Laying the Groundwork:

Building Sustainable, Robust and Integrated Health Care Services For Ontarians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Environmental Sensitivities/Multiple Chemical Sensitivities (ES/MCS)

July 16, 2021

This document is an assessment and action plan created pursuant to the request of the Honourable Christine Elliott, Deputy Premier and Minister of Health, based on the recommendations of the December 2018 Final Report of the Task Force on Environmental Health: “Care Now: An Action Plan to Improve Care for People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Environmental Sensitivities/Multiple Chemical Sensitivities (ES/MCS)”[1]

Public Health Ontario

Public Health Ontario (PHO) is an agency of the Government of Ontario dedicated to protecting and promoting the health of all Ontarians and reducing inequities in health. PHO provides scientific and technical advice and support to clients working in government, public health, health care, and related sectors.

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Executive Summary

In January 2020, the Honourable Christine Elliott, Deputy Premier and Minister of Health asked Public Health Ontario (PHO) to lead a review of the report of the Task Force on Environmental Health (TFEH) entitled *Care Now, an Action Plan to Improve Care for People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS)*. This Report, submitted in 2018, found there was: (a) little recognition of the seriousness and severity of these conditions; (b) a shortage of knowledgeable care providers; (c) a lack of clinical tools to support and guide care; (d) a shortage of services and supports for people living with these conditions; (e) a dearth of research and leadership to improve the management of these conditions as well as health outcomes for those affected; and (f) a failure to acknowledge the stigma associated with these conditions and its devastating impact on people's lives.[1]

The Minister requested that PHO assess the TFEH's recommendations and identify practical real solutions to directly benefit Ontarians, with a focus on (a) practical next steps where prompt action could be taken, and (b) actions that were both cost-effective to implement and aligned with the evolving health care system. The TFEH Final Report listed 10 recommendations for action [**Appendix B**].

The assessment was to include:

- A review of the recommendations to determine opportunities to quickly improve care, with an emphasis on primary care settings;
- Advice on the sequencing of potential investments and/or system changes to provide effective and efficient solutions that would directly benefit Ontarians, including:
    - A plan for early actions supported by options with work plans and cost estimates to be delivered within six months

PHO was further asked to monitor the progress of the early actions and report six months post-implementation with an updated plan that included additional actions and proposed options for long-term leadership of this work.

Methods

We considered evidence and sought advice from more than 70 individuals in more than 140 single and small-group sessions, using virtual means due to social distancing restrictions related to the COVID-19 global pandemic. The individuals involved included: people with lived experience; environmental health physicians; primary care physicians; healthcare system leaders; clinical/healthcare experts in interdisciplinary, primary and community care; academic/research thought leaders; and professional associations and regulatory bodies.

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Background

A 2016 Canadian Community Health Survey study found that more than 740,000 Ontarians were living with one or more of the following chronic complex conditions: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS).[1] That number will likely increase more rapidly than expected;[2] a subset of Coronavirus Disease 2019 (COVID-19) patients who exhibit prolonged illness, known as Long COVID (Post-Acute Sequelae of COVID-19 or PASC) patients, have been found to exhibit symptoms "highly suggestive" of ME/CFS.[3]

Symptoms of these conditions vary greatly in type and severity, they have been described as "profoundly life-altering",[1] drastically affecting people's health and quality of life, and in many cases rendering them housebound or bedbound. People with these conditions are more than twice as likely to be in the lowest income category, they often suffer from a lack of safe housing and they have challenges accessing education and employment -- half report not working in the past year. They are more likely to have poorer social and health outcomes .[1] Women are also disproportionately affected by these conditions[1] with further societal implications regarding parenting, family cohesiveness and poverty.

These Environmental Health Conditions (described in **Appendix A**) have a profound impact on individuals, their families, communities and the population at large. ME/CFS, FM and ES/MCS affect people of all backgrounds and ages. Although affecting approximately six per cent of Ontarians over the age of 12 -- comparable to heart disease in terms of prevalence[1] --the public has little awareness of these three conditions and little to no recognition of their impact on affected individuals, leading to stigmatization at workplaces and in society at large. Symptoms are often perceived to be mainly psychological even when the evidence indicates this is not the case.

Despite a growing receptivity, this stigma continues to permeate the medical community, which marginalizes these conditions. They are not well-recognized, in addition to being under-researched and poorly understood. Often they are misdiagnosed or diagnosed late and/or are poorly managed. Without a specific etiology, patients, who are predominantly women and potentially subject to gender bias, are often told that their symptoms are purely psychological. People living with chemical sensitivities also face the additional challenge of accessing health care in a safe, e.g., fragrance-free environment.

The aggregate economic impact of these conditions is significant. A 2013 report estimated that the limited participation in the labour market of people with these conditions reduces net wages across Ontario by CDN $4.7 billion annually.[2] It further suggested that fixing the current fragmented care model and addressing the systemic barriers to equity for those living with these conditions could reduce Ontario's health care budget by more than $157 million per year.[2]

In May 2016, the then Minister of Health and Long-Term Care established a Task Force on Environmental Health (TFEH) with a three-year term to provide recommendations.

The TFEH Final Report, submitted in 2018, listed 10 recommendations for action [**Appendix B**].

Mandate

In January 2020, the Honourable Christine Elliott, Deputy Premier and Minister of Health asked Public Health Ontario (PHO) to lead a review of the final report, with the key objective of assessing the TFEH’s recommendations and identifying practical real solutions to directly benefit Ontarians, with a focus on (a) practical next steps where prompt action could be taken, and (b) actions that are both cost-effective to implement and aligned with the evolving health care system.

The assessment was to include:

- A review of the recommendations to determine opportunities to quickly improve care, with an emphasis on primary care settings;
- Advice on the sequencing of potential investments and/or system changes to provide effective and efficient solutions that would directly benefit Ontarians, including:
    - A plan for early actions supported by options with work plans and cost estimates to be delivered within six months

PHO was asked to consult with a small group of key stakeholders that had primary care, policy and health system expertise, expertise in interdisciplinary primary and community care, academic/research expertise pertaining to ME/CFS, FM and ES/MCS, and lived experience with one or more of these health conditions. The group was to include patient advocates, health care professionals and academic researchers.

PHO was further asked to monitor the progress of the early actions and report six months post implementation with an updated plan that included additional actions and proposed options for long-term leadership of this work.

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Consultations with Stakeholders/Experts

PHO's initial six-month timeframe to submit a plan for early actions supported by options with work plans and cost estimates dictated that its response was developed largely by considering evidence and seeking advice from stakeholders and experts, including those with lived experience with one or more of ME/CFS, FM and ES/MCS.

From October 2020 to April 2021, we connected through more than 70 individual and more than 140 small group virtual interviews/consultations with individuals with lived experience, health service providers, environmental-health physicians, primary-care and community-care providers, academics, leaders with health system responsibilities and professional associations and regulatory bodies.

The COVID-19 pandemic posed challenges throughout -- many of the stakeholders and experts, including individuals from primary and community care, and other health care leaders, had additional responsibilities to provide patient care and participate in other response activities that were pandemic-related. Social distancing made engagement more challenging due to the inability to meet with stakeholders face-to-face. However, productive consultations were undertaken through multiple individual and small group virtual interviews/consultations.

In developing the Action Plan, two forms of engagement were undertaken:

1. Regarding advice when developing a particular recommendation or option, the sequencing of action items and other issues, PHO requested specific advice from stakeholders and experts in the form of individual and small group interviews and review of evidence-based/best practice documents and proposals.

2. Regarding advice when developing specific plans of action and the sequencing of initial and future deliverables, PHO received advice from health care or related experts and/or organizational leaders as well as people with lived experience. This included consultations with experts in both primary care and policy; health system expertise; clinical/healthcare expertise in interdisciplinary, primary and community care; academic/research expertise and professional associations and regulatory bodies.

Throughout the consultations, it became clear that although there is still a long way to go, the manner in which people view and think about these conditions is evolving to become more receptive. Leaders in the medical community were forthcoming in their offers to support this initiative.

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Appendix A - Environmental Health Conditions and Their Impact

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

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

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

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

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

Refer to Care Now Report [1]

Appendix B - Task Force on Environmental Health's (TFEH) Recommendations 2018

Rec #1 - Develop a one-to-three year awareness campaign that targets the general public, health care facilities and providers and primary care settings.

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

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

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

Rec #2 - Develop and disseminate clinical tools and information that support evidence-informed treatment and management.

Rec #3 - Establish a system to develop and support a cadre of primary health care and specialized providers skilled in managing ME/CFS, FM and ES/MCS.

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

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

Rec #4 - Create and support a network of enhanced primary care programs throughout Ontario.

R**ec #5** - Develop a shared care planning tool.

Rec #6 - Modernize the OHIP K037 fee code to include all three conditions and use it to help gather data on their prevalence.

Rec #7 - Support research to fill critical gaps in knowledge about the pathogenesis, prevention and treatment of ME/CFS, FM and ES/MCS.

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

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

Rec #8 - Create a centre of excellence in ME/CFS, FM and ES/MCS care, education and research in Ontario.

Rec #9 - Establish a transitional implementation committee to provide the leadership in the initial phases of putting this plan into action.

Rec #10 - Provide regular updates and progress reports on the implementation of the proposed action plan.

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