledge, while others were holding out for advances in new drug treatments.



*I think more symptomatic research is needed, if that means long-term follow up of the individuals. Some of these individuals may develop an autoimmune disorder, or some other thing. **Specialist – hematologist / oncologist, 10 or less years***

*There are centres [...] throughout North America and the world that look at these conditions. [They] have specialized clinics, and a host of physicians and support staff that deal with this and research this and collect all kinds of data on their patient population. [...] For example, in the case of chronic fatigue syndrome. If, in the specialized research facilities, they found there is no valid correlation between the finding of the Epstein virus antibody and chronic fatigue syndrome, well that would be really good to know. **Family physician – group practice, 10+ years***

*There isn't really a perfect medication. [...] I'm not saying pharma-therapy is the only solution. What I'm hoping for, which is now the way medicine are progressing, there are new biologic treatments for certain conditions like arthritis or even osteoporosis. [...] So I'm hoping there may be one of those available, maybe even to cure these conditions. **Family physician – solo practice, 10+ years***

5.2 Guidelines and toolkits

The general perception was that there is little on offer beyond the guidelines on pain points for FM provided by rheumatology. And while many had developed their own approaches, there was still appreciation for clearer guidelines on all three conditions, especially in the case of ES/MCS, which could be used consistently across the board.

*I think the problem with these conditions is the severe lack of guidelines [...] and objective approach. Everybody's kind of on their own, doing their own thing, getting more frustrated. **Family physician – group practice, 10+ years***

*[...] any information at this point would be information to me, because I don't come across that many patients with environmental health sensitivities [...] I think there's a clinic at Women's Health hospital that deal with patients who have environmental health issues [...]. Apart from that I don't know what to do with these patients. [...] The two patients I saw, [I] didn't end up following up. So any information [would be good] to know; what we should be looking out for, what [to] advise our patients. **Family physician – group practice, 10+ years***

Content suggestions participants made included: diagnostic criteria and the most appropriate testing that should be conducted; proven management and treatment options; local referral pathways for management options; a tool that physicians can use to track patients' progress over time (such as that for ADHD); patient handouts to empower patients by helping them understand their conditions and how they can manage their condition. It was stressed that the content and suggestions should be "evidence based". In addition to helping physicians, such guidelines would mitigate over testing in the system.

What are the criteria that are necessary in order to diagnose a patient with either one of these conditions, and then having resources available, and a toolkit of sorts that would allow us to provide suggestions to patients. Suggestions that might be somewhat evidence based.



*I'm not sure if there's tons of evidence based medicine and research that is available for us, in terms of treating some of these conditions, and if there is, then that's great, and I'd love to hear more about it so then I can share that with patients. **Family physician – family health team, 10 or less years***

*Well there are some diagnoses, for example ADHD, we have scales and patients will fill out a form and you'll get a score, and a 2 is really bad, a 7 is great, and you can see how they're doing over time. **Family physician – group practice, 10 or less years***

*Knowing what local referral pathways there are, I think that's really key as well. I want to know not just what it is and how it presents, but, what options there are if you can't manage these patients. **Family physician – group practice, 10+ years***

*A list of community resources, or somewhere I can potentially refer patients to, considering how complex that condition is, I think that might be potentially helpful [...] from a management perspective. **Family physician – group practice, 10 or less years***

*Patient handouts are helpful. If they created some sort of [...] the importance of eating properly and what that looks like, and sleeping properly and what that looks like. Exercising enough and options that might be feasible for people who are in pain. **Family physician – group practice, 10 or less years***

In terms of format preferences, there were suggestions for an “algorithmic” or “pathway” approach. When asked to give examples of guidelines or toolkits or resources that they use know that work well, there was mention of UpToDate and material available for diabetes, osteoporosis and hypertension. Conciseness and accessibility via smartphone were also appreciated.

*It would be an algorithm approach. Patient presents these symptoms, what do you do if these are present but these are not present, so starting with a path with arrows showing where to proceed next if it's negative or positive. What to look for in history, what to look for in physical examinations, what tests would be helpful or not. Sometimes I think we do too many tests that are useless, so I'd like to know what test would be helpful and what tests would not be helpful, and management approaches - what works and what doesn't, and this would be all based on the current, best evidence we have. [...] We have guidelines for osteoporosis, how to diagnose and treat, and they're good algorithms. I like the one we have for hypertension as well. There's ones for anemia that worked well. **Family physician – solo practice, 10+ years***

*Start with A and then depending on the result of A, then B or C. And kind of a flow sheet to help guide one in terms of their investigation based on research and based on experience. **Family physician – group practice, 10+ years***

I check UpToDate, [...] It's a subscription service where they have essentially periodically review particular conditions and they publish a summary type of document for all these conditions. [...] It's searchable and I have it on my phone [and] accessible over [the] internet.



*That's probably where I would go first if I had a patient that I was suspecting chronic fatigue syndrome. **Family physician – group practice, 10 years or less***

Email again would be a somewhat effective way to disseminate new guidelines and toolkits. There was also interest in accredited CME online courses or events to learn about these items. Former was seen as more convenient, whilst latter allows for socialising with colleagues or a more hands-on learning through case studies, group exercises or talks by experts. Participants commented that much of current CME offered in these areas were from pharmaceutical companies who manufacture prescription drugs used in the treatment of FM.

*MD Briefcase is a wonderful site. I recommend that you look into that. They have accredited, highly regarded CME sessions. I mean that's basically-- making something accredited would be important, too. If I'm going to spend my time, I want to make sure I'm getting credits for it. **Family physician – group practice, 10 years or less***

*Online CMEs which are good, and of course I personally like in-person CMEs, because then there's an ability to interact with other physicians. [...] I think in the form of an evening CME format or a "morning with the experts". **Family physician – solo practice, 10+ years***

Participants noted that this may be a challenging toolkit to put together given the perceived scarcity in scientific evidence on these three conditions.

*My perception of this is that it continues to be ill-defined; that no one has a handle on this that can set down clear-cut diagnostic criteria. [...] I took the time to look this up before this interview took place, and I looked at some search criteria in some of the well-accepted medical information sources, and didn't find any very specific set of criteria. **Specialist – neurologist, 10+ years***

5.3 Approaches to managing chronic conditions

There were some suggestions related to the option to refer patients to multidisciplinary teams that specialize in these conditions. These teams would comprise relevant specialities in the diagnosis and management of the conditions such as rheumatologists, psychologists, CBT therapists and so on. The main benefit of this approach was that patients could access the most relevant tests and best practices to management.

*A multidisciplinary service that's got occupational health therapists, CBT therapists, and psychologists and rheumatologists, that would be brilliant if there was this service. I'm not sure if there is. [This way] at least [patients] have a proper assessment and have a place that can provide the treatment [that] is the gold standard right now for chronic fatigue, which is CBT. **Family physician – group practice, 10+ years***

*If there were more chronic pain clinics where people could have all their care under one roof. And they could still come to see me as their family doctor, but to have all those allied supports like social workers and physio and acupuncture, fitness classes, those sorts of things all under one roof covered by OHIP, that would be great. **Family physician – group practice, 10 or less years***



This view however was not universal and one participant commented that such an approach may be counterproductive as these patients require a “deeper, meaningful” connection to one primary care provider, as opposed to “shallow” relationships with multiple providers.

*I think the family physician [should] probably still [...] remain in charge of these individuals, and maybe the family physician can put a little more time and they can run a particular chronic fatigue slash fibromyalgia clinic. But I think extending these individuals [to] multiple different providers may or may not be very useful for many reasons. They are tired to begin with. Going to so many different people now in their life, and each one of them spends very little time, I think leads to very shallow provider patient relationships. These are the individuals that you want to have a bit deeper, meaningful connection with your provider. [...] Referring them to other physicians may or may not be the most optimum way [...] [patients] will have to wait extra. So our healthcare system has limited resources, and so that will actually act like a bottleneck. **Specialist – hematologist / oncologist, 10 or less years***

Beyond a multidisciplinary approach to care, some family physicians questioned whether the primary care setting was the most appropriate place for the ongoing management of these conditions. These participants suggested other types of professionals may have more time to devote to patients such as social workers, dieticians or public health units. This view was somewhat reinforced in the interview with a psychiatrist who noted that some physicians are more focused on diagnosis and are unable to commit the time required for longer-term management of chronic conditions (an approach the participant was accustomed to in psychiatric medicine).

*Perhaps public health [units] should be the place for referring people like this, because if it's not a cough or a cold, these are city issues, access issues, work issues. And as a physician, you sort of feel like an outsider trying to fix a problem. **Family physician – group practice, 10 years or less***

*I tend to refer a lot of people to our social workers who actually have that kind of skill that they can sit down. Specialists like myself or rheumatologists, we can see these patients but we don't have as much time. [...] There are lot of other people that do have actually structural diseases, so as a result, the patient may or may not feel quite satisfied with that. **Specialist – hematologist / oncologist, 10 or less years***

*I know there was specific billing codes for patients with chronic fatigue syndrome[...] that's sort of a 30 minute[...] unit. Often, we don't have the time to spend a double appointment with patients, so, I think probably the system is not set up for dealing with these chronic patients, and I don't know whether it needs to be acknowledged that these are really complicated patients that need more time than most, [I] don't know if it's realistic to keep bringing them back to primary care setting. I think maybe, yeah it needs to be more commissioned services and secondary care and specialist care. **Family physician – group practice, 10+ years***

I find it very limited, so for us to spend a considerable amount of time on the education piece of things, unless it's more of an environmental allergy or more of a food allergy or food sensitivity for example, sometimes it's very difficult for us to be able to spend the amount of



time that's required going through what to try and avoid, so I think having better access to, for example, dieticians, could be helpful for our patients[...] So I think that that would certainly be helpful, better access to support that isn't necessarily a physician. **Family physician – family health team, 10 years or less**

I can see some physicians don't want to deal with the complexity of that over time [...] some people are focused more on the diagnosis. [...] I have found that the patients [should be] manage[d] over time, in order to get the best result for the patient. [...] I'm accustomed to the idea that things happen in increments, slowly and over time, and will require, most psychiatric conditions do require that kind of approach I believe, that [type of] management. **Specialist – psychiatrist, 10+ years**

5.3 Billing codes

Billing codes were discussed in a small subset of interviews. In some, there was awareness that there are codes for CFS and FM and these participants were comfortable with using these. Others were not aware of any specific codes and felt that a code is required that reflects the time required on the part of physicians to provide “proper” care to ES / MCS, ME / CFS and FM patients

So in terms of when I send my bills-- when I do my OHIP billing, OHIP uses the same code for chronic fatigue and FM. **Family physician – solo practice, 10+ years**

I know there was specific billing codes for patients with chronic fatigue syndrome, and obviously that's sort of a 30 minute, the better half of a 30 minute unit. **Family physician – group practice, 10+ years**

You have to spend an extended period of time in the interview, and then once the investigations are commenced, and the time explaining to them and counseling to them, [...] These conditions almost need to have a fee code of their own, and not limited to two times per year. [...] You might say, well, I'm going to bill the Ministry for a general assessment, but then there's a limited number of general assessments you can do on a patient in a year. Or I'm going to charge a psychotherapy fee or that kind of a thing, a counseling fee. Again, they're limited as to the number you're allowed to do per year. So you very quickly exhaust your compensation or reward for doing a good job, to the point where you say, well, I'm working for free. **Family physician – group practice, 10+ years**

5.4 Better patient access to tests and management options

Beyond supports for physicians, a number of participants called for addressing the waitlists for tests and mental health services as well as more OHIP funding for physical therapies. The perception was that this would lead to better patient access to care.

If I look at some of our patients here in Northern Ontario, there's long waiting list for even something like allergy testing, so, allergy testing here takes up to a year, year and a half before anyone can get in for testing. **Family physician – family health team, 10 years or less**

Chronic fatigue syndrome, the evidence and the sort of research suggests, in terms of conventional practices, is exercise or cognitive behavioural therapy. [They are] the ones that



are most significant benefits in the long term, but, certainly access [is difficult]. It's all privately funded, [...] there's not huge amounts of easily accessible OHIP funded psychologists [...] There's CAMH, but they have a very long waiting list, so limited amounts. So, I think that's the financial barrier to a lot of people to access, see a therapist or to see a psychologist. **Family physician – group practice, 10+ years**

OHIP fund[ing] for more chronic management [options]. So counseling, support groups, aquafit classes, yoga classes, things like that targeted towards people with fibromyalgia or any sort of chronic pain syndrome would be invaluable to so many of my patients. I mean it's so challenging for these people. They have chronic pain, [...] poor employment, and money is limited, and we're suggesting to them to do all these therapies including psychological therapies as well as physical therapies that are just simply not affordable. **Family physician – group practice, 10 or less years**

Having mental health resources, support groups, subsidize things like physio, therapy-- it's very hard to get patients-- you can make suggestions like go to yoga and do meditation. Well it's an 18-month waitlist to get into a subsidized program, so people are frustrated and it feeds into their illness. **Family physician – group practice, 10 or less years**



Appendix: Discussion Guide

INTRODUCTION (5 MINS)

- Thank participant
- Explain purpose: understand physicians' views and experiences with respect to treating patients with Environmental Sensitivities/Multiple Chemical Sensitivities (ES/MCS), Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM)
- Explain confidentiality and recording
- Ask participant to introduce themselves: name, years of practice, type of practice setting PROBE IF IT IS SOLO VS. MULTI-PHYSICIAN VS. MULTI-DISCIPLINARY SETTING

WARM-UP / TOP-OF-MIND ISSUES (5 MINS)

As I mentioned at the start, we are specifically interested in:

- Environmental Sensitivities/Multiple Chemical Sensitivities (ES/MCS)
- Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)
- Fibromyalgia (FM)
- Overall, what are your beliefs/understandings about these conditions? What drives these beliefs?
- What are some of the main issues or challenges you face when seeing patients with these conditions? And what are your suggestions about addressing these?

ATTITUDES & EXPERIENCES OF TREATING PATIENTS (25 MINS)

I'd like to obtain a more in-depth understanding of your experiences of caring for patients with these conditions.

- How many patients have you seen in the last year that were affected or, to the best of your understanding were likely affected by...
 - ...ES/MCS?
 - ...ME/CFS?
 - ...FM?

Talk me through how you typically go about dealing with these patients from the very first consultation....

- As far as you are aware, are you the first service provider patients see or have they seen other healthcare professionals or tried other things?
 - Who have they seen or what have they done before seeing you?
 - How, if at all, does it vary between the three conditions?
- What happens during the first consultation session?
 - What symptoms or complaints or asks do patients come in with? Probe: which of the three specific conditions are you referring to?
 - What tends to be your advice to them?



- What tools or strategies, if any, may you turn to at this point? LISTEN OUT FOR ANY SPECIALIST SUPPORTS OR MULTIDISCIPLINARY APPROACHES // PROBE TO UNDERSTAND WHICH CONDITION THEY ARE REFERRING TO
- What is their reaction to your advice?
- How do you feel professionally during these consultation sessions?
- PROBE FOR ANY DIFFERENCES BETWEEN THE 3 CONDITIONS
- What happens afterwards?
 - Do they come back to you?
 - What do they come back to you with?
 - What tends to be your advice to them then?
 - What tools or strategies, if any, may you turn to at this point? LISTEN OUT FOR ANY SPECIALIST SUPPORTS OR MULTIDISCIPLINARY APPROACHES // PROBE TO UNDERSTAND WHICH CONDITION THEY ARE REFERRING TO
 - What is their reaction to your advice?
 - How do you feel professionally during these consultation sessions?
 - PROBE FOR ANY DIFFERENCES BETWEEN THE 3 CONDITIONS
- Based on your experiences and the health care services currently available to Ontarians, what is the best-case outcome for these patients?
 - In reality, what is the most common outcome?
 - What would the ideal outcome be from your perspective?
 - PROBE FOR ANY DIFFERENCES BETWEEN THE 3 CONDITIONS

SUPPORTS – CURRENT & FUTURE (20 MINS)

You mentioned earlier that the main supports that you turn to are [SUMMARISE]. I want to spend a bit more time on your views of what is available now and what could be provided in the future to physicians.

Let's start off with what is available now, beyond what we already discussed...

- Are there other specialised supports in Ontario that you turn to? PROBE TO UNDERSTAND WHICH CONDITION THEY ARE REFERRING TO
- Have you read about or used any multidisciplinary or system care (IF NEEDED: mix of practitioners under one venue) approaches for treating other chronic conditions that could apply in these cases? Which ones?

Looking to the future...

- What are the main information gaps for physicians like yourself? PROBE SPECIFICALLY IN RELATION TO THE MAIN BARRIERS UNCOVERED DURING EARLIER DISCUSSION
- What do you want to know about...
 - ...ES/MCS?
 - ...ME/CFS?
 - ...FM?
- How should this information be provided to you? PROBE: email from professional association? Medical journal? CME courses? Conferences?
- If a toolkit on each of the conditions was provided, would you use it? Why / why not? What are the features of a good toolkit? Are there any toolkits that you use at the moment that you really like and could apply to these conditions?



FINAL ADVICE (5 MINS)

- That's all my questions for you today. Is there anything we haven't covered that you would like to add?
- Given everything we discussed, what is your main advice to my client on what they should do in the future?



Appendix G - CEP Clinical Case Definitions

Consensus Process to Develop Clinical Case Definitions for Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS), Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), and Fibromyalgia (FM)

The Centre for Effective Practice (CEP) was engaged by the Ministry of Health and Long-Term Care (MOHLTC), Health Equity Branch in 2017 to recruit and convene a panel of experts to develop consensus-based clinical case definitions for Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS), Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FM).

The goal of this work was to support future development of guidelines, care pathways, and supports for patients living with these conditions and their caregivers. It builds from the Task Force's interim recommendations, which highlighted a lack of knowledge and resources for providers about these conditions and a need for consensus on case definitions to support improved standardization of patient care.

Given these objectives, the CEP developed a modified Delphi process approach in consultation with the MOHLTC and the Task Force to create a framework for diagnosing ES/MCS, ME/CFS, and FM in Ontario. The process undertaken by the CEP included:

- Recruitment and engagement of qualified clinical and scientific experts from Canada and abroad.
- Development and facilitation of a consensus process to clinically define ES/MCS, ME/CFS and FM.
- Development of clinical definitions that are relevant to Ontario and useable in clinical practice for the purpose of diagnosis.
- Identification of recommendations for future work brought forward by the panel during the consensus process; and dissemination of the materials developed by the panel to clinical, scientific and academic audiences in Ontario.

Modified Delphi Process

In consultation with the MOHLTC and the Task Force, the CEP developed and executed a modified Delphi process with a panel of 16 clinical and scientific experts that comprised of two rounds of anonymous Delphi surveys to gain consensus on diagnostic indicators for each of the three conditions, followed by a panel meeting to discuss results to date, a third survey round to validate the panel discussion, and a final round of open panelist review of the draft materials developed.

Case Definitions

The Delphi panel generally agreed with existing case definitions for each condition with additional symptoms and caveats that may help providers to better understand the overall picture of each condition in light of their patients' unique experiences. The CEP was also able to synthesize panelists' feedback to provide greater clarity on current variability in practice and considerations for future work in developing materials on ES/MCS, ME/CFS and FM for use in clinical practice.

Future Recommendations

The CEP and the panel identified a number of areas where additional research is needed in order to better understand the pathophysiology, chronicity, and symptomology of these conditions.

While there are core symptoms to ES/MCS, ME/CFS and FM, patients with these conditions do not have a uniform experience. Future work in this area should account for the individualized disease experience of each patient, particularly given the lack of research evidence. Additional recommendations for future work identified by the panel are included below:

- Further work to better differentiate between ES/MS, ME/CFS and FM given the overlapping symptoms and potential comorbidities present within each condition.
- Additional work to better understand the difference in symptom prevalence and presentation in male and female patients, as well as in pediatric patients.
- Improved provider training on standardized physical assessment and standardized documentation of pain for FM patients.
- Resources for providers to aid in differentiating these conditions from other conditions (e.g., depression).
- Improved access to testing (e.g., sleep function, polysomnography).
- Validation of existing diagnostic tools.
- Continued research and refinement on the diagnostic indicators and the combination of symptoms necessary for effective diagnosis of each of the conditions.



Providers

Guiding Principles for the Diagnosis of Environmental Sensitivities/Multiple Chemical Sensitivity

The following document is based on input and feedback obtained from a panel of experts using a modified Delphi panel process. These experts were engaged by the Centre for Effective Practice on behalf of the Ministry of Health and Long-Term Care.¹ The following principles represent a suggested approach for the diagnosis of Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS) in primary care, based on available literature and expert opinion. This resource is intended to help primary care providers diagnose and treat patients with ES/MCS.

The panel supports the use of the [1999 Multiple Chemical Sensitivity Consensus Statement](#).^{2,3}

Providers may also consider the following in diagnosing patients using these definitions:

- The 1999 Consensus Statement narrowly defines “chemical exposure” as environmental chemicals (e.g. scents, solvents). Patients’ symptoms may also be provoked by common foods, ingestants, medications, or allergens.
- Severity of patients’ sensitivity may also be assessed as part of diagnosis. Patients’ sensitivity is generally moderate to severe and affects multiple organs.
- Patient responses to exposure may be challenging to test or validate in clinical settings (e.g. inadequate opportunity to blind participants, confounding chemical agents, etc.) and have not generally occurred reproducibly in the literature.^{4,5}
- Patients may also have increased incidence of fatigue, cognitive difficulties (e.g. difficulty concentrating, feeling dull/groggy/spacey); and/or odor hypersensitivity.^{5,6}

Guiding Principles for the Diagnosis of Environmental Sensitivities/Multiple Chemical Sensitivity

Additional Notes and Resources

- Additional work is needed to understand the full scope of exposures that may result in the manifestation of symptoms.⁷ The diagnosis of ES/MCS will change as scientific research reveals new information about the symptoms, causes and treatments of this condition.
- ES/MCS is a chronic and often comorbid condition – a diagnosis of ES/MCS is valid irrespective of other diagnoses and a diagnosis of ES/MCS does not exclude the presence of other conditions.

Related Resources

- [36-Item Short Form Survey \(SF-36\)⁸](#)
- [Functional Capacity Scale⁹](#)

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Providers

Guiding Principles for the Diagnosis of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

The following document is based on input and feedback obtained from a panel of experts using a modified Delphi panel process. These experts were engaged by the Centre for Effective Practice on behalf of the Ministry of Health and Long-Term Care.¹ The following principles represent a suggested approach for the diagnosis of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) in primary care, based on available literature and expert opinion. This resource is intended to help primary care providers diagnose and treat patients with ME/CFS.

The key features of ME/CFS are:

Fatigue

- New/defined onset
- Persistent
- Not resulting from other diagnoses, medical problems, medications
- Accompanied by malaise and a range of other symptoms

Post-Exertional Malaise

- Worsening of symptoms (e.g. soreness, feeling drained or sick) resulting from minimal physical, mental, or cognitive exertion
- Episodes of immobilizing post-exertional physical and/or mental fatigue and/or malaise

Consensus was achieved among the panel to support the use of the [Canadian Consensus Definition for ME/CFS](#)² or the [Institute of Medicine 2015 Criteria for the Diagnosis of ME/CFS](#).³

Providers may consider using one, or both, of these resources in supporting their diagnosis, depending on their familiarity with ME/CFS.⁴

Providers may also consider the following in diagnosing patients using these definitions:

- Orthostatic intolerance, as listed in the Institute of Medicine definition, may be present in patients but is not essential for a diagnosis of ME/CFS. Similarly, some symptoms listed in the Canadian Consensus Definition (i.e. autonomic, neuroendocrine, and immune manifestations) may be present in patients but will vary significantly from patient to patient. Providers should consider all of these symptoms and each patient's history, clinical examination, and differential diagnoses and comorbidities that may aggravate ME/CFS in order to appropriately manage these symptoms.
- The assessment of symptom severity may be conducted using the patient reported questions and scales outlined by the Institute of Medicine, by patient-reported severity, or by the criteria outline by the International Consensus Criteria.^{2,3}
- Patients may also report: unrefreshing sleep, new sensitivities to food, medications, and/or chemicals; and/or reduced cognitive function (e.g. memory problems, difficulty concentrating/paying attention).



Providers

Guiding Principles for the Diagnosis of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Additional Notes and Resources

- ME/CFS is a chronic condition that can cause significant lifestyle changes and functional impairment in affected patients. ME/CFS is often a comorbid condition – a diagnosis of ME/CFS is valid irrespective of other diagnoses and a diagnosis of ME/CFS does not exclude the presence of other conditions.
- The diagnosis of ME/CFS will change as scientific research reveals new information about the symptoms, causes and treatments of this condition.

Related Resources

- [Functional Capacity Scale](#)⁵
- [NASA Lean Test](#)⁶

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¹ Ontario Ministry of Health and Long-Term Care. Time for Leadership: Recognizing and Improving Care, Task Force on Environmental Health - Phase 1 Report. 2017. Available from: http://www.health.gov.on.ca/en/common/ministry/publications/reports/environmental_health_2017/default.aspx

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Guiding Principles for the Diagnosis of Fibromyalgia

The following document is based on input and feedback obtained from a panel of experts using a modified Delphi panel process. These experts were engaged by the Centre for Effective Practice on behalf of the Ministry of Health and Long-Term Care.¹ The following principles represent a suggested approach for the diagnosis of Fibromyalgia (FM) in primary care, based on available literature and expert opinion. This resource is intended to help primary care providers diagnose and treat patients with FM.

Consensus was achieved among the panel to support the use of the [American College of Rheumatology 2016 criteria](#)² as a starting point for diagnosis of FM. Clinicians should consider additional symptoms listed, and use their clinical judgment to ensure an appropriate diagnosis.

The [2012 Canadian Guidelines for the Diagnosis and Management of Fibromyalgia Syndrome](#)³ also aligns with many of the concepts considered important to the diagnosis of FM highlighted by the panel and may be useful to clinicians in diagnosis and management.

Providers may also consider the following in diagnosing patients using these definitions:

- FM is a complex 'constellation of symptoms' with historically varied symptomology.⁴ Providers should consider all of these symptoms and each patient's history, clinical examination, differential diagnoses and comorbidities that may aggravate FM in order to appropriately manage these symptoms.
- FM is primarily characterized by chronic, widespread pain with varying intensity and severity. Patients' pain can fluctuate or change in intensity on a daily or monthly basis, or due to other circumstances (e.g. stress, strenuous exercise, prolonged inactivity, weather or temperature changes). Providers should consider physical examinations over a series of visits to ascertain pain patterns and patient progress.
- Patients also commonly experience: fatigue, sleep issues (e.g. unrefreshing sleep, lack of sleep), and/or cognitive issues (e.g. trouble concentrating, forgetfulness).

Guiding Principles for the Diagnosis of Fibromyalgia

Additional Notes and Resources

- FM is a chronic and often comorbid condition – a diagnosis of FM is valid irrespective of other diagnoses and a diagnosis of FM does not exclude the presence of other conditions.
- The diagnosis of FM will change as scientific research reveals new information about the symptoms, causes and treatments of this condition.

Related Resources

- [Widespread Pain Index & Symptom Severity Score⁵](#)
- [Visual Analogue Scale & Numerical Pain Rating Scale⁶](#)
- [Functional Capacity Scale⁷](#)
- [Fibromyalgia Impact Questionnaire⁸](#)

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Appendix H - Report on NS and BC clinics

Canadian clinics specializing in myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS), fibromyalgia (FM) and environmental sensitivities/ multiple chemical sensitivity (ES/MCS)

**The Complex Chronic Diseases Program (British Columbia)
Integrated Chronic Care Service (Nova Scotia)**

The Task Force on Environmental Health
November 2018

Executive Summary

As part of their mandate to provide recommendations on improving care to the Ontario Minister of Health and Long-Term Care, the Ontario Task Force on Environmental Health assessed the model of care provided at two clinics in Canada that specialize in providing care for people with myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS), fibromyalgia (FM) and environmental sensitivities/ multiple chemical sensitivity (ES/MCS). This report summarizes the services offered at the Complex Chronic Diseases Program in British Columbia (BC) and the Integrated Chronic Care Service in Nova Scotia (NS).

Key insights:

- Both the BC and NS clinics apply elements of the Prevention and Management of Chronic Disease Model, including: interdisciplinary teams, patient empowerment and self-management, and coordination with primary care providers.
- Both clinics use a “whole-patient” approach, incorporating each individual’s functionality, emotional state and social environment to understand the disease in a systematic and personal way to better individualize the care they provide to each patient.
- Both clinics use evaluative frameworks that include health outcomes as well as patient experience, among other measures.
- Despite knowledge transfer/education and primary care coordination efforts, the BC clinic still experiences long wait times, and many re-referrals. This suggests engagement with the broader health system should be a key area of focus when developing a system of care for these conditions.

Introduction

The Task Force on Environmental Health is proposing a system of care for people with myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS), fibromyalgia (FM) and environmental sensitivities/ multiple chemical sensitivity (ES/MCS) that relies on a “centre of excellence” to provide care for severely ill patients referred from across Ontario. The centre will support a network of interdisciplinary primary care sites focused on the management of complex chronic disease. The centre will also undertake research and educational initiatives to support primary care providers and the development of providers specializing in the conditions.

This report profiles two Canadian centres that provide services that include specialized care for these conditions. The task force is recommending a more distributed system of care than those supported by these clinics, but an examination of the models provides useful insights.

The information in this report comes from websites, scholarly articles about the Nova Scotia clinic, and presentations given by clinic staff to the ME/CFS Canadian Collaborative Team Conference in Montreal, Canada, May 2018.

The Complex Chronic Diseases Program in British Columbia

The BC Women's Hospital Complex Chronic Diseases Program (CCDP) was established in 2013⁴⁴ as a referral centre for the province of BC. It has a mandate for care, education/knowledge transfer, and quality improvement/research for complex chronic diseases, including ME/CFS, FM, Multiple Chemical Sensitivities and Alternatively Diagnosed Chronic Lyme Syndrome.⁴⁵

The key elements of the CCDP model of care include:

- Providing interdisciplinary care,
- Empowering patients and supporting self-management, and;
- Coordinating with, and educating primary care providers to ensure smooth discharge and transition of care.

Interdisciplinary care

Assessment, diagnosis, and the development of treatment plans are provided by an interdisciplinary team. The team includes: an acupuncturist, a counsellor, a dietitian, a naturopath, nurses, a nurse practitioner, an occupational therapist, physicians (including internal medicine specialists, infectious disease specialists and general practitioners with a special interest and knowledge in these conditions), physiotherapists, researchers, and social workers, and support staff.⁴⁶ Patients are referred to different team members as their needs are determined. Care is individualized, and addresses a holistic range of patient needs such as functional needs, psycho-social needs, dietary/lifestyle choices and health system navigation.

Patient centeredness

Engaging patients as partners in care is central to the model. Engagement includes education for patients and families about the disease(s), causes and potential treatment and management strategies, support for self-management, connecting patients to community resources where appropriate, and empowering patients to make informed treatment and lifestyle decisions.⁴⁷

⁴⁴ [BC Women's Hospital and Health Centre Foundation \(2013\). First BC Complex Chronic Disease Program Opens. BC Women's Hospital and Health Centre Foundation webpage.](#)

⁴⁵ [BC Women's Hospital and Health Centre \(2016, November\). Complex Chronic Diseases Program: Mission and Mandate.](#)

⁴⁶ [BC Women's Hospital and Health Centre \(2018\). The Complex Chronic Diseases Program Clinical Team Members.](#)

⁴⁷ [BC Women's Hospital and Health Centre \(2016, November\). Complex Chronic Diseases Program: Mission and Mandate.](#)

The clinic is governed by a steering committee which considers input from a community advisory group comprised of community and patient organizations, along with clinical and research advisory groups.⁴⁸

The clinic has also undertaken efforts to increase accessibility including a virtual health pilot, a young adults group, online feedback cards and an annual friends and family webinar.⁴⁹

Coordination/outreach with primary care

A patient's referring primary care provider is engaged throughout the process to support a smooth transition for patients after discharge. Tools and resources for interested clinicians are available on the program's website, including a tool box for ME/CFS and FM, diagnostic criteria, treatment protocols, fact sheets and research reviews for these conditions.⁵⁰

CCDP staff provide education and training to physicians, and other health care providers across the province on chronic disease management (with a focus on these conditions). It is part of their mandate to partner with health care organizations, providers and community groups to raise the overall standard of care for complex chronic conditions.⁵¹

health care provider support includes:

- Website resources such as diagnostic criteria, treatment protocols, videos, and educational resources
- Primary care physician phone consultations
- Health professional to health professional support
- Medical and allied health learners
- Educational presentations

The clinic also works with a community advisory group on opportunities for advocacy, raising awareness, and disability forms/letters.⁵²

⁴⁸ Ric Arseneau et al. (2018, May3). ME/CFS and Related Disorders: Complex Chronic Diseases Program BC Women's, Hospital University of British Columbia [Presentation given to the ME/CFS Canadian Collaborative Team Conference: Advancing an International Research Agenda to Address ME/CFS Research Priorities: from Basic Research to Clinical Practice](#). Montreal, May 3-5, 2018.

⁴⁹ Ibid.

⁵⁰ [BC Women's Hospitals and Health Centre \(2018\). CCDP Clinician Resources.](#)

⁵¹ [BC Women's Hospital and health Centre \(2016, November\). Complex Chronic Diseases Program: Mission and Mandate.](#)

⁵² Ric Arseneau et al. (2018, May3). [Presentation.](#)

Evaluation and Improvement

The third aim of the CCDP is focused on research and quality improvement. The CCDP website describes these activities as:

- 1) Increasing understanding of these conditions and their complications.
- 2) Evaluating new, innovative tests and treatments.
- 3) Improving the quality of care provided to patients.⁵³

The CCDP's current research project is the creation of a CCDP data registry, which enrolls new patients on a voluntary basis. This data registry supports research by collecting data on the patient population, and assessing outcomes over time.⁵⁴ Outcome measures reflect goals important to patients, and are measured with standardized questionnaires that capture general health status, pain, fatigue and anxiety, as well as an interdisciplinary assessment tool and an Adverse Childhood Experiences Questionnaire.⁵⁵

Ongoing evaluation has documented good results (for example, 92% of patients in the 2016-2017 ranked their experience as very good to excellent),⁵⁶ and the specific success of allowing patients to feel heard and providing them hope, having compassionate staff, and providing expertise and practical information. Identified challenges include:

- Wait times for the external waitlist to enter the program (up to two years) and the internal waitlist between resources;
- Staffing, including recruiting and retaining members and managing compassion fatigue;
- Difficulty rescheduling missed and cancelled appointments, and;
- Increase to patient volumes due to re-referrals.

Moving forward, the clinic is addressing these challenges with several measures, including:

- A revised primary care provider toolkit;
- Piloting a virtual health option where patients can attend some appointments virtually (audio and visual), and;⁵⁷
- A separate patient stream for re-referrals.

⁵³ [BC Women's Hospital and health Centre \(2016, November\). Complex Chronic Diseases Program: Mission and Mandate.](#)

⁵⁴ [BC Women's Hospital and Health Centre \(2018\).Complex Chronic Diseases Research. BC Women's Hospital and Health Centre webpage.](#)

⁵⁵ Ric Arseneau et al. (2018, May3). [Presentation.](#)

⁵⁶ Ibid.

⁵⁷ [BC Women's Hospital and health Centre \(2018\). CCDP Virtual Health. Complex Chronic Disease Program Webpage.](#)

The Integrated Chronic Care Service in Nova Scotia.

The Integrated Chronic Care Service (ICCS) is administered by Nova Scotia's provincial health authority, and receives local, national and international referrals. It is one of several primary health care services (along with diabetes management centers and community health teams for example) that are directly administered by the provincial health authority, and typically act as launching points to supporting services.⁵⁸ ICCS uses a "whole-patient" and interdisciplinary model of care for complex and co-morbid chronic disease. This approach was derived from a model of care developed for ES/MCS by the Nova Scotia Environmental Health Clinic.⁵⁹ This clinic, established in 1994, has now been folded into the ICCS.

Central to ICCS's approach is a de-emphasis on determining specific diagnoses and a focus on the needs of each individual patient, their quality of life and functional health. This approach reflects the model's roots in applied management of ES/MCS, where, despite having the same diagnosis, no two patients are prescribed the exact same treatment regime. Instead, the aim is to provide standardized delivery of the "global" elements of care deemed necessary for a complex, comorbid population.⁶⁰

The key elements of the ICCS model of care include:

- A multidisciplinary team that coordinates to assess, diagnose and provide care;
- Interventions and education modules that can be individualized for each patient and emphasize patient-education, empowerment, and supported-self management, and;
- An emphasis on coordination with primary care and community resources.

Multidisciplinary care

The ICCS's multidisciplinary team includes a care coordinator, physicians, occupational therapists, a nurse practitioner, registered nurse, licensed practical nurse, psychologist psychotherapists and a clinical dietitian.⁶¹ This team supports a range of health care needs including lifestyle, dietary, psychological, psycho-social, functional and rehabilitation needs.

⁵⁸ Sampali, Tara, Robert Dickson, Jill Hayden, Lynn Edwards and Arun Salunkhe (2016). Meeting the needs of a complex population: a functional health-and patient centered approach to managing multiborbidity. *Journal of Comorbidity* 6 (2): 76-84. DOI: 10.15256/joc.2016.6.83

⁵⁹ Sampalli, Tara, Roy A Fox, Robert Dickson and Jonathan Fox (2012, October 24). Proposed model of integrated care to improve health outcomes for individuals with multimorbidities . *Patient Preference and Adherence* 6: 757-764. DOI: 10.2147/PPA.S35201

⁶⁰ Ibid.

⁶¹ Nova Scotia Health Authority (2017). Integrated Chronic Care Service. *Webpage*. <http://www.nshealth.ca/content/integrated-chronic-care-service-iccs>

Patient Centeredness

The ICCS makes a thorough effort to centre their service around the patient, commencing care with groups visits where patients work with care coordinators to:

- 1) Explore whether the service meets their expectations;
- 2) Identify their current health care needs and gaps;
- 3) Educate patients about the whole care model;
- 4) Initiate conversations around self-management, and;
- 5) Examine needs and support from primary care providers and community resources.⁶²

Coordination with Primary Care and Community Resources

Care coordination is considered a key aspect of care delivery, and involves coordinating relevant patient information and action between multiple health care providers (both between ICCS's multidisciplinary team, and between the ICCS team and primary providers), caregivers, such as family members, and community services and employers. On the ICCS team the coordination processes are supported primarily by occupational therapists.⁶³

Evaluation and improvement

The ICCS has developed an evaluation framework that considers four domains of outcomes, reflecting its whole patient approach by measuring individual and societal outcomes, as opposed to disease specific outcomes.⁶⁴ These domains are (1) health outcomes, measured for example by functional health measurements such as Canadian Occupational Performance Measurement^{65,66}; (2) experiential outcomes, measured for example by the Patient Assessment of Chronic Illness Care *Hopes and Needs Survey*, and the satisfaction of referring physicians, (3) process outcomes such as waiting times and new patient volumes, and (4) health care costs as measured by patients' utilization of the broader health system and participation in economic/social life.

Members of the ICCS team have conducted research on their model of care, showing promising results with regards to experiential and self-reported health outcomes such as overall perception of health, fatigue and other self-selected functional health goals,⁶⁷ as

⁶² Sampali et al. Meeting the needs of a complex population.

⁶³ Ibid.

⁶⁴ Ibid.

⁶⁵ Law, Mary, Sue Baptiste, Mary Ann McColl, Anne Opzoomer, Helene Polatajko and Nancy Pollock (1990). The Canadian Occupation Performance Measure: an outcome measure for occupational therapy. *Canadian Journal of Occupational Therapy* 57 (2): p. 82-87 <https://doi.org/10.1177/000841749005700207>

⁶⁶ Carswell, Anne, Mary Ann McColl, Sue Baptiste, Mary Law, Helene Polatajko and Nancy Pollock (2004). The Canadian Occupational Performance Measure: A Research and Clinical Literature Review. *Canadian Journal of Occupational Therapy* 71 (4): p. 210-222.

⁶⁷ Sampali et al. Meeting the needs of a complex population.

well as process outcomes, such as the reduction of their wait times from up to 24 months to no anticipated wait times for the year 2015.⁶⁸

A more comprehensive research design is planned for the future, to look at data on health care utilization, usage of emergency services, and health outcomes.

⁶⁸ Sampalli et al. (2015). Improving wait times to care for individuals with multimorbidities and complex conditions using value stream mapping. *International Journal of Health Policy and Management* 4 (7), 459-466.
[10.15171/ijhpm.2015.76](https://doi.org/10.15171/ijhpm.2015.76)

