

Time for Leadership:

Recognizing and Improving Care for those
with ME/CFS, FM and ES/MCS

TASK FORCE ON ENVIRONMENTAL HEALTH PHASE 1 REPORT

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LETTER TO THE MINISTER

Dear Minister Hoskins:

On behalf of the Task Force on Environmental Health, I am pleased to report that one year into our three year mandate, we have completed the first phase of our work. In the process, we identified a number of critical steps that the ministry and the health care system could take – right now – to greatly enhance the health care experience for Ontarians living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia (FM) and environmental sensitivities/multiple chemical sensitivity (ES/MCS).

The task force spent its first few months developing a shared understanding of 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 environmentally linked conditions. We found that, throughout the health care system and in society at large, there is:

- a lack of recognition of the seriousness and severity of these conditions
- a profound shortage of knowledgeable care providers
- a dearth of clinical tools to support and guide care
- a discouraging shortage of services and supports for people living with these conditions
- an absence of support for family caregivers.

The lack of knowledge and appropriate accessible care has devastating effects on Ontarians struggling with ME/CFS, FM and ES/MCS. It can take years of clinical referrals and fruitless (and often unnecessary and costly) testing for them to finally get a full assessment and correct diagnosis. Once they have a diagnosis, there are very few effective treatment options and social supports to help them live well with their conditions.

For those living with ME/CFS, FM and ES/MCS, the lack of recognition of these serious and debilitating conditions is as harmful as the lack of treatments. It means that the conditions are not identified early so any care that is available is delayed. Requests for disability benefits and for accommodation at work, in housing and in health care are refused. Individuals and their families become socially isolated.

We urge the Minister to act now to raise awareness of these conditions and address the barriers that keep people with ME/CFS, FM and ES/MCS from getting the care and services they need.

We thank you for the opportunity to bring attention to the urgent need to improve care for these conditions. We also commend you for having established a task force that recognizes the value of bringing together both clinical and lived experience to tackle these truly challenging health issues.

Sincerely,

A handwritten signature in black ink, appearing to read "Howard Hu". The signature is fluid and cursive, with the first name "Howard" and the last name "Hu" clearly distinguishable.

Dr. Howard Hu

EXECUTIVE SUMMARY

The more than half a million Ontarians of all ages living with myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS), fibromyalgia (FM) and environmental sensitivities/ multiple chemical sensitivity (ES/MCS) face overwhelming barriers accessing high quality, appropriate patient-centred care. Despite the large number of people affected by these devastating, life-altering medical conditions, there is a discouraging lack of: recognition and understanding of their impact and severity; knowledge about their underlying causes and treatment; effective clinical care pathways; and knowledgeable care providers. People struggle to get the care, support and accommodation they need. They also face significant stigma and discrimination within the health care system, in the workplace and in 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 these gaps in knowledge, care and attitudes. In the first year of its three-year mandate, this group of expert clinicians, patients, researchers, advocates and representatives from health system organizations has identified a number of early concrete steps can be taken now to establish the foundation for an effective, patient-centred system of care.

1. Change the conversation and increase understanding and recognition of these conditions

Recommendation #1.1: Make a formal public statement recognizing ME/CFS, FM and ES/MCS

The task force recommends the Minister of Health and Long-Term Care make a statement recognizing ME/CFS, FM and ES/MCS, reinforcing the serious debilitating nature of these conditions, dispelling the misperception that they are psychological and making a commitment to improve care, education and support for caregivers.

Recommendation #1.2: Establish academic chairs focused on ME/CFS, FM and ES/MCS

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.

Recommendation #1.3: Modernize the K037 fee code to include all three conditions

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.

2. Develop a common understanding of ME/CFS, FM and ES/MCS

Recommendation #2.1: Develop clinical case definitions and clinical practice guidelines to support standardized, high-quality, patient-centred care.

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.

3. Lay the groundwork for a patient-centred system of care

Recommendation #3.1: Establish detailed clinical care pathways to support the development of an evidence-based system of care.

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.

Recommendation #3.2: Make hospitals safe for people with ME/CFS, FM and ES/MCS

The task force recommends that the ministry work with its partners, such as the Ontario Hospital Association, and with expert patients, caregivers and physicians to ensure hospitals comply, as quickly as possible, with relevant accessibility and accommodation legislation.

Recommendation #3.3: Make long-term care homes safe for people with ME/CFS, FM and ES/MCS.

The task force recommends that the ministry work with its partners, such as long-term care provider organizations, and with expert patients, caregivers and physicians to ensure long-term care homes comply, as quickly as possible, with relevant accessibility and accommodation legislation.

4. Increase the number of knowledgeable providers

Recommendation #4.1: Continue to fund the Enhanced Skills Program for 3rd Year Residents in Clinical Environmental Health.

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.

INTRODUCTION

More than 550,000 Ontarians – or approximately five of every 100 people (age 12 and older)¹ in the province – live with one or more of three chronic debilitating conditions that may be triggered by environmental factors: myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia (FM) and/or environmental sensitivities/multiple chemical sensitivity (ES/MCS). That is almost nine times the number with Alzheimer’s disease.²

Despite the large number of Ontarians of all ages affected by these conditions, they have received little attention. As a result:

- the pathophysiological mechanisms that cause these conditions have not yet been identified
- the three conditions are extremely difficult to diagnose, treat and manage
- the people affected by these debilitating conditions experience stigma and discrimination in their efforts to find care and treatment.

In May 2016, to help improve knowledge, 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).

People with **myalgic encephalomyelitis/ chronic fatigue syndrome** (ME/CFS) suffer from chronic and disabling fatigue that does not improve when they rest or sleep. They have no stamina and find it very difficult to do simple everyday tasks. Symptoms are significantly worse after any exertion and it takes a long time to regain strength. People with ME/CFS also experience varying degrees of pain, weakness, sleep disturbances and problems with memory and concentration. ME/CFS affects multiple systems in the body (e.g. respiratory, nervous, digestive).

People with **fibromyalgia** (FM) suffer from widespread chronic pain as well as 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 abnormal brain chemistry and function.

People with **environmental sensitivities/ multiple chemical sensitivity** (ES/MCS) suffer from a range of recurrent symptoms 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. Symptoms include headache, respiratory problems, irritated eyes, nose and throat, and problems thinking or concentrating.

¹ Canadian Community Health Survey 2014, Ministry of Health and Long-Term Care Share File, Statistics Canada.

² Canadian Community Health Survey 2014, Ministry of Health and Long-Term Care Share File, Statistics Canada.

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. As part of the ministry's commitment to *Patients First: Action Plan for Health Care*³ and patient-centred care, one-third of task force members are people with lived experience.

Our Mandate

The task force's goal is to move the yardstick on care and improve the patient experience for the more than half a million Ontarians living with these conditions. Its three-year mandate is to:

- Inform possible guidelines and policies to support patients with conditions triggered by environmental factors
- 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.

The task force's work is happening in two

A note about terminology

When the task force was created, the terms *environmental health* and *environmentally linked conditions* were chosen as convenient “umbrella” terms for all three conditions. However, the task force acknowledges that:

(1) While evidence points to these conditions having an environmental link, the precise role of environmental factors (i.e. any non-genetic factor, such as physical trauma, infectious agents and chemical exposures) is not well understood and requires more research.

(2) The task force's mandate *does not* cover other well-established environmentally-related conditions, such as environmentally-related cancer, asthma and lead poisoning.

For more information, see *Recognition, Inclusion and Equity: Environmental Connections and Features*
<http://recognitioninclusionandequity.org/about-the-conditions/environmental-connections-features/>.

³ http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/

phases. Phase 1 (now complete) focused primarily on assessing the evidence base and recommending early steps that could be taken to enhance awareness and knowledge. In Phase 2 (now underway), the task force will develop a comprehensive set of recommendations for a much needed system of care for people with ME/CFS, FM and ES/MCS as well as for research and both professional and public education.

Our Approach

To complete its work, the task force formed three working groups – research, care and education – to examine the current state of knowledge in each of these areas, identify gaps and opportunities, and report back with their findings and recommendations. Each group was asked to identify priorities and suggest early interventions that could spark widespread recognition of these chronic conditions and support the second phase of the task force’s work.

The task force is using an evidence-based approach that integrates evidence, lived experience and clinical experience⁴. Evidence, information and key resources have been gathered 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
- the Ontario Human Rights Commission
- data and research gathered and analyzed by the task force secretariat.

The task force has benefited from its members’ broad range of expertise. (See Appendix A for a list of members and their expertise.) Members acknowledge the critical importance and value of lived experience – the knowledge and experience of the individuals and families living with these conditions – in helping to inform the deliberations of all three working groups and develop recommendations to improve research, patient care and support, and education.

Our Phase 1 Report

Our Phase 1 Report provides a brief summary of our findings to date, identifies the key issues facing people living with ME/CFS, FM and ES/MCS, and makes a series of recommendations that could be implemented now, while the task force continues to work diligently to complete its tasks.

⁴ 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

THE CASE FOR ACTION

ME/CFS, FM and ES/MCS are life altering conditions. They have a drastic impact on people's health and quality of life. In some cases, the symptoms are so severe as to keep people housebound and even bedbound.

Compared to Ontarians without these conditions, people who have ME/CFS, FM and/or ES/MCS, are significantly more likely to:

- have unmet health care needs (24% versus 10%)
- have one or more other chronic conditions⁵ (77% versus 36%)
- experience life stress (37% versus 21%)
- have fair or poor self-perceived health (45% versus 11%)
- have fair or poor self-perceived mental health (23% versus 7%)
- have a weak sense of belonging to their community (41% versus 31%)
- not have worked in the last year (54% versus 24%)
- be in the lowest income category (53% versus 32%).

See Appendix B for a more detailed statistical profile of people with ME/CFS, FM and ES/MCS.

They also struggle to access timely care, manage their conditions and their treatments, and get insurance and social benefits.⁶ These poor health outcomes are the result of a range of gaps, barriers and attitudes in the health system and in society at large.

Lack of Knowledge

ME/CFS, FM and ES/MCS are relatively “new” medical conditions. Although there are reports of the symptoms dating back more than 100 years, it was only in the 1980s that these conditions started to be widely recognized and defined. Over the past 30 years, the body of evidence for each one has been growing. Each of the three conditions – ME/CFS, FM and/or ES/MCS – is distinct and scientifically recognized. Their characteristics and symptoms are known

Although ME/CFS, FM and ES/MCS are distinct conditions, they share some common symptoms – particularly fatigue and memory and concentration problems. A substantial proportion of people have two or all three of the conditions, which suggests the underlying pathophysiological mechanisms may be overlapping.

⁵ Refers to select chronic conditions including: asthma, arthritis, COPD, diabetes, hypertension, heart disease, cancer and stroke.

⁶ The challenges of living with these conditions have been well documented in the business case for an Ontario Centre of Excellence in Environmental Health. <http://recognitioninclusionandequity.org/about-the-conditions/community-consultation-and-patient-survey/>

although their causes and underlying pathophysiological mechanisms are still unclear⁷:

- Based on twin and family studies, both genetic and environmental factors may play a role in ME/CFS but no single genetic mutation has been found to explain most cases of the illness. A growing body of evidence suggests that problems with inflammation, the immune system, the microbiome, neurotransmitters, the metabolic system and the mitochondria (the organelles that generate energy for cells) are important in the mechanisms underlying ME/CFS.
- With fibromyalgia, scientists agree that the central nervous system is likely involved. FM is often but not always triggered by physical injury or infection, and genetics may contribute to half the risk of developing the condition. Researchers are looking closely at genetic variations related to the metabolism of the neurotransmitters involved in pain modulation.
- Few rigorous investigations have been done on ES/MCS. Nevertheless, a spate of relatively recent research using advanced neuroimaging, metabolomics and genomic approaches (conducted outside North America) indicates that fundamental neurobiologic, metabolic and genetic susceptibility factors may play a role.

There is a large body of evidence on supportive therapies (i.e. non-curative, symptom based) for both ME/CFS and FM, including Cochrane Reviews of randomized controlled trials on exercise therapy for ME/CFS and on oral non-steroidal anti-inflammatory medications for FM. However, there is no consensus on the effectiveness of these treatments. There have been very few research studies on therapies for ES/MCS.

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. Furthermore, the stigmatization that patients with these disorders often experience likely contributes to anxiety and depression.

The growing body of evidence on ME/CFS, FM and ES/MCS clearly indicates that these conditions are not mainly psychological and psychological approaches to care have very limited success.

⁷ Hu H. 2017. Current State of Recognition and Understanding of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS): A White Paper for the Ontario Task Force on Environmental Health.

Lack of Research

Progress in understanding the causes of these conditions and identifying effective treatments is severely hindered by the lack of research.⁸ Despite the fact that these conditions have been recognized by expert scientific and professional bodies (see box) and affect a significant proportion of the population, research investments remain very low – particularly in ES/MCS. In 2007, 2012 and currently, the U.S. National Institutes of Health funded 34, 37 and 48 studies in ME/CFS and 58, 54 and 53 in FM, but none in all years for ES/MCS. Between 2012 and 2015, the Canadian Institutes of Health Research (CIHR) invested a total of \$1,812,334 in 13 studies into ME/CFS (2 studies) and FM (11 studies). There were no studies funded on ES/MCS in those three years. Although these conditions affect significantly more people than many other diseases, they receive significantly less Canadian research funding: about 2% of the funding invested in research into Alzheimer’s Disease and 4% of that spent on research into Parkinson’s disease. (See table on page 57 for a more detailed comparison of CIHR research investments by disease.)

In 2001, a number of U.S. federal agencies along with private industry supported a conference on the role of environmental factors in medically unexplained symptoms. However, there has been no major research effort in the U.S. since that time. In Canada, there was some research on ES/MCS published between 2000 and 2007, funded by the provinces of Ontario and Nova Scotia.

To improve care for people living with ME/CFS, FM and ES/MCS, the health care system needs research that would help: identify the underlying causes of these conditions; understand their physical mental, economic and social impacts; guide clinical practice; and improve treatment and support.

The U.S. Institute of Medicine has confirmed that ME/CFS is a serious debilitating disease that affects millions.

The American College of Rheumatology and the American College of Physicians describes fibromyalgia as a common neurologic health problem and provides information on both diagnosis and treatment.

The American College of Occupational and Environmental Medicine has highlighted the impact of ES/MCS on well-being, productivity and lifestyle and advocates for research to help describe the characteristics of ES/MCS and define clinical interventions.

⁸ Hu H. 2017. Current State of Recognition and Understanding of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS): A White Paper for the Ontario Task Force on Environmental Health.

One of the greatest barriers to research on ME/CFS, FM and ES/MCS is stigma. Task force members are aware of anecdotal reports of clinicians being unwilling to manage patients and scientists avoiding research on these conditions because of the scepticism and controversies surrounding these illnesses. Many people with these chronic conditions are either unable to work or seek workplace accommodations or compensation, which – because the diseases are not widely recognized and difficult to diagnose -- can lead to suspicions of malingering and litigation.

Shortage of Skilled Providers

There is a profound shortage of specialized doctors skilled in diagnosing and treating ME/CFS, FM and ES/MCS, and only a handful of primary care practitioners who are knowledgeable about these conditions and confident managing them.

The Environmental Health Clinic (EHC) at Women’s College Hospital in Toronto is the only specialized assessment and diagnosis centre in Ontario. This clinic, established by the ministry and in operation since 1996, is unable to meet the growing demand for assessments. People often wait for more than a year to see a clinic physician. Until recently, when the EHC began to use the Ontario Telehealth Network (OTN), people had to travel to Toronto for all their appointments, which created another barrier to assessment and care. While being able to direct someone’s care via video may improve the patient experience – especially for those so ill that travel is difficult -- it will not reduce the long wait for appointments or compensate for the shortage of providers that currently limits the amount of care and follow-up people receive. More trained physicians are required urgently to meet demand.

One of the barriers to a much needed system of care for people with ME/CFS, FM and ES/MCS is strong academic and research leadership. To date, Ontario’s academic health science centres have devoted little attention to research and teaching on these conditions.

The severity of these diseases varies. As noted earlier, some people become so ill that they are housebound; others are bedbound. Because each person’s situation can be unique, those living with these conditions will need a personalized care plan. Without skilled health care providers to help develop those plans, individuals and their caregivers are forced to manage on their own.

Lack of Timely Appropriate Care

Because there are still unanswered questions about these conditions, the path to diagnosis is long and frustrating. When people first become so ill that they see their primary care doctor, the physician often doesn't have the knowledge to adequately evaluate and manage their health. Ontarians struggling with these conditions and the lack of recognition can go through weeks of often inappropriate and costly testing and investigations and spend months waiting for referral appointments with specialists – only to receive inconclusive results. During this time their illness becomes worse and its impact more devastating for them, their families and society at large (e.g. loss of productivity, economic impacts, social impacts).

Although there is a biological basis for these conditions, patients are often told that their problems are psychological. Provider attitudes contribute to the stigma and increase patients' isolation and stress.

Lack of Treatments

Once someone is diagnosed, there is a dearth of evidence-based, appropriate and affordable treatment options. With no known cure for these conditions, the only option people have is to struggle on their own with limited or no resources to create the healthiest possible living and working environments, and to maintain their health as best they can.

Symptoms of these conditions can be triggered by environmental factors, such as bright lights, noise, scents and low levels of chemicals and other substances. That means that, for many people with these conditions, their housing is often environmentally unsafe or it can exacerbate their symptoms. To manage their illness, people often have to make significant changes to their home environment, diet and daily activities. Finding safe affordable housing can be extremely difficult if not impossible.

Because of their sensitivity to environmental factors, people with ME/CFS, FM and ES/MCS can also find it unhealthy and harmful to seek care in emergency departments: hectic, noisy, brightly lit places that make heavy use of chemicals for cleaning and do not strictly enforce scent-free policies.

As is often the case with chronic conditions, finding the resources to live well can be expensive, demoralizing and isolating. Many people with ME/CFS, FM and ES/MCS cannot work and so their incomes drop. Living with these debilitating conditions for years can result in depression, poverty and even homelessness. Because the traditional

health care system has little to offer in the way of care or treatment, people often turn to uninsured treatments and supplements (e.g. naturopathic care), which they have to pay for out of pocket, exacerbating the financial impact of their illness.

Lack of Support for Family Caregivers

People with ME/CFS, FM and ES/MCS often rely heavily on family and friends. Given the chronic and often severe nature of these conditions, the caregiving burden can take a major emotional, mental, physical and financial toll on the family. In a very short period of time, caregivers and families can go from full careers and active social lives to a state where their finances, shelter and food security become precarious. Families often face these challenges in virtual isolation. There are no sources of information or support for family caregivers. In some cases, family caregivers may not believe these conditions are real and/or face the stigma of having a family member with these illnesses.

Lack of Recognition

The same stigma that has a chilling effect on research and care plays out in much more devastating ways in the day-to-day lives of people with these environmentally linked conditions. Because diagnosis is so difficult, their spouses, family members and friends often struggle to empathize with their experience and to believe that they are truly unwell.

Because of the lack of recognition of these conditions, people are often denied insurance benefits, social services, social supports and personal support carers. In many cases people cannot obtain supporting letters from their physicians and specialists to access resources and assistance. As a result, they often struggle to get the accommodations they need (e.g. quieter, more dimly lit spaces; scent free areas, use of non-toxic cleaning products) in their housing, at work or in emergency departments.

Scepticism on the part of friends, family, health care providers and employers about the legitimacy of their symptoms and environmental triggers can lead to isolation, job loss, homelessness and poverty. Isolation and these other social determinants of health can, in turn, lead to other health complications that require more medical care and interventions.

RECOMMENDATIONS

1. Change the Conversation

Despite compelling scientific evidence that ME/CFS, FM and ES/MCS are real, these conditions have not been adequately recognized by health policy makers, health care professionals and their educators, employers, or society at large.

This lack of recognition has been the biggest single barrier to improving care and support for Ontarians with these conditions. It helps explain why the recommendations of so many previous reviews have failed to gain traction and be fully implemented.

Leadership

To change the conversation, reduce the stigma associated with these conditions and gain the recognition required to improve care, we need leadership at the highest level in our health system. We need the Minister of Health to draw attention to the scale and depth of suffering these conditions cause.

Recommendation #1.1
Make a formal public statement recognizing ME/CFS, FM and ES/MCS
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.

We also need academic and clinical leadership: researchers and clinicians who will champion these environmentally linked conditions and undertake the work required to develop evidence-based, high quality care. We need dedicated leadership to:

- understand the prevalence and impact of these conditions
- develop deep expertise in the science and relevant clinical practices
- promote recognition and understanding
- shape professional education programs to ensure that, in the future, physicians and other health professionals are better equipped to support those affected by these conditions

- shape and guide the implementation of a research agenda so that these environmentally linked illnesses can be prevented, effective treatments are identified, and individuals with these conditions and their caregivers receive more support.

Recommendation #1.2

Establish academic chairs focused on ME/CFS, FM and ES/MCS

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.

OHIP Fee Codes

The task force believes one reason that ME/CFS, FM and ES/MCS are not widely recognized in health care settings is the lack of specific reference to these conditions in the OHIP Schedule of Benefits.

While an OHIP fee code does exist for CFS and FM (K037), it does not include ES/MCS or specifically mention ME. A billing code that explicitly includes these difficult-to-diagnose-and-treat conditions would signal the ministry's recognition of these conditions.

Recommendation #1.3

Modernize the K037 fee code to include all three conditions

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.

2. Develop a Common Understanding of ME/CFS, FM and ES/MCS

To help close gaps in knowledge and improve care, the research working group recommends that the health system focus first on ensuring a common understanding of these three conditions. To do that, the group identified two priorities: case definitions and clinical practice guidelines.

Case Definitions

Case definitions are a type of diagnostic criteria usually used for disease surveillance and outbreak investigations, and to identify patients with a specific illness. They are also essential for disease-related research.^{9, 10} Clear agreed-upon case definitions make it easier for clinicians to diagnose conditions and easier for the system to track their prevalence. They also support well structured, high quality research.

A rapid literature review¹¹ (i.e. peer-reviewed literature, grey literature, websites) conducted by the ministry's Research, Analysis & Evaluation Branch revealed significant gaps and variations in the case definitions currently in use (see box next page), which were confirmed by the group's own experience. Various definitions exist for each condition and there is no agreed upon "gold standard".

Variability in case definitions causes confusion among clinicians and leads to difficulties and inconsistencies in diagnosing and treating Ontarians with ME/CFS, FM and ES/MCS in Ontario. A common understanding of the signs and symptoms of these conditions is important to minimize any delays in diagnosis and to ensure timely care and support.

The conversation about environmentally linked illnesses needs to start with a common understanding of these conditions and their signs and symptoms. The task force believes that having a common, working definition which reflects the current evidence-based understanding for each condition, for both pediatric and adult populations, will

⁹ Evidence Synthesis Unit. (2016). Rapid Response on Definitions of Selected Environmentally Linked Diseases. Ontario Ministry of Health and Long-Term Care.

¹⁰ Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; Board on the Health of Select Populations; Institute of Medicine. Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. Washington (DC): National Academies Press (US); 2015 Feb 10. Current Case Definitions and Diagnostic Criteria, Terminology, and Symptom Constructs and Clusters. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK284898/>

¹¹ Evidence Synthesis Unit. (2016). Rapid Response on Definitions of Selected Environmentally Linked Diseases. Ontario Ministry of Health and Long-Term Care.

help focus the conversation between and among patients and health care providers and is a critical component of recognizing these illnesses, particularly among health care providers, researchers and government policy makers. Given the current state of knowledge, these case definitions cannot and will not be “gold standards”; however, they will allow appropriate care and research to proceed in Ontario.

Summary of Literature Review Findings: Case Definitions

ME/CFS: ME/CFS is a combined term and the terms ME and CFS have both been used to describe a debilitating multi-systemic condition characterized by chronic, disabling fatigue, post-exertional malaise¹², and other symptoms. More than eight definitions (with different selection and exclusion criteria) were identified in the literature review and some definitions (e.g. Oxford, Fukuda, NICE¹³) have been widely criticized. The definitions have been developed for different applications (e.g. clinical vs. research).

FM: Generally defined as a common illness characterized by chronic widespread pain, sleep problems, physical exhaustion, and cognitive difficulties. This condition has been controversial and definitions have repeatedly changed over the last 100 years of its existence. Most epidemiological studies have used the 1990 American College of Rheumatology (ACR) classification or the modified 2010 ACR diagnostic criteria.

ES/MCS: Encompasses a range of symptoms linked to environmental chemical exposures. The majority of the literature refers to the 1999 consensus criteria, which is considered the most comprehensive and well-known definition, and is used by a number of countries including the United States and Germany. Various names are used for this condition (e.g., Environmental Hypersensitivity, Idiopathic Environmental Intolerance), though it is most widely referred to as MCS.

Clinical Practice Guidelines

Clinical practice guidelines (CPGs) are recommendations informed by a systematic review of evidence and an assessment of the benefits and harms of different care options. They are intended to optimize patient care.¹⁴

¹² The literature review on case definitions did not describe the symptoms of ME/CFS in great detail. The research working group discussed the 2015 Institute of Medicine (IOM) report, which was referenced in the literature review. This report concluded that “there is sufficient evidence that post-exertional malaise (PEM) is a primary feature that helps distinguish ME/CFS from other conditions.”

Source: IOM (Institute of Medicine). 2015. Beyond myalgic encephalomyelitis/chronic fatigue syndrome: Redefining an illness. Washington, DC: The National Academies Press.

¹³ National Institute for Health and Clinical Excellence (NICE)

¹⁴ Institute of Medicine. 2011. Clinical Practice Guidelines We Can Trust. *The National Academies Press*.

The ministry's literature review¹⁵ identified seven CPGs for both ME/CFS and FM and none for ES/MCS.

- For ME/CFS: three CPGs were from Canada (two national and one from Alberta); two were from the UK; and one was from both Australia and South Australia. Except for one of the UK CPGs, which were developed by the Royal College of Paediatrics and Child Health, the CPGs were all developed by task forces composed of clinicians, researchers and patients, which were established by government, physician colleges or patient groups.

Methodology for Assessing Clinical Practice Guidelines

Ten of the 14 guidelines identified in the CPG review – six for ME/CFS and four for FM* – were assessed using the Appraisal of Guidelines for Research and Evaluation (AGREE II) instrument: an international tool for evaluating the methodological rigour of guideline development (see <http://www.nccmt.ca/resources/search/100>). This work was completed by the Centre for Effective Practice (CEP) – an international leader in the assessment and review of CPGs. Two reviewers from CEP reviewed the CPGs and provided the average domain scores for each one. (Please see Appendix 3 for a list and brief description of the CPGs identified in the literature and the results from the AGREE II evaluation.)

To create a shortlist of two to three CPGs for both ME/CFS and FM, the CEP recommended that the Research Working Group consider the utility of each CPG focusing on:

- the “rigour of development” domain, which is the benchmark domain
- the publication date, as most guideline databases and developer groups consider guidelines to be out of date after approximately five years.

Each reviewer also recommended whether they would support the use of each CPG. In addition, the research working group took into account the Health Quality Ontario (HQO) quality standards methodology, which recommends that a Canadian guideline also be included in the shortlist if one is not identified as high scoring.

**CEP advised that four CPGs could not be reviewed: one was a guideline review rather than a “true” guideline; another was out-dated and the review instead focussed on the newer version; and the other two were not available in English.*

¹⁵ Evidence Synthesis Unit. (2017). Rapid Response on Clinical Practice Guidelines for the Three Environmentally Linked Diseases. Ontario Ministry of Health and Long-Term Care

- For FM, CPGs were identified from Canada, Australia, Germany, Israel and Spain, as well as one each from a European and an international task force. The German guideline was published by a number of collaborating scientific societies, while the other six guidelines were drafted by multidisciplinary task forces of health care professionals.

The highest scoring CPGs for ME/CFS in terms of “rigour of development” were those developed by the Royal College of Paediatrics and Child Health (UK) and the Royal Australasian College of Physicians (Australia). However, these CPGs were developed in 2004 and 2002 and the UK CPGs were developed specifically for children and young people, so they would have to be assessed for their applicability to adults. Despite these findings, both were recommended for use with modifications. Two of the Canadian CPGs were evaluated; one was recent (2016) and the other out of date, however both scored low and were not recommended for use.

These results highlight the absence of CPGs for ES/MCS as well as the fact that more work is required to modify existing CPGs for both ME/CFS and FM for the Ontario context.

The highest scoring CPGs for FM in terms of “rigour of development” were those developed by the European League Against Rheumatism (EULAR) in 2017, which were recommended for use with modifications. Although the Canadian guidelines, developed in 2012, scored the second highest and can still be considered “current”, they were not recommended for use.

Recommendation #2.1

Develop clinical case definitions and clinical practice guidelines to support standardized, high-quality, patient-centred care.

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.

3. Lay the Groundwork for a Person-Centred System of Care

In Phase 2 of its work, the task force will focus on developing a person-centred system of care for people with ME/CFS, FM and ES/MCS: one that is accessible and includes quality primary care, relevant specialised services, timely diagnosis and assessment as well as access to necessary support services such as housing, employment and family supports.

In Phase 1 care working group identified a number of building blocks that, based on existing evidence and best practice, could be put in place now to address people's urgent unmet needs and lay the groundwork for that person-centred system of care. The working group focused specifically on improving care pathways and on enhancing accessibility and accommodation – particularly in hospitals and long-term care homes.

Pathways to a Person-Centred System of Care

In *The Case for Action*, the task force described the profound shortcomings of the current patient experience for people living with ME/CFS, FM and ES/MCS. The working group's initial appraisal and assessment of the current system of care found that it is characterized by:

- difficulty finding a primary care doctor or specialist who is knowledgeable about the diagnosis, treatment and management of the conditions
- time wasted seeing doctors and specialists who cannot help
- costly tests, procedures and medications that do not help
- delays in diagnosis and misdiagnosis, resulting in increased illness and prolonged suffering
- patients not being believed and negative interactions with care providers who stigmatize patients.

An individual's health experience is also affected by other factors outside the health system, such as access to safe housing and working environments, flexible employment, income supports, social support and more.

To develop a comprehensive system of care and support for Ontarians with ME/CFS, FM and ES/MCS, an expert and patient-centred consensus on appropriate clinical care pathways for people living with these environmentally linked conditions is required. It is necessary to map out an appropriate patient-focused system of care: one that gives

people a much improved patient experience, provides options for treatment and living well with their condition(s), and identifies the supports required for effective care. The system of care must reflect the research evidence, the current literature, clinical expertise and lessons from the experience of people living with these conditions.

The care pathways will:

- integrate the findings from the research, care and education working groups, including the application and promotion of clinical practice guidelines and educational supports
- give decision-makers a basis for setting priorities when it comes to implementing the system of care within a resource-constrained health care system
- improve access to appropriate primary and specialized care, timely diagnosis, treatment and ongoing management, and other necessary support services
- leverage technologies and existing structures that can keep care close to home.

To develop these care pathways and map out the system of care, the task force requires assistance. Even with the recommended pathways and system of care, strong leadership will be required to ensure full and successful implementation.

Recommendation #3.1
Establish detailed clinical care pathways to support the development of an evidence-based system of care.
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.

Better Access and Accommodation in the Health System

People affected by ME/CFS, FM and ES/MCS deserve respectful care, free from harm: care that protects their health, safety and wellbeing. Yet most people with these environmentally linked conditions face barriers accessing health care. Health care providers, family caregivers, employers and others may not know about the conditions or believe they are real. Faced with patients with these conditions, they may not know how substances in the care or working environment can trigger reactions or sensitivities or how to improve access and provide accommodation.

The task force reviewed the existing legal and policy frameworks for accessibility and accommodation of disabilities.

Accommodations for individuals with environmental sensitivities generally involve minimizing the use of triggering substances, filtering triggers from the environment or avoiding the trigger-filled environment.¹⁶

Both the Ontario Human Rights Code (the code) and the Accessibility for Ontarians with Disabilities Act (AODA) recognize non-evident disabilities. The task force believes strongly that Ontario must seize the opportunity provided by the code and the AODA to fully recognize and address the disabilities arising from ME/CFS, FM and ES/MCS.

The task force understands that widespread recognition of the debilitating nature of these conditions – which should improve access and accommodation – will take time. In the meantime, the task force has identified a number of concrete initiatives that can have an immediate impact, using existing health system resources and policies.

As a first step, the task force is focusing on hospitals and long-term care homes: settings that can be challenging for Ontarians living with ME/CFS, FM and ES/MCS. We believe that, with the right policies, practices and attitudes, a hospital or long-term care home can provide patient-specific accommodation that is designed to prevent reactions, minimize discomfort, and build trust with patients and families. While these strategies can be difficult to enforce, we know from the experience of some health care settings (see box) that, with the right leadership, they can be implemented successfully.

There are a number of simple steps that a

The Accessibility for Ontarians with Disabilities Act (AODA) is a law that applies to all levels of government, non-profits and private sector businesses in Ontario that have one or more employees. It aims to identify, remove and prevent barriers for people with disabilities. The goal is to make Ontario accessible to people with disabilities by 2025. The AODA uses the same definition of disability as the Ontario Human Rights Code, and includes both evident and non-evident disabilities. An AODA Health Standard is currently being developed.

Quinte Healthcare Corporation (QHC) Excerpt from Policy on Multiple Chemical Sensitivities

Patients at Quinte Healthcare Corporation (QHC) who have multiple chemical sensitivities will have all available interventions and alternatives implemented in their plan of care to accommodate their disability. The objectives of care related to multiple chemical sensitivities are to: prevent reactions, minimize discomfort, enhance patient confidence and trust, reduce families' fears, decrease length of hospital stay, and increase the likelihood of successful treatment outcomes. (Marshall & MacLennan, 2001)

¹⁶ http://www.chrc-ccdp.gc.ca/sites/default/files/legal_sensitivity_en_1.pdf

hospital or long-term care home can take to be more accessible and accommodating and to balance patient safety (including the need for infection control) with accessibility and accommodation. For example:

- implement and enforce a rigorous fragrance and chemical avoidance policy
- ensure all employees are aware of the need to accommodate patients or residents with these disabilities
- create awareness of measures such as adjusting lighting and sound, and developing a care plan that supports care with minimal touch
- provide patient room signage to eliminate the need for patients to continuously advocate for their needs while receiving care
- develop procurement and contractor policies to purchase low-emitting furnishings and materials, use low or no VOC paints, and adopt cleaning supplies that meet provincial standards while also being low or no scent.

Recommendation #3.2

Make hospitals safe for people with ME/CFS, FM and ES/MCS

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.

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 *Marshall, LM, MacLennan JG. Environmental health in hospital: A practical guide for hospital staff. Part I Pollution prevention, Part II Environment-sensitive care (2001)*.

In February 2017, two members of the task force presented to the Long-Term Care Home Design Working Group of the Ministry of Health and Long-Term Care on the importance of accessibility and accommodation, including the critical importance of air quality for people with these environmentally linked conditions and all other residents. The task force will continue to seek opportunities to make presentations and influence policy and programs being developed as part of health system transformation.

Recommendation #3.3

Make long-term care homes safe for people with ME/CFS, FM and ES/MCS.

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.

The MOHLTC 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.

4. Increase the Number of Knowledgeable Providers

There is an urgent and dire shortage of health providers who are knowledgeable about ME/CFS, FM and ES/MCS. Many doctors and other health care providers lack a fundamental understanding of these environmentally linked conditions and many assume they are psychological. For example:

- In a 2013 survey of Ontario community health centre physicians and nurse practitioners, the majority of respondents said they were not comfortable with their ability to diagnose and treat patients with the conditions.¹⁷
- 55% of rheumatologists in Ontario think that fibromyalgia is psychosomatic.¹⁸

To support patient-focused, high quality care, the education working group is focusing on the urgent need for more skilled providers, looking specifically at:

The key challenges will be:

- providing concise and clear information, including relevant and practical tools, for primary health care providers
- making changes to medical and nursing school curriculum at all levels
- building interest among practicing health care providers and overcoming the lack of recognition and respect for the conditions
- improving general public awareness.

¹⁷ Molot J. 2012. Academic and Clinical Perspectives. Compendium 3/4 of the Business Case for an OCEEH. October 2013

¹⁸ Ghazan-Shahi S, Towheed T, Hopman W. 2012. Should rheumatologists retain ownership of fibromyalgia? A survey of Ontario rheumatologists. Clin Rheumatol 2012;31:1177–8.

- the lack of knowledgeable primary care providers and specialized physicians
- the lack of education programs as well as interest in obtaining specialized training in these conditions
- low public awareness of these conditions among medical specialists, employers and housing providers, family caregivers and Ontarians who may have one of these conditions but have not yet sought care.

In Phase 1, the group concentrated on understanding the issues. In Phase 2, the working group will focus on developing recommendations related to educating medical, nursing and nurse practitioner students, family medicine residents, and primary health care providers, advanced education and targeted public awareness strategies.

Primary Care Provider Education

Patients' first point of contact is their primary care provider. From a patient experience perspective, it is critically important that primary care providers be able to recognize the symptoms of ME/CFS, FM and ES/MCS and respond appropriately.

There is currently no consistent academic education on these environmentally linked conditions for primary care physicians or nurses in undergrad or specialized training (i.e. family medicine specialty, nurse practitioners) and limited learning opportunities for professionals already in practice.

To raise health care provider awareness of and build interest in specializing in these environmentally linked conditions, Ontario needs a comprehensive education strategy that would include:

- providing basic awareness and information about the conditions to all physicians and nurses in training as well as those in practice
- ensuring students who specialize in family medicine or primary care nursing develop the skills and competencies required to know the questions to ask at intake and how to take an environmental exposure history.

A comprehensive education strategy will lead to:

- greater social awareness and understanding of these conditions and their symptoms
- more effective care (i.e. by including the conditions as possible causes of diverse symptoms)
- more interest in these conditions as an area of clinical focus for future specialization.

To increase the number of primary health care providers who have the basic skills and knowledge to provide diagnosis, treatment and self-management strategies to patients with these conditions, the system must address some key issues and challenges. The working group is currently considering a number

of interventions that the health professional education system could implement to get information to the greatest number of primary care providers and enhance their skills.

Advanced Specialised Education

While there is no formal medical speciality that treats or champions care for people with these environmentally linked conditions, a few physicians (from family medicine and other disciplines) have developed expertise in diagnosis and treatment. In Ontario, most of these physicians practice out of the Environmental Health Clinic (EHC) at the Women's College Hospital in Toronto and provide a much needed service for patients unable to find care through their primary care providers. These physicians have offered training and support to students and health care providers around the province, though they are limited in what they can provide by a lack of time and funding. As a result, there is very little training available in the management and treatment of these disorders. The EHC physicians also provide valuable knowledge as expert witnesses and as researchers, though their reach is very limited.

The education working group identified one key challenge: how to leverage existing limited clinical and academic expertise to enhance specialized education. Practical hands-on training occurs at the intersection of education and the point of care. To provide this training, it will be important to tap into the few experts who currently provide care and build on existing opportunities to expand education and, in doing so, get more care to more people.

There is currently a ministry-funded program for a 3rd year family medicine residency in clinical environmental health offered through the University of Toronto and taking place at the EHC. The program has faced challenges recruiting interested residents. While the education working group assesses other potential strategies to increase the knowledge base among physicians across the province, it recommends that the ministry continue to support the University of Toronto program.

Recommendation #4.1

Continue to fund the Enhanced Skills Program for 3rd Year Residents in Clinical Environmental Health.

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.

Public Awareness

To enhance public recognition of the conditions, reduce stigma and improve care, the education working group has identified key audiences to target with awareness messages including:

- the general public
- medical specialties strongly associated with the conditions including rheumatology, internal medicine and endocrinology
- employers
- social services
- housing providers
- family caregivers.

In Phase 2, the working group will identify key components of the message each group should receive as well as appropriate channels to reach these diverse groups.

THE YEAR AHEAD: NEXT STEPS

In our Phase 1 report, we ask the minister and the ministry to take some critical first steps to change the conversation and enhance recognition 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 environmentally linked conditions.

In Phase 2, the task force will turn its attention to developing more detailed recommendations on:

- the components of a comprehensive patient-centred system of care
- the type of research required to improve care
- both the recognition and health care provider and public education required to end the stigma associated with ME/CFS, FM and ES/MCS.

The goal is to enhance quality of care, establish a model of care that will relieve the stresses on people of all ages living with these conditions and on their families, and improve their health and quality of life.

APPENDICES

Appendix 1 Task Force on Environmental Health Membership

Name	Biography
Neil Stuart (Vice-Chair)	Neil Stuart served for many years as a partner and practice leader in the Canadian health care consulting practices of Price Waterhouse, PricewaterhouseCoopers and then IBM. He 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. Neil is an active board member of Patients Canada and VON Canada. He also recently served on the boards of Cancer Care Ontario, The Change Foundation, the Ontario Hospital Association and Toronto East General Hospital. Neil received his PhD in health policy from Brandeis University where he was a fellow in the University's Health Policy Center.
Bill Manson	Bill Manson is 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.
Cornelia Baines	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 in the 1980s, 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.

Denise Magi	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. Denise has been on various steering committees, including the initial steering committee that developed a business case proposal for the Ontario Centre of Excellence in Environmental Health. She is a patient with personal knowledge of ME/CFS, FM and ES/MCS and is a long-standing health advocate and volunteer for health based organizations.
Howard Hu (former chair)	Howard Hu, M.D. (Albert Einstein); M.P.H., Sc.D. (Harvard) is 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).
Izzat Jiwani	Izzat Jiwani has been diagnosed with ME, FM, MCS. She and her husband have had the role and experience of being primary caregivers and supporter of their adult child who has debilitating ME and MCS. She has a Ph.D. and has been a post-doctoral fellow at the Academic Chair, Governance and Transformations of Health Care Organizations and Systems (University of Montreal). Izzat's interest areas include: integrated health and social service systems, chronic disease prevention and management, and health policy.
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	John Molot has been a member of the Environmental Health Committee of the Ontario College of Family Physicians since 1994. He has developed and provided workshops for both the Canadian and Ontario Colleges of Family Physicians regarding sick building syndrome, 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 and Climate Change for 17 years in the Environmental Sciences and Standards Division. Her current role is as the Standards Development Branch's (SDB'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 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.
Mike Ford	Mike Ford is a successful 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.

Nancy Sikich	Nancy Sikich is a Registered Nurse and Clinical Epidemiologist. She has been working in the area of Health Technology Assessment for 13 years developing evidence to support health policy recommendations. Currently, she is the Director of Health Technology Assessment at Health Quality Ontario in Toronto, Ontario.
Sharron Ellis	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.
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 has all three illnesses ME/FM /MCS and continues to be 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	
Varda Burstyn (stepped down February 2017)	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.
Dona Bowers (stepped down May 2017)	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.

Appendix 2 Prevalence and profile estimates

Methods

The 2014 Canadian Community Health Survey (CCHS)¹⁹ was used to:

- Measure the prevalence of the Ontario population (age 12+) with:
 - Fibromyalgia, Chronic fatigue syndrome, or Multiple chemical sensitivities
 - One or more of: Fibromyalgia, Chronic Fatigue Syndrome, or Multiple Chemical Sensitivities
- Develop a profile of the Ontario population (age 12+) who has one or more of: Fibromyalgia, Chronic Fatigue Syndrome, or Multiple Chemical Sensitivities

The CCHS is a cross-sectional survey that collects information related to health status. Data are self-reported and may be subject to recall errors, over and under reporting, and errors associated with proxy reporting. Those living in institutions, on reserves, or in the Canadian Forces are not included. In accordance with Statistics Canada's Guidelines for Analysis and Release:

- All results are weighted using sampling weights supplied by Statistics Canada.
- Confidence intervals (95%) and coefficients of variation (CV), which indicate the reliability of the estimates, were calculated. Estimates with a CV of greater than 33.3 are considered too unreliable to be released, published, or used for analysis. Estimates with a CV between 16.6 and 33.3 have high sampling variability and must be interpreted with caution.
- Total weighted numbers are rounded to the nearest 100 unit. Percentages and 95% confidence intervals are presented to one decimal place.

Results

Condition	Sex	#	%	CV	95% Confidence Interval
Fibromyalgia	Male	42,600*	0.7%*	23.6	0.4% – 1.1%*
	Female	179,700	3.0%	9.0	2.5% – 3.5%
	All	222,300	1.9%	8.6	1.6% – 2.2%
Chronic fatigue syndrome	Male	52,900	0.9%	12.7	0.7% – 1.2%
	Female	102,500	1.7%	11.0	1.3% – 2.1%
	All	155,400	1.3%	8.3	1.1% – 1.5%
Multiple chemical sensitivities	Male	54,100	0.9%	12.1	0.7% – 1.2%
	Female	196,400	3.3%	7.8	2.8% – 3.8%
	All	250,500	2.1%	6.6	1.9% – 2.4%
Has one or more of the three conditions	Male	138,600	2.4%	9.3	2.0% – 2.9%
	Female	414,500	6.9%	5.7	6.1% – 7.7%
	All	553,100	4.7%	4.8	4.3% – 5.2%

**Estimate should be used with caution due to high sampling variability*

¹⁹ Canadian Community Health Survey (CCHS) 2014, Ministry of Health and Long-Term Care Share File, Statistics Canada.

Table 2: Profile of Ontarians age 12 and older Fibromyalgia, Chronic Fatigue Syndrome, or Multiple Chemical Sensitivities

Variables (N=553,100)		1+ condition(s)				No conditions		
		#	%	CV	95% CI	%	CV	95% CI
Sex*	<i>Male</i>	138,600	25.1%	8.20	21.0% - 29.1%	50.0%	0.24	49.7% - 50.2%
	<i>Female</i>	414,500	74.9%	2.74	70.9% - 79.0%	50.0%	0.24	49.8% - 50.3%
Age*	<i>Aged 12-49</i>	169,500	29.0%	8.40	24.2% - 33.7%	58.7%	0.63	57.9% - 59.4%
	<i>Aged 50+</i>	383,600	71.0%	3.42	66.3% - 75.8%	41.3%	0.90	40.6% - 42.1%
Marital status	<i>Have a partner</i>	323,300	58.6%	4.12	53.9% - 63.3%	56.9%	0.89	55.9% - 57.9%
	<i>No partner</i>	228,400	41.4%	5.83	36.7% - 46.1%	43.1%	1.18	42.1% - 44.1%
Education	<i>High school or less</i>	224,089	41.3%	6.37	36.1% - 46.5%	38.5%	1.57	37.3% - 39.7%
	<i>More than high school</i>	318,538	58.7%	4.48	53.5% - 63.9%	61.5%	0.98	60.3% - 62.7%
Income	<i>No income</i>	Supressed		74.57	Supressed		33.76	Supressed
	<i>\$>0-\$49,999</i>	290,200	52.5%	5.12	47.2% - 57.7%	31.8%	1.99	30.6% - 33.1%
	<i>\$50,000-\$99,999</i>	159,600	28.9%	8.26	24.2% - 33.5%	33.8%	1.82	32.6% - 35.0%
	<i>\$100,000 +</i>	94,400	17.1%	12.66	12.8% - 21.3%	34.1%	1.89	32.8% - 35.3%
Unmet health care needs*	<i>No</i>	417,500	75.6%	2.92	71.3% - 79.9%	90.2%	0.49	89.4% - 91.1%
	<i>Yes</i>	134,700	24.4%	9.06	20.1% - 28.7%	9.8%	4.53	8.9% - 10.6%
Chronic condition*,\$	<i>No</i>	129,400	23.4%	9.83	18.9% - 27.9%	64.2%	0.97	63.0% - 65.4%
	<i>Yes</i>	423,700	76.6%	3.00	72.1% - 81.1%	35.8%	1.73	34.6% - 37.0%
Physical activity*	<i>Active</i>	225,281	42.5%	6.47	37.1% - 47.9%	53.5%	1.33	52.1% - 54.9%
	<i>Inactive</i>	304,993	57.5%	4.78	52.1% - 62.9%	46.5%	1.53	45.1% - 47.9%
Self-perceived health*	<i>Fair/Poor</i>	415,700	45.1%	5.74	40.0% - 50.1%	10.8%	3.86	10.0% - 11.6%
	<i>Excellent/VGood/Good</i>	135,300	54.9%	4.70	49.9% - 60.0%	89.2%	0.47	88.4% - 90.0%
Self-perceived mental health*	<i>Fair/Poor</i>	283,000	22.5%	10.31	18.0% - 27.1%	6.6%	4.87	6.0% - 7.2%
	<i>Excellent/VGood/Good</i>	246,500	77.5%	3.00	72.9% - 82.0%	93.4%	0.34	92.8% - 94.0%
Life Stress*	<i>No</i>	344,500	62.6%	4.12	57.6% - 67.7%	79.4%	0.72	78.3% - 80.5%
	<i>Yes</i>	205,500	37.4%	6.90	32.3% - 42.4%	20.6%	2.78	19.5% - 21.7%
Sense of belonging*	<i>Strong</i>	307,800	59.2%	4.54	53.9% - 64.4%	68.6%	0.89	67.4% - 69.8%
	<i>Weak</i>	212,300	40.8%	6.58	35.6% - 46.1%	31.4%	1.95	30.2% - 32.6%
Working status (last week)*€	<i>No</i>	285,820	59.9%	4.82	54.2% - 65.5%	31.7%	1.88	30.6% - 32.9%
	<i>Yes</i>	191,611	40.1%	7.19	34.5% - 45.8%	68.3%	0.88	67.1% - 69.4%
Working status (last 12 months)*€	<i>No</i>	262,538	54.2%	5.18	48.7% - 59.7%	23.9%	2.19	22.9% - 25.0%
	<i>Yes</i>	221,524	45.8%	6.14	40.3% - 51.3%	76.1%	0.69	75.0% - 77.1%

Notes:

- For income, estimates are suppressed 'no income' responses as estimates with a CV of greater than 33.3 are considered too unreliable to be published.
- Due to rounding and excluded responses, the number of Ontarians with the conditions by individual variable may not add up to the total.
- *Indicates measures where there is a statistically significant difference between the two populations, based on assessment of the 95% CIs.
- §Refers to select chronic conditions including: asthma, arthritis, COPD, diabetes, hypertension, heart disease, cancer, or stroke.
- € Working status questions are restricted to those age 15-75 making the total numbers for these variables lower than the overall total (i.e., 553,100)

Description of variables

Category	Variable	Description of question/variable*
Fibromyalgia	CCC_041	Diagnosed by a health professional as having fibromyalgia
Chronic fatigue syndrome	CCC_251	Diagnosed by a health professional as having chronic fatigue syndrome
Multiple chemical sensitivities	CCC_261	Diagnosed by a health professional as having multiple chemical sensitivities
Has 1+ conditions	CCC_041, CCC_051, CCC_261	Based on those who had any one or more of the conditions: Fibromyalgia, Chronic Fatigue Syndrome or Multiple Chemical Sensitivities.
Sex	DHH_SEX	
Age group	DHH_AGE	
Marital status	DHH_MS	What is your marital status?
Education	EDU_4A	What is the highest certificate, diploma or degree completed?
Income	INCDHH	Household income variable (derived) <i>Note: Asked to respondents age 17+</i>
Unmet health care needs	UCN_010	During the past 12 months, was there ever a time when you felt that you needed health care but you didn't receive it?
Has other chronic conditions	CCC_031, CCC_051, CCC_091, CCC_101, CCC_071, CCC_121, CCC_131	Based on responses to questions about 8 chronic conditions: asthma, arthritis, COPD, diabetes, hypertension, heart disease, cancer and stroke (derived) <i>Note: Chronic condition questions are asked to respondents age 12+, except for arthritis (14+) and COPD (35+)</i>
Physical activity	PACDPAI	Categorizes respondents activities in their transportation and leisure time based on total daily energy expenditure values (derived)
Self-perceived health	GENDHDI	Indicates health status based on own judgement (derived)
Self-perceived mental health	GENDMHI	Mental health status based on his/her own judgement (derived)
Life stress	GEN_07	Thinking about the amount of stress in your life, would you say that most days are...?
Sense of belonging to community?	GEN_10	How would you describe your sense of belonging to your local community?

Working status (last week)	LBSDWSS	Classifies the respondent based on his/her working status in the week prior to the interview (derived) <i>Note: Asked to respondents age 15-75</i>
Working status (last month)	GEN_08	Have you worked at a job or business at any time in the past 12 months? <i>Note: Asked to respondents age 15-75</i>
Note: For all analyses, denominators exclude those who were categorized as 'don't know', 'refused', 'not stated' or 'not applicable'.		

Appendix 3 Overview of CPGs identified in AGREE II Results

Overview of the CPGs identified in the literature and AGREE II results						
#	Title	Author	Jurisdiction	Rationale for development	Year	Score
MYALGIC ENCEPHALOPATHY / CHRONIC FATIGUE SYNDROME (ME/CFS)						
1	CFS Clinical Practice Guidelines	Royal Australasian College of Physicians (RACP)	Australia	Primarily to assist GPs, but relevant to specialists/other providers involved in managing people with fatigue states.	2002	51 – recommended with modification
2	CFS Guidelines	Carruthers et al	Canada	To assist health care professionals with patients with unusual fatigue states.	2003	27 – not recommend
3	ME/CFS Management Guidelines for General Practitioners	South Australian Department of Human Services	South Australia	To guide the diagnosis/management in community or primary care setting.	2004	8 – not recommend
4	Evidence Based Guideline for the Management of CFS/ME in Children and Young People	Royal College of Paediatrics and Child Health	UK	To develop the required competences pediatricians need for diagnosis/management of ME/CFS	2004	79 - recommended
5	ME/CFS: A Clinical Case Definition and Guidelines for Medical Practitioners	Carruthers et al	Canada	To develop a clinical definition and diagnostic and treatment protocols.	2005	Not reviewed (Not a guideline; is a guideline review)
6	CFS/ME (or encephalopathy): diagnosis and management of CFS/ME (or encephalopathy) in adults and children	Turnbull et al and National Institute for Health and Clinical Excellence (NICE)	UK	To increase recognition; influence real world practice; improve access and care; emphasize multidisciplinary work; provide guidance on best practice for children; balance clinical guidance with flexibility and management; facilitate	2007	63 – not recommend

				communication.		
7	Identification and Symptom Management of ME/CFS Clinical Practice Guideline	Toward Optimized Practice (TOP) Me/CFS Working Group	Alberta	To provide clinicians in Alberta with the information and tools necessary to detect key symptoms and manage symptoms over the long-term.	2016	10 – not recommend
FIBROMYALGIA						
1	Evidence Based Recommendations for the Management of FM Syndrome	European League Against Rheumatism (EULAR)	Europe	To ascertain strength of evidence on treatment effectiveness; develop recommendations for management based on evidence and expert opinion.	2008	Not reviewed (Has been updated – see #7 below)
2	Interdisciplinary Consensus Document for the treatment of fibromyalgia	Alegre de Miquel et al	Spain	To develop a consensus on treatment by selected representatives supported by the principal medical associations that intervene in treatment and patient associations' representatives.	2010	33 – not recommend
3	Canadian Guidelines for the Diagnosis and Management of FM Syndrome: Executive Summary	Fitzcharles et al	Canada	To provide directions for optimal patient care (adult) that aligns with best available evidence.	2012	55 – not recommend
4	Guideline of the Association of the scientific Medical Societies in Germany on the Definition, Pathophysiology, Diagnosis, and Treatment of FM Syndrome	German Interdisciplinary Association of Pain Therapy; Association of the Scientific Medical Societies; & other Associations	Germany	To address high prevalence, the association of reduced health-related quality of life, high health care costs, and controversies surrounding diagnosis and management.	2012	Not reviewed (not available in English)
5	Guidelines for the Diagnosis and Treatment of the FM Syndrome	Albin et al	Israel	To develop practical and evidence based guideline recommendations for the Israeli health care system.	2013	Not reviewed (not available in English)
6	Australian Clinical Practice Guidelines for FM	Guymer, E., & Littlejohn, G	Australia	To discuss when FM should be considered as a diagnosis; how it is diagnosed; understanding of pathophysiology; management strategies. Intended for GPs.	2013	14 – not recommend
7	EULAR revised recommendations for the management of fibromyalgia	Macfarlane, G.J. et al	Europe	Revised 2008 guidelines (#1 above) – incorporates new evidence regarding pharmacological/non-pharmacological management. Move away from guidelines (based on expert opinion) to those based on scientific evidence.	2017	67– recommended with modification
* Domain scores are calculated by summing up all the scores of the individual items in a domain and by scaling the total as a percentage of the maximum possible						

score for that domain. Although the domain scores are useful for comparing guidelines and will inform whether a guideline should be recommended for use, there are no set minimum domain scores or patterns of scores across domains to differentiate between high quality and poor quality guidelines. These decisions should be made by the user and guided by the context in which AGREE II is being used." (Source: AGREEtrust.org)

Appendix 4 Evidence Brief: White Paper

Current State of Recognition and Scientific Understanding of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) Fibromyalgia (FM) and Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS)

A White Paper for the
Ontario Task Force on Environmental Health

June, 2017

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Background

This white paper was generated by the Research Working Group of the Task Force on Environmental Health, (see Appendix 1 for a list of contributors). The task force was formed by the Ontario Ministry of Health and Long Term Care (MOHLTC) to provide advice and recommendations to the Minister on issues related to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS)¹.

It is critical to acknowledge at the outset that neither the Research Working Group nor the task force was designed to be a scientific review body with a primary focus on understanding the scientific evidence as it relates to the recognition, pathogenesis and clinical treatment of the three conditions of interest, ME/CFS, FM and ES/MCS. Thus, although the task force included members with advanced training in clinical medicine, public health, and/or clinical research; physicians with experience managing patients with one or more of the conditions of interest; and scholars with current faculty appointments at the University of Toronto and other leading universities, only two of the task force's members have direct experience in conducting scientific research specifically related to one or more of the three conditions². Nevertheless, with the support of the MOHLTC's research arm, the task force has taken a close look at (and continues to review) the available scientific literature relevant to the three conditions and provides this very brief overview of the state of recognition and understanding of the conditions from a scientific perspective.

Purpose

The very creation of this task force is, of course, arguably predicated on the assumption that each of these conditions is distinct and scientifically "recognized". On the other hand, the task force understands that there remains a significant amount of skepticism in the medical as well as lay community regarding this assumption, particularly since none of these conditions are characterized by clear objective findings on physical exam or standard laboratory testing, and although research on these conditions has been on-

¹ In terms of terminology/nosology, the task force recognizes that there are a number of synonyms that exist with respect to each of these three conditions, such as, "chronic fatigue immune dysfunction syndrome (CFIDS)" for ME/CFS, "Musculoskeletal Pain Syndrome (MPS)" for FM, and "Idiopathic Environmental Intolerances (IEI)" for ES/MCS. The Taskforce also recognizes that all three conditions have sometimes been included under the umbrella category of "Medically Unexplained Symptoms" (along with other entities such as Gulf War Syndrome, Sick Building Syndrome, Post-Treatment Lyme Disease Syndrome, and others). Nevertheless, for the purpose of meeting its mandate, the task force has chosen to rely on the terms ME/CFS, FM and ES/MCS and to limit its scope to these conditions. ES/MCS is intended to also include sensitivities that have been reported to electromagnetic fields, although the task force will not otherwise address potential sensitivities to electromagnetic fields as a distinct topic.

² Dr. Howard Hu and Dr. Cornelia Baines

going, the underlying mechanisms remain quite obscure for all three. In addition, patients who have one or more of these conditions typically are also at risk of experiencing anxiety, depression, or other psychiatric morbidities, persuading some skeptics to opine that one or more of the conditions are purely psychogenic and/or related to other recognized psychopathologies. This white paper describes the findings of the task force as a result of its own search of the literature, and from input from task force members, and is used by the task force to develop its Interim Report (June 2017) and early recommendations.

Findings

The Research Working Group of the task force, having conducted a search of the literature and received the input of task force members with lived experience related to one or more of these conditions as well as the input of task force members with clinical experience managing patients with one or more of these conditions, reaches the following conclusions:

1. There exist substantial bodies of scientific evidence for each of the three conditions, i.e., Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS).
2. ME/CFS is debilitating multisystem condition characterized by chronic and disabling fatigue not improved by rest, and, to varying degrees in individual patients, pain, sleep disturbances, neurologic and cognitive changes, weakness, and altered immune and autonomic responses. Some experts require the presence of post-exertional malaise and also consider memory or concentration problems to be critical components³.
3. FM is a debilitating condition characterized by diffuse chronic pain accompanied by poor sleep, physical exhaustion and cognitive difficulties⁴. Early criteria that included the requirement of “trigger points” (areas of muscle tenderness) have since been dropped.
4. ES/MCS is a debilitating condition characterized by recurrent nonspecific symptoms (common symptoms include, but are not limited to, cognitive difficulties, fatigue,

³ Smith ME, Haney E, McDonagh M, Pappas M, Daeges M, Wasson N, Fu R, Nelson HD. Treatment of Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome: A Systematic Review for a National Institutes of Health Pathways to Prevention Workshop. *Ann Intern Med.* 2015 Jun 16;162(12):841-50. doi: 10.7326/M15-0114. Review. PubMed PMID: 26075755.

⁴ Häuser W, Ablin J, Fitzcharles MA, Littlejohn G, Luciano JV, Usui C, Walitt B. Fibromyalgia. *Nat Rev Dis Primers.* 2015 Aug 13;1:15022. doi: 10.1038/nrdp.2015.22. Review. PubMed PMID: 27189527.

upper and lower respiratory complaints) referable to multiple organ systems that sufferers report to be provoked by exposure to low levels of multiple (and typically, but not always, unrelated) chemical, biologic, or physical agents, with relief or improvement of symptoms when inciting agents are removed. No consistent physical findings or laboratory abnormalities have yet been found to differentiate MCS patients from the remainder of the population⁵.

5. There is significant overlap in the clinical expression of the three conditions, particularly with respect to patients reporting symptoms of cognitive dysfunction and fatigue, and a number of clinical studies have reported that a substantial proportion of patients have two or all three of the conditions. Overall, the lived experience of patients and current scientific evidence supports the view that the three conditions are clearly distinct, but there may be significant overlap in mechanisms underlying the conditions.
6. The size of the evidence base appears to be significantly larger for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FM) than for Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS). For example, recent searches conducted on the U.S. National Library of Medicine's PubMed⁶ system using terms known for these conditions uncovered approximately 7,453 references specific for ME/CFS, 9,846 references specific for FM, but only 320 specific references for ES/MCS.
7. The aforementioned imbalance in research is likely related to the history and balance in associated research funding, which appears to have been sustained, albeit modest (in comparison to other chronic diseases) for ME/CFS and FM, but virtually non-existent for ES/MCS. For example, a recent search of the NIH Reporter⁷ database of grants funded in 2007, 2012, and currently by the U.S.

⁵ For this statement and for these de facto definitions of the conditions, the RWG sought and prioritized multi-authored publications in the peer-reviewed scientific literature that, in our opinion, were recent, balanced, well-researched, representative of as wide a consensus as possible, and published in authoritative journals or other outlets. This was especially difficult for ES/MCS, for which no such publication fitting this description that is recent (i.e., within the last 3-5 years) could be found. The description of ES/MCS herein represents the Taskforce's opinion, for which the closest published definition is a statement made in the literature in 1999 (Multiple chemical sensitivity: a 1999 consensus. Arch Environ Health. 1999 May-Jun;54(3):147-9. PubMed PMID: 10444033.) that, in turn, was found to have high discriminant ability in identifying patients clinically verified to have ES/MCS in a study published by researchers from the University of Toronto (McKeown-Eyssen GE, Baines CJ, Marshall LM, Jazmaji V, Sokoloff ER. Multiple chemical sensitivity: discriminant validity of case definitions. Arch Environ Health. 2001 Sep-Oct;56(5):406-12. PubMed PMID: 11777021.)

⁶ <https://www.ncbi.nlm.nih.gov/pubmed>, accessed and searched on June 2, 2017

⁷ <https://projectreporter.nih.gov/reporter.cfm>, accessed and searched on June 2, 2017; "chronic fatigue syndrome" and "fibromyalgia" used as search terms in either the Project Title or Abstract for ME/CFS and

National Institutes of Health revealed for ME/CFS: 34 in 2007, 37 in 2012 and 48 current; for FM: 58 in 2007, 54 in 2012, and 53 currently; and for ES/MCS, 0 in all years.

8. Patients with lived experience, clinicians, and researchers have all experienced and/or observed the social stigmatization that affects patients with the conditions.^{8 9} This is arguably particularly acute for patients with ES/MCS, given the common need for such patients to isolate themselves from everyday exposures that trigger their symptoms, such as fragrances, cleaning products, marking pens, etc.^{10 11} The Taskforce also recognizes that stigmatization may increase the risk of anxiety, depression and other psychological symptoms that, in turn, can be mistaken as causes rather than effects of the diseases themselves.
9. The task force is also aware of anecdotal reports of scientists avoiding research on these conditions due to perceived stigmas associated with being a researcher in this area. The task force is also aware of the reluctance of many clinicians and researchers to handle patients and/or conduct research in this area because of the controversies and litigation that are often associated with these conditions in relation to disability, suspicions of malingering and/or secondary gain, requests for accommodations, etc. The issues of stigma, controversy, and litigation are particularly acute with respect to ES/MCS, which regularly involves questions regarding environmental or occupational causation.
10. The preponderance of literature related to ME/CFS and FM indicates wide support for the existence of these conditions as distinct disorders with a likely organic /physiologic basis that, for each, remains to be defined. This is reflected by the sheer numbers of papers describing the results of mechanistic research and clinical research into these two disorders; the number of U.S. federally funded grants supporting research into the disorders and the multiple and recent efforts to provide and update case definitions of the disorders, both for research and clinical care.

FM, respectively; “multiple chemical sensitivities”, “multiple chemical sensitivity syndrome”, or “idiopathic environmental intolerances” used as search terms in either the Project Title or Abstract for ES/MCS.

⁸ Whitehead LC. Quest, chaos and restitution: living with chronic fatigue syndrome/myalgic encephalomyelitis. *Soc Sci Med*. 2006 May;62(9):2236-45. Epub 2005 Oct 19. PubMed PMID: 16236413.

⁹ Armentor JL. Living With a Contested, Stigmatized Illness: Experiences of Managing Relationships Among Women With Fibromyalgia. *Qual Health Res*. 2015 Dec 14. pii: 1049732315620160. [Epub ahead of print] PubMed PMID: 26667880.

¹⁰ Koch L, Rumrill P, Hennessey M, Vierstra C, Roessler RT. An ecological approach to facilitate successful employment outcomes among people with multiple chemical sensitivity. *Work*. 2007;29(4):341-9. Review. PubMed PMID: 18057574.

¹¹ Lipson JG. Multiple chemical sensitivities: stigma and social experiences. *Med Anthropol Q*. 2004 Jun;18(2):200-13. PubMed PMID: 15272804.

11. Moreover, both ME/CFS and FM have been reviewed by recent high-level scientific bodies such as the U.S. Institute of Medicine, which, while acknowledging the many scientific uncertainties regarding ME/CFS, has essentially confirmed its existence as a disease that is serious, debilitating, and affects millions¹². Similarly, professional bodies such as the American College of Rheumatology and the American College of Physicians acknowledge the existence of FM and its impact on health and society¹³
¹⁴.
12. With respect to causation and underlying mechanisms and ME/CFS, there does not yet appear to be any consensus on likely causes and/or mechanisms underlying the condition. It has long been reported that ME/CFS is often preceded and likely triggered by an infection, though it is less clear that the ongoing chronic illness is perpetuated by an infection¹⁵. Twin and family studies support the contribution of both genetic and environmental factors, but no single mutation and polymorphism has been found that explains most cases of the illness, and a polygenetic explanation for increased susceptibility is most likely. A growing body of evidence indicates that immunologic and inflammatory pathologic conditions, neurotransmitter signaling disruption, microbiome perturbation, and metabolic or mitochondrial abnormalities are potentially important in the mechanisms underlying ME/CFS¹⁶.
13. Similarly, with respect to FM, there does not yet appear to be any consensus on likely causes and/or mechanisms underlying the condition. However, there appears to be agreement that the central nervous system is likely involved¹⁷. Various triggers have been cited, including physical trauma and infections. Twin studies have demonstrated inheritance may contribute to half of the risk of developing the condition, and some studies suggest the involvement of genetic polymorphisms

¹² Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Board on the Health of Select Populations, Institute of Medicine. *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness*. Washington (DC): National Academies Press (US); 2015 Feb 10. PubMed PMID: 25695122.

¹³ <https://www.rheumatology.org/I-Am-A/Patient-Caregiver/Diseases-Conditions/Fibromyalgia> , accessed June 2, 2017.

¹⁴ https://www.acponline.org/system/files/documents/patients_families/products/facts/fibromyalgia.pdf , accessed June 2, 2017

¹⁵ Unger ER, Lin JS, Brimmer DJ, Lapp CW, Komaroff AL, Nath A, Laird S, Iskander J. CDC Grand Rounds: Chronic Fatigue Syndrome - Advancing Research and Clinical Education. *MMWR Morb Mortal Wkly Rep*. 2016 Dec 30;65(5051):1434-1438. doi: 10.15585/mmwr.mm655051a4. PubMed PMID: 28033311.

¹⁶ Green CR, Cowan P, Elk R, O'Neil KM, Rasmussen AL. National Institutes of Health Pathways to Prevention Workshop: Advancing the Research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Ann Intern Med*. 2015 Jun 16;162(12):860-5. doi: 10.7326/M15-0338. PubMed PMID: 26075757.

¹⁷ Häuser W, Ablin J, Fitzcharles MA, Littlejohn G, Luciano JV, Usui C, Walitt B. Fibromyalgia. *Nat Rev Dis Primers*. 2015 Aug 13;1:15022. doi: 10.1038/nrdp.2015.22. Review. PubMed PMID: 27189527.

related to the metabolism of neurotransmitters that, in turn, are involved in pain modulation.

14. A body of research exists on supportive (i.e., non-curative, symptom-based) therapies for both ME/CFS and FM that is large enough, for example, to have served as the basis for Cochrane Reviews of randomized clinical trials conducted on exercise therapy for ME/CFS and randomized clinical trials conducted on oral non-steroidal anti-inflammatory medications for FM. However, no consensus exists on the effectiveness of such treatments; and they only address approaches that are supportive (versus curative, since the basic mechanisms underlying both of the conditions remain unknown).
15. By contrast, the literature related to ES/MCS is not only small to the extreme, but what exists is characterized by a relative paucity of scientific papers that describe rigorous research investigations as opposed to commentaries, opinion pieces, and reviews.
16. A number of the papers in the peer-review literature (including recent publications) have continued to espouse the view that ES/MCS is purely a psychogenic disorder that can only be managed through behavioural approaches.
17. With regards to North America, in its most recent statement (1999¹⁸), the “mainstream” professional body perhaps most closely associated with ES/MCS, the American College of Occupational and Environmental Medicine (ACOEM), opined that “...evidence does not exist to define MCS as a distinct entity. Because of uncertainties about the cause and pathophysiology of this condition, ACOEM believes that the term idiopathic environmental intolerance more accurately reflects the current state of knowledge.” Nevertheless, ACOEM also stated that *“Irrespective of the scientific uncertainties regarding the diagnosis, cause, and management of MCS, the impact of these symptoms on the well-being, productivity, and lifestyle of those affected can be dramatic. It is neither helpful nor appropriate to address the problem solely by hypotheses that emphasize malingering or a desire for compensation. Controversies about specific theories of MCS, diagnostic approaches, or treatment modalities should not preclude the compassionate care of patients presenting with complaints consistent with MCS... The College supports scientific research into the phenomenon of MCS to help explain and better describe its pathophysiologic features and define appropriate clinical interventions.”*

¹⁸ ACOEM position statement. Multiple chemical sensitivities: idiopathic environmental intolerance. College of Occupational and Environmental Medicine. J Occup Environ Med. 1999 Nov;41(11):940-2. PubMed PMID: 10570497.

18. Despite this statement by ACOEM supporting research on MCS as well as a fairly robust conference (2001) on the role of environmental factors in medically unexplained symptoms and related syndromes that occurred with support from multiple U.S. federal agencies and private industry¹⁹, no major research effort on ES/MCS has since emerged in the United States of which this task force is aware.
19. In Canada, after a surge of research on ES/MCS in Toronto funded by the province of Ontario (2000-2007) and the commencement of a research effort on ES/MCS in Halifax funded by the province of Nova Scotia (2000), no further progress has been made of which this task force is aware.
20. On the other hand, over the last two decades a pattern of research has emerged that provides support for the notion that there are fundamental neurobiologic, metabolic, and genetic susceptibility factors that underlie ES/MCS. Most recently (2012-present), such research has emerged from centres that have apparently developed focused research programs on ES/MCS in Italy, Denmark, and Japan (see Appendix 2 for examples).
21. Moreover, in terms of population impacts, the evidence is strong that all three conditions, including ES/MCS, are affecting hundreds of thousands of individuals in Ontario and elsewhere. This is underscored by a recent analysis conducted by the MOHLTC of self-reported data generated by the 2010 and 2014 Canadian Community Health Survey (CCHS). The analysis generated estimates showing that in 2014, the number of Ontarians age 12 or older (and associated prevalence rates based on the total population of Ontario age 12 and older) who have ME/CFS, FM, and/or ES/MCS were 155,400 (1.3%), 222,300 (1.9%), and 250,500 (2.1%), respectively (see table).

¹⁹ Kipen HM, Fiedler N. The role of environmental factors in medically unexplained symptoms and related syndromes: conference summary and recommendations. *Environ Health Perspect.* 2002 Aug;110 Suppl 4:591-5. PubMed PMID: 12194891; PubMed Central PMCID: PMC1241210.

Prevalence of Ontarians age 12 who have Fibromyalgia, Chronic Fatigue Syndrome, or Multiple Chemical Sensitivities (2010 and 2014)									
Condition	Sex	2010				2014			
		#	%	95% Confidence Interval		#	%	95% Confidence Interval	
				lower	upper			lower	upper
Fibromyalgia	Male	51,800*	0.9%*	0.4%*	1.5%*	42,600*	0.7%*	0.4%*	1.1%*
	Female	155,100	2.7%	2.2%	3.2%	179,700	3.0%	2.5%	3.5%
	All	206,900	1.8%	1.5%	2.2%	222,300	1.9%	1.6%	2.2%
Chronic fatigue syndrome	Male	59,600*	1.1%*	0.7%*	1.4%*	52,900	0.9%	0.7%	1.2%
	Female	126,500	2.2%	1.8%	2.7%	102,500	1.7%	1.3%	2.1%
	All	186,100	1.7%	1.4%	1.9%	155,400	1.3%	1.1%	1.5%
Multiple chemical sensitivities	Male	76,500	1.4%	1.0%	1.8%	54,100	0.9%	0.7%	1.2%
	Female	200,500	3.5%	3.0%	4.0%	196,400	3.3%	2.8%	3.8%
	All	277,000	2.5%	2.1%	2.8%	250,500	2.1%	1.9%	2.4%

**Estimate should be used with caution due to high sampling variability*

22. Furthermore, with respect to ES/MCS, estimates based on published surveys conducted in samples of the general population in the United States that elicited responses to questions such as “are you allergic or unusually sensitive to everyday chemicals?” suggest that 10-14% of adults experience some form of associated sensitivities^{20, 21}.
23. In Canada, the state of research funding for the three conditions is much smaller but otherwise similar to the pattern in the US, with some funding for ME/CFS and FM and very little (and, at present, nothing) for ES/MCS. In addition, in comparison to research on other chronic, non-communicable diseases (such as diabetes, osteoarthritis, etc.), what funding exists for ME/CFS and FM is small. For example, a summary of research expenditures (total and per patient) on chronic diseases by the Canadian institutes for Health Research in a recent 3 year period (2012-2015) demonstrates wide disparities in funding for all three conditions in relation to other chronic conditions, many of which affect far fewer Canadians (See Appendix 3²²). Again, as demonstrated above with respect to funding by NIH, this exercise shows that CIHR has not funded any research on ES/MCS.
24. Finally, the Research Working Group notes that research in both psychology and neuroscience is converging, with a general sense that the distinction between

²⁰ Kreutzer R, Neutra RR, Lashuay N. Prevalence of people reporting sensitivities to chemicals in a population-based survey. Am J Epidemiol. 1999 Jul 1;150(1):1-12. PubMed PMID: 10400546.

²¹ Caress SM, Steinemann AC. Prevalence of multiple chemical sensitivities: a population-based study in the southeastern United States. Am J Public Health. 2004 May;94(5):746-7. PubMed PMID: 15117694; PubMed Central PMCID: PMC1448331.

²² http://mefmaction.com/images/stories/quest_newsletters/Quest101.pdf , accessed June 8, 2017.

“organic” and “psychogenic” diseases is false. For example, research using advanced neuroimaging and other modalities to clarify the biological processes that relate to emotions and behaviours is accelerating. This insight, coupled with the reality that thousands of individuals with these conditions are clearly suffering, heightens the importance of making progress on defining these conditions and setting forth clinical practice guidelines and patient care strategies.

Conclusion

In summary, ME/CFS, FM, and ES/MCS are serious, debilitating, chronic diseases that are characterized by symptom complexes that have a significant degree of overlap, but are also sufficiently distinct to identify each as separate conditions for which environmental triggers (infection, physical trauma, and chemical exposures) typically play a significant role.

Current scientific evidence has not yet identified the likely mechanisms underlying any of the conditions. However, for ME/CFS and FM, there is a growing body of evidence (stemming from a modest infrastructure of research supported by federal funding agencies in North America and other institutions) that demonstrates there is a likely organic/physiologic basis for these 2 conditions, with recent research suggesting that (a) immunologic and inflammatory pathologic conditions, neurotransmitter signaling disruption, microbiome perturbation, and metabolic or mitochondrial abnormalities play a role in ME/CFS; and (b) pain modulation and neurotransmitter metabolic abnormalities play a role in FM. Both of these conditions (ME/CFS and FM) have also received endorsements as serious, debilitating diseases affecting millions that warrant intensive research efforts by mainstream high-level scientific and/or professional bodies. Both of these conditions have also been the subject of a number of randomized clinical trials. However, in the absence of an understanding of their basic mechanisms, such trials have focused on supportive (rather than curative) approaches, and even for such approaches, no clear evidence supporting any particular approach has emerged. By contrast, with respect to ES/MCS, except for some research conducted in Ontario and Nova Scotia in the early 2000's, there has been very little rigorous peer-reviewed research and almost a complete lack of any funding for such research in North America. Most recently, some peer-reviewed clinical research has emerged from centres in Italy, Denmark and Japan suggesting that there are fundamental neurobiologic, metabolic, and genetic susceptibility factors that underlie ES/MCS.

Overall, with respect to all three conditions (ME/CFS, FM, and ES/MCS), the lived experience of patients, the physicians who treat them, and, to some extent, scientists who have worked in this area indicate an extraordinary degree of patient suffering,

exacerbated by stigma, lack of understanding (and, in many cases, compassion) amongst clinicians, and lack of research (and funding for research).

In considering the marked imbalance in evidence and investments in research noted above, a national effort to increase/initiate research directed at all three conditions is a priority. A provincial research effort in Ontario that is particularly translation-oriented is also strongly encouraged.

Appendices

Appendix 1 – Contributors

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Howard Hu (co-chair)	Dean, Dalla Lana School of Public Health, University of Toronto, MD (Albert Einstein); MPH., ScD (Harvard), Professor of Environmental Health, Epidemiology, Global Health and Medicine
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Neil Stuart	PhD Health Policy (Brandeis University), adjunct appointment Institute of Health Policy Management and Evaluation, health care advocate

Appendix 2 – Examples of Reports of Original Research on ES/MCS (2013-2017)

Neuroimaging

- Alessandrini M, Micarelli A, Chiaravalloti A, Bruno E, Danieli R, Pierantozzi M, Genovesi G, Öberg J, Pagani M, Schillaci O. Involvement of Subcortical Brain Structures During Olfactory Stimulation in Multiple Chemical Sensitivity. *Brain Topogr.* 2016 Mar;29(2):243-52. doi: 10.1007/s10548-015-0453-3. Epub 2015 Oct 5. PubMed PMID: 26438099.
- Azuma K, Uchiyama I, Tanigawa M, Bamba I, Azuma M, Takano H, Yoshikawa T, Sakabe K. Assessment of cerebral blood flow in patients with multiple chemical sensitivity using near-infrared spectroscopy--recovery after olfactory stimulation: a case-control study. *Environ Health Prev Med.* 2015 May;20(3):185-94. doi: 10.1007/s12199-015-0448-4. Epub 2015 Feb 15. PubMed PMID: 25682122; PubMed Central PMCID: PMC4434236.
- Azuma K, Uchiyama I, Takano H, Tanigawa M, Azuma M, Bamba I, Yoshikawa T. Changes in cerebral blood flow during olfactory stimulation in patients with multiple chemical sensitivity: a multi-channel near-infrared spectroscopic study. *PLoS One.* 2013 Nov 21;8(11):e80567. doi: 10.1371/journal.pone.0080567. eCollection 2013. PubMed PMID: 24278291; PubMed Central PMCID: PMC3836968.
- Chiaravalloti A, Pagani M, Micarelli A, Di Pietro B, Genovesi G, Alessandrini M, Schillaci O. Cortical activity during olfactory stimulation in multiple chemical sensitivity: a (18)F-FDG PET/CT study. *Eur J Nucl Med Mol Imaging.* 2015 Apr;42(5):733-40. doi: 10.1007/s00259-014-2969-2. Epub 2015 Feb 18. PubMed PMID: 25690545.
- Hillert L, Jovanovic H, Åhs F, Savic I. Women with multiple chemical sensitivity have increased harm avoidance and reduced 5-HT(1A) receptor binding potential in the anterior cingulate and amygdala. *PLoS One.* 2013;8(1):e54781. doi: 10.1371/journal.pone.0054781. Epub 2013 Jan 22. PubMed PMID: 23349968; PubMed Central PMCID: PMC3551905.

Autonomic responses, biomarkers

- Andersson L, Claeson AS, Dantoft TM, Skovbjerg S, Lind N, Nordin S. Chemosensory perception, symptoms and autonomic responses during chemical exposure in multiple chemical sensitivity. *Int Arch Occup Environ Health.* 2016 Jan;89(1):79-88. doi: 10.1007/s00420-015-1053-y. Epub 2015 Apr 28. PubMed PMID: 25917753.
- Dantoft TM, Skovbjerg S, Andersson L, Claeson AS, Lind N, Nordin S, Brix S. Inflammatory Mediator Profiling of n-butanol Exposed Upper Airways in Individuals with Multiple Chemical Sensitivity. *PLoS One.* 2015 Nov 23;10(11):e0143534. doi:10.1371/journal.pone.0143534. eCollection 2015. PubMed PMID: 26599866; PubMed Central PMCID: PMC4657963.
- Dantoft TM, Elberling J, Brix S, Szecsi PB, Vesterhauge S, Skovbjerg S. An elevated pro-inflammatory cytokine profile in multiple chemical sensitivity. *Psychoneuroendocrinology.* 2014 Feb;40:140-50. doi: 10.1016/j.psyneuen.2013.11.012. Epub 2013 Nov 24. PubMed PMID: 24485486.

- Katoh T, Fujiwara Y, Nakashita C, Lu X, Hisada A, Miyazaki W, Azuma K, Tanigawa M, Uchiyama I, Kunugita N. [Application of Metabolomics to Multiple Chemical Sensitivity Research]. *Nihon Eiseigaku Zasshi*. 2016;71(1):94-9. doi: 10.1265/jjh.71.94. Japanese. PubMed PMID: 26832623.
- Mizukoshi A, Kumagai K, Yamamoto N, Noguchi M, Yoshiuchi K, Kumano H, Sakabe K, Yanagisawa Y. In-situ Real-Time Monitoring of Volatile Organic Compound Exposure and Heart Rate Variability for Patients with Multiple Chemical Sensitivity. *Int J Environ Res Public Health*. 2015 Oct 5;12(10):12446-65. doi: 10.3390/ijerph121012446. PubMed PMID: 26445055; PubMed Central PMCID: PMC4626978.

Genetic susceptibility

- Cui X, Lu X, Hiura M, Oda M, Miyazaki W, Katoh T. Evaluation of genetic polymorphisms in patients with multiple chemical sensitivity. *PLoS One*. 2013 Aug 13;8(8):e73708. doi: 10.1371/journal.pone.0073708. eCollection 2013. PubMed PMID: 23967348; PubMed Central PMCID: PMC3742528.

Therapy

- Alessandrini M, Micarelli A, Bruno E, Ottaviani F, Conetta M, Cormano A, Genovesi G. Intranasal administration of hyaluronan as a further resource in olfactory performance in multiple chemical sensitivity syndrome. *Int J Immunopathol Pharmacol*. 2013 Oct-Dec;26(4):1019-25. PubMed PMID: 24355241.

Appendix 3 – CIHR Funding Research into Chronic Conditions 2012-2015

Keyword	Average Annual per patient funding 2012-2015	Canadians affected CCHS 2010	CIHR funding (3 years) 2012-2015	Number of studies funded 2012-2015
Parkinson	\$428.16	39,000	\$50,094,279	234
Alzheimer	\$287.05	111,500	\$96,016,737	433
Muscular dystrophy	\$178.34	26,000	\$13,910,775	83
Epilepsy	\$76.33	134,500	\$30,800,227	133
Multiple Sclerosis	\$66.46	108,500	\$21,631,220	106
Cerebral palsy	\$60.38	36,000	\$6,521,061	30
Diabetes	\$37.11	1,841,500	\$205,010,686	1,024
Crohn	\$36.23	102,500	\$11,141,448	70
Tourette	\$34.74	18,000	\$1,875,895	7
Dystonia	\$26.10	15,500	\$1,213,861	14
Heart Disease	\$24.21	1,431,500	\$103,971,956	475
Spina Bifida	\$10.10	35,000	\$1,060,941	8
Bronchitis, Emphysema, COPD	\$8.39	805,000	\$20,272,121	75
Asthma	\$6.59	2,246,500	\$44,425,625	212
Arthritis	\$4.63	4,454,000	\$61,807,451	352
Fibromyalgia	\$0.89	439,000	\$1,166,409	11
Chronic Fatigue Syndrome	\$0.52	411,500	\$645,925	2
Multiple Chemical Sensitivities	\$0.00	800,500	\$0	0

Using keyword searches; Updated to Oct 23, 2014; Funding provided by CIHR – April 2012-March 2015