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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.

Findings

Following review of the TFEH recommendations, consideration of the feedback from stakeholders and experts, and an assessment of the current environment and recent literature, we found that (a) a solid and sustainable foundation is needed upon which to grow and advance care for people living with these debilitating conditions, and (b) there is a need for an overarching organizational structure and leadership model that the Ontario government and other partner organizations could identify as the "go-to" organization committed to advancing care for these conditions, with a clear purpose, mission and authority.

Further deliverables that can be implemented quickly will support a more robust system and create opportunities for future investment.

The action plan consists of four pillars: a solid foundation and leadership model; emphasis on primary care; evidenced-informed clinical guidelines and information; and research and evaluation.

1. Establish an Environmental Conditions Organization (ECO) and Leadership Model for Ontario

The foundational recommendation is to establish an Environmental Conditions Organization (ECO) and leadership model that is both cost-effective and aligned with the evolving health care system for the purposes of improving health outcomes for people with ME/CFS, FM and ES/MCS. The newly-created, overarching ECO, housed within an existing healthcare organization, will lay the groundwork upon which to scale upward from a start-up to a mature organization that will oversee programs for environmental health conditions across Ontario. Along with the remaining initial recommendations, it will be the core of a more robust system, creating opportunities for future investment.

2. Develop a Primary Care Plan

The second recommendation is for the newly-established ECO to develop a primary care plan for people living with one or more of ME/CFS, FM and ES/MCS, with practical and concise guidelines and tools for the management of these conditions. With input from primary care providers the plan can incorporate not only their perspective but also their preferred format and technology. The guidelines and tools can fit within the existing Family Physician (FP) care models, and FPs and nurse practitioners will benefit greatly from the opportunity to consult directly with environmental health experts and specialists in rheumatology, neurology, internal medicine, rehabilitation medicine and cardiology in person or virtually. Involvement from physiotherapists, occupational therapists, social workers and other health professionals with knowledge and experience in treating patients with these conditions is also necessary for quality care.

3. Development of Clinical Guidelines and Informational Resources

The third recommendation is for the newly-established ECO to create a structure and processes for the development and dissemination of clinical definitions, guidelines and easy-to-use practical tools for PCPs. This includes the evaluation of peer-reviewed research and existing national and international guidelines, and the involvement of clinical experts and patients. This will be achieved by including this responsibility in the deliverables of the proposed Provincial Professional Health Advisory Committee for Environmental Health Conditions (PPHAC-EHC). The Committee will provide advice to the leadership of

ECO on clinical definitions, guidelines and tools necessary to promote the highest standards of medical care for all three conditions (ME/CFS, FM and ES/MCS).

4. **Develop a Research and Evaluation Component**

The fourth recommendation is for the ECO to develop an initial Research Plan, working with the proposed Provincial Research and Evaluation Committee for Environmental Health Conditions (PREC-EHC). This will include an initial structure for the development of the research and evaluation component, establish partnerships and connections with researchers locally, nationally and internationally and promote research on a comprehensive scale.

Conclusion

The proposed initial action plan is a direct response to the Minister's request. Based on feedback from the consultation process, these early actions are practical, achievable, and will lay the groundwork to build a system of care for the more than 700,000 people who live with ME/CFS, FM and ES/MCS in Ontario. Housed within an existing healthcare organization the ECO is cost-effective to implement. Moreover the primary care plan and clinical guidelines development are aligned with the evolving health care system led by Ontario Health.

Sequencing future deliverables will be as important as the foundation in building sustainable, robust and integrated health care services for people living with ME/CFS, FM and ES/MCS. With a strong foundation in place, there is a recognized need to advance awareness, all levels of clinical care, education and training of health professionals and research along with continuous updating of clinical guidelines and information to provide patient-centred health care with excellence in quality, service and access. In partnership with people with lived experience, the implementation of the four recommendations will be the first steps towards implementing the comprehensive, patient-centred care they need and deserve.

Summary of Recommendations

#1- Environmental Conditions Organization (ECO) and Leadership Model for Ontario

TFEH Recommendation #8

Establish an overarching Environmental Conditions Organization (ECO) and leadership model that is both cost-effective and aligned with the evolving health care system for the purposes of improving health outcomes for people with ME/CFS, FM and ES/MCS.

1.1. The ECO will implement the remainder of the Initial Action Plan, assess and sequence the balance of the 2018 Care Now recommendations.

1.2. The ECO will be scalable from a start-up to a mature organization that will oversee programs for environmental health conditions across Ontario, creating opportunities for future growth (potentially scalable to a Centre of Excellence for ME/CFS, FM and ES/MCS care, education, research and policy development).

1.3. The Leadership of the ECO will establish three main advisory committees to include a community voice and to advise on Primary Care/Clinical Guidelines and Tools and Research and Evaluation Plans.

1.4. The ECO will monitor implementation of the Action Plan and address organizational risk and performance.

1.5. The ECO will develop a monitoring framework to measure the success of the implementation of the Initial Action Plan.

#2 – Develop a Primary Care Plan

TFEH Recommendations #1.3, #3, #3.1, #4

The ECO will develop a Primary Care Plan for Primary Care Providers (PCPs) providing care to people living with one or more of ME/CFS, FM and ES/MCS.

2.1 The ECO will create a structure and process for developing a Primary Care Plan to increase awareness of these conditions in the primary care setting.

2.2 The ECO will create a process for the dissemination and adoption of Clinical Guidelines and Tools for PCPs.

2.3 The ECO in its Primary Care Plan will include a strategy to support a cadre of PCPs skilled in managing ME/CFS, FM and ES/MCS and establish a community of practice to provide training and support a network of PCPs across the province.

#3 - Clinical Guidelines and Information

TFEH Recommendation #2

The ECO will develop a plan for Clinical Guidelines and Tools.

3.1 The ECO will create a structure and processes for bringing together key stakeholders with expertise pertaining to these conditions and those with lived experience to develop clinical tools (e.g., definitions, guidelines, and critical pathways) to support evidence-informed treatment and management of ME/CFS, FM and ES/MCS.

3.2 The ECO will organize medical education to facilitate adoption of the guidelines and tools in partnership with academic health sciences centres, patient partners, primary care experts, professional associations and regulatory bodies.

#4 - Research and Evaluation

TFEH Recommendation #7

The ECO will develop an initial Research Plan and act as a catalyst to encourage research pertaining to ME/CFS, FM and ES/MCS.

4.1 The ECO will conduct an environmental scan to assess the current research landscape.

4.2 The ECO will collaborate with research partners and capitalize on relationships with well-known research leaders.

4.3 The ECO will work with research funding organizations to create a spirit of enquiry, innovation, and evaluation.

4.4 The ECO will develop a process to Identify and closely monitor new research and promising practices to ensure information is readily available to care providers and to update clinical guidelines.

Financial Summary:

The annual ongoing and one-time funding for this proposal are as follows:

Table 1: The proposed budget estimates are for the initial set up of the new overarching Environmental Conditions Organization (ECO) and leadership model within a host organization.

	Q3/Q4 2021/22	Fiscal 2022/23
Annual Operating Cost	$640,000	$2,560,000
One-time Cost	$290,000	$160,000
Total Annual Funding	**$930,000**	**$2,720,000**

The funding includes the necessary resources to start up and operationalize the ECO as well as deliver on the Primary Care, the Clinical Guidelines and Information and the Research and Evaluation Plans.

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.

Considerations for Assessment of the TFEH Recommendations

With the ultimate goal of improving the lives of people living with these conditions, the assessment of the recommendations of the 2018 TFEH "Care Now" Final Report and the confirmation of its initial deliverables was based on the following considerations.

Figure 1: PHO Considerations

Foundational: A strong initial foundation is essential to build a system of care for people living with these conditions in Ontario that can expand and mature with future investment. This foundation needs to support a well-orchestrated, stepwise approach to help advance the treatment of ME/CFS), FM and ES/MCS.

Mindful of Current Environment: The number of deliverables attainable within the stipulated six-month period is affected by the evolving COVID-19 pandemic and the transformation of the health care system led by Ontario Health. Furthermore, many of the experts involved in this review, including individuals from primary and community care, and other health care practitioners, had additional responsibilities to provide patient care and participate in other response activities.

Focus on Primary Care: The mandate includes an emphasis on primary care systems. Primary care practitioners provide a system of front-line healthcare that is accessible, high-quality, comprehensive and continuous, improving the overall health of the population.

Builds Primary Care Knowledge: Any system of care requires physicians and other health care providers to have the clinical information, guidelines and tools required to effectively manage patients with these conditions.

Aligns with Ontario Health Teams (OHTs): Ontario's healthcare system is evolving. Ontario Health, a newly-created provincial agency, is advancing its mandate to connect and coordinate the provincial healthcare system. This includes implementing OHTs, a new model for organizing and delivering health care that better connects patients and providers in their communities to improve patient outcomes. Health Care Providers, including hospitals, doctors and home and community care providers, work as a coordinated team no matter where they provide care, impacting the care of people close to their homes.[4]

Prompt Action: PHO was asked to provide recommendations to quickly improve care. Swift initiatives will significantly impact the care of Ontarians with these conditions. Deliverables that can be implemented quickly will be the foundation upon which to build a more robust and sustainable system of care.

Initial Investment: A timely modest investment in environmental health will begin the process of building a more comprehensive environmental health program in Ontario.

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.

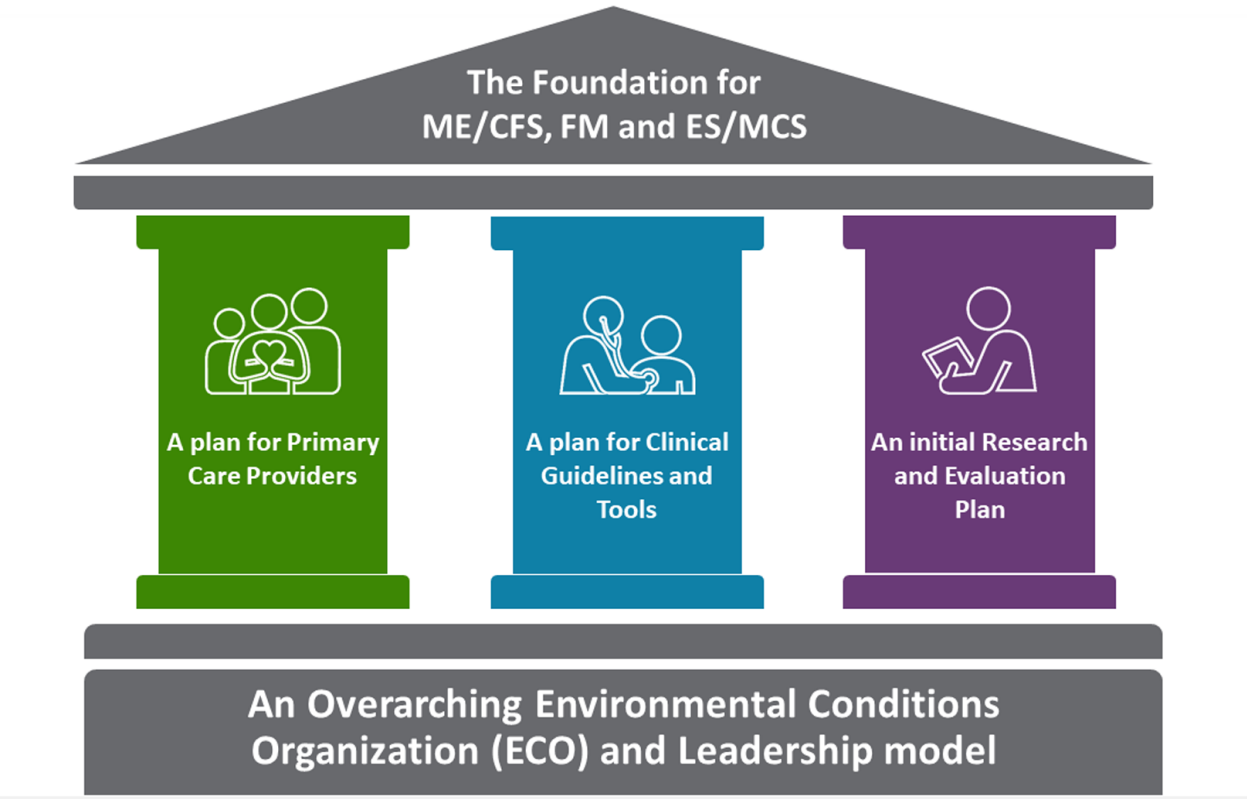
2. Regarding advice when developing specific plans of action and the sequencing of initial and future deliverables, PHO received advice from health care or related experts and/or organizational leaders as well as people with lived experience. This included consultations with experts in both primary care 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.

The Initial Action Plan

This proposed initial action plan is a direct response to the Minister's request. It is also based on feedback from the consultation process indicating that a solid foundation is needed upon which to build a robust, sustainable and integrated healthcare system for Ontarians living with ME/CFS, FM and ES/MCS. By working in partnership with people living with these conditions to lay the groundwork to build a system of care that will last, they will begin to receive the medical treatment they need and deserve.

Figure 2: Building the Foundation



I. Establish an Environmental Conditions Organization (ECO) and Leadership Model for Ontario

The foundational recommendation is to establish an Environmental Conditions Organization (ECO) and leadership model that is both cost-effective and aligned with the evolving health care system for the purposes of improving health outcomes for people with ME/CFS, FM and ES/MCS. A newly-created, overarching ECO will lay the groundwork upon which to scale upward from a start-up to a mature organization that will oversee programs for environmental health conditions across Ontario. Along with the remaining initial recommendations, it will be the core of a more robust system, creating opportunities for future investment. Throughout the consultations, the consensus from stakeholders and experts was that: (a) a solid and sustainable foundation is needed upon which to grow and advance care for people living with ME/CFS, FM and ES/MCS; and (b) there is a need for an overarching organizational structure and leadership model that the Ontario government and other partner organizations could identify as the "go-to" organization committed to advancing care for these conditions, with a clear purpose, mission and authority.

Currently, there is no one organization identifiable as the authoritative source for building capacity, increasing knowledge and awareness, and strengthening and developing programs specifically pertaining to ME/CFS, FM and ES/MCS. There is no single organization in Ontario with a clear purpose or mission that speaks with a unified voice and is identifiable when the need arises to engage or consult with a trusted partner regarding care or services for people with these conditions. For example, it may have been helpful to the government, physicians and other health services providers to engage an organization to advise in developing strategies aimed at addressing the needs of Long COVID patients.

This structure should ideally be hosted by an academic health sciences centre to support research and clinical excellence, and be committed to a coordinated and collaborative approach amongst all parties. Its goals include becoming a credible partner to work with other health care providers and educational institutions, ensuring integrated care and knowledge transfer. It also includes a community advisory committee structure inclusive of people with lived experience and experts in the field intended to speak with a unified voice to advance care and services.

Consultations established that there is an opportunity to coordinate existing resources within the Ontario system. There exists a dedicated group of advocates, physician experts and researchers that are passionate and driven to make a difference for people living with these conditions. A move to a more coordinated and collaborative approach amongst all parties is necessary to create momentum for change, and the expectation is that the new structure will be the foundation to achieve it.

The ECO will be scalable to a recognized, strategic and operational organization that oversees models of care, education and research as well as knowledge translation and dissemination, ensuring its viability well into the future. This ECO would initially be hosted by an existing academic health care organization

with the potential to be transitioned in the future to a more permanent entity consistent with the evolving healthcare system. This initial overarching organization and leadership model will be considered the foundation on which to build the future of environmental health care with the potential to evolve into a recognized Centre of Excellence for Environmental Health Conditions (ME/CFS, FM and ES/MCS).

The ultimate and final structure is intended to become the "go to" place for all things related to these environmental health conditions in Ontario, become known as the "trusted partner" for knowledge and the architect of an effective, coordinated and integrated system of care for these conditions in Ontario. Such trusted organizations, rooted in integrated health care and providing strong stewardship, are also viewed as more secure and are therefore more able to attract funding, from government and other sources such as foundations.

The first and foremost focus of the new structure and leadership team will be to deliver the remainder initial deliverables and to then assess and address the remaining deliverables of the 2018 TFEH "Care Now" report. **[Appendix B]**.

Current issues, such as Long COVID, or the challenges the pandemic creates for people with chemical sensitivities seeking to access care, will need to be addressed. This will be the responsibility of the leadership of the ECO.

Feedback from Consultations re: Establishment of ECO and Leadership Model

- **Committed to its purpose –** It is important that the ECO embrace and be committed to the need to improve care for ME/CFS, FM and ES/MCS.

- **Connected to an Academic Centre** – Ideally, the ECO should be aligned with a creative, recognized academic centre for research and education. The treatments for these complex, chronic conditions are continuously evolving. Guidelines and treatment options perceived as emanating from a trusted source are preferable, and patients require access to a scientifically advanced, recognized interprofessional treatment centre.

- **Supported by a Community Advisory Committee connected to community voices** – It will be important for the ECO to implement a Provincial Community Advisory Committee made up of advocates, people with lived experience and those who care for people living with these conditions, including: primary care and community providers, speciality physicians, researchers, health system experts; clinical/healthcare experts in interdisciplinary care; and academic/ research experts. The committee's success is contingent on it being:

    - **A unified voice** -- Working with advocacy groups, patients, physician experts and researchers to speak with a unified voice; speaking with one voice to advance patient-centred care and services for people with these conditions.

    - **Recognized as a "trusted source" of knowledge by physicians and other health care professionals** -- Building a research and promising practice plan, acting as a research knowledge transfer centre, and supporting and participating in the creation of research partnerships and networks.

    - **Trusted by the people it represents** -- Facilitating processes that strive to make safe, current treatments available to patients and influencing public policy.

- **Committed to effective partnerships** – A commitment to effective partnerships with other health care providers across the continuum will ensure integrated care for people with these conditions, consistent with Ontario's evolving health care system, including Ontario Health Teams.

- **Effective collaborator with colleges and universities** – Collaboration with educational institutions is necessary to educate health sciences students in the management of environmental health conditions and support Continuing Medical Education.

- **Committed to increasing awareness and reducing stigma** – An important initiative for the ECO will be to create awareness campaigns for the general public, health care organizations and health care providers to decrease stigma.

- **Focus on performance, quality and improved health outcomes** – The ECO will best achieve its goals by focusing on performance, quality and improved health outcomes, evaluating the performance of the overall organization and assessing the effectiveness of evidence-based treatments and guidelines and their impact on patient care and health outcomes.

- **A project management approach** – Adopting a project management approach is essential to manage the plan, initiate the work, execute, monitor, and complete the steps required to successfully implement the Initial Action Plan.

- **Expand any additional clinical services to include Long COVID patients** – To meet the challenges of the current environment, the ECO should consider expanding clinical services to include Long COVID patients. These patients exhibit prolonged illness, some including symptoms "highly suggestive" of ME/CFS. COVID-19 is a multisystem disease and the Long COVID patients face similar challenges to those faced by people living with environmental health conditions (ME/CFS).[5]

Options for Structuring the Environmental Conditions Organization (ECO) and Leadership Model

The initial structure for the ECO will be mainly administrative, yet scalable so as to oversee and support clinical services in the future. Thus, it is important to create a structure and leadership model that enables and facilitates integration into the overall healthcare system plan.

The ECO will initially be established within a host organization, selected through an objective, fair, and equitable process. Ultimately it may evolve to a health care delivery organization that, like all health service providers in Ontario, will be overseen by Ontario Health.

Several leading organizations were consulted to help define the criteria for determining the most appropriate structure and leadership models. The following comparison chart shows three options to be considered in choosing a preferred interim structure and leadership model: (1) a department within a parent health service provider organization, e.g., an academic health sciences centre or hospital; (2) an independent structure with its own funding but located within a host health service provider; or (3) an independent single-mission organization located in a stand-alone facility.

Table 2: Comparison Chart of Options for the New Structure for Environmental Health Conditions

	Option 1 - A department within a parent health service provider organization, e.g., an academic health sciences centre or a hospital	**Option 2 - An independent structure with its own funding but located within a host health service provider e.g., an academic health sciences centre or a hospital**	**Option 3 – An independent single-mission organization located in a stand-alone facility**
Organization committed to its purpose/ Leadership	Organization may not be as committed to the overall purpose of the new department/ the parties may not find mutual benefit to their relationship	Leadership selected specifically to advance its mission, vision and values with a strong commitment to its purpose, supported by the host organization	Leadership selected specifically to advance its mission, vision and values with a strong commitment to its purpose
Prestige as an academic leader	Potential to be a program within an academic parent organization	Potential to be affiliated with/ located within an academic host organization	Academic affiliation through an affiliation agreement or with a university maybe a challenge
Identifiable as a trusted source	Challenge to be uniquely identifiable/branded as a trusted source as it is a part of a parent organization	Uniquely identifiable/ branded once it becomes a trusted source as an independent entity within the host organization	Uniquely identifiable/branded once it becomes a trusted source as a stand-alone facility
Access to government funding	The parent organization is set up to receive government funds	Set up to receive government funding flow through the organization directed to the ECO	Structured to receive government funding directly

	Option 1 - A department within a parent health service provider organization, e.g., an academic health sciences centre or a hospital	Option 2 - An independent structure with its own funding but located within a host health service provider e.g., an academic health sciences centre or a hospital	Option 3 – An independent single-mission organization located in a stand-alone facility
Cost effective - shared back office services	Cost effective – receives back office support (IT, HR, Finance, equipment and supplies etc.) from parent organization	Cost effective – shared back office services or purchased from the host organization	High cost option from both an operating and a maintenance perspective
Financial stability	Services may be at risk when competing for funding with other programs in the parent organization	Financial stability as full control of operating budget and arrangement for purchase of or in-kind support for back office and other services	Financial stability as full control of budget. More funding at risk during budget reductions
Capital outlay	Minimal capital outlay as infrastructure is likely in place in the parent organization. May need some renovations	Minimal capital outlay will be required to create space within the host organization	Capital costs are high for building or leasing a stand-alone facility
Quick to implement	Relatively quick to implement for either administrative or clinical care depending on space available within the parent organization	Quick to implement as could rent on or off-site space on an interim basis from a host organization	Although leasing is an option and would be somewhat quicker to implement, capital builds take considerable time to raise funds, get approval and be ready for occupancy
Scalable for future growth into a Centre of Excellence	Less flexibility for future expansion/ scalability. Introducing new services may be a challenge when competing for funding and space with other	Scalability or expansion could be achieved by purchasing services from other organizations without having to duplicate supports required to provide clinical services	A stand-alone facility is purpose-built but will take time to be ready for full functionality

	Option 1 - A department within a parent health service provider organization, e.g., an academic health sciences centre or a hospital	Option 2 - An independent structure with its own funding but located within a host health service provider e.g., an academic health sciences centre or a hospital	Option 3 – An independent single-mission organization located in a stand-alone facility
	programs within the parent organization		
Challenge to get approval for use of new promising practices	May be a challenge to get practices or complementary treatments approved within the parent organization	Approval and use of promising practices and complementary medicine will be easier with an independent organization	Approval and use of promising practices and complementary medicine will be easier with a stand-alone organization
Access to a safe environment	Creating a safe environment may be a challenge within an existing parent organization	Creating a safe environment may be a challenge depending on where the new structure is located within an existing host organization	Having a stand-alone option will make it easier to create an environmentally friendly facility
Ease of adding clinical services	Adding clinical services could be a challenge when competing for funding and space with other programs within an existing parent organization	Clinical services may be secured from host or another health care organization	Facility would be purpose built for clinical services.
Ease of transfer of the initial structure to a permanent home	New structure is easily defined within the parent organization and could be transferred to another organization if appropriate	New structure is easily defined within the host organization and could be readily transferred to another organization if appropriate	Not applicable as this option includes building or acquiring a building in which to situate the administrative and clinical services – purpose built
Integration with the current and evolving health care system	Clinical Services will be integrated into the health care system as a department in an established parent organization	Clinical services will be well integrated into the health care system	May be seen as isolated from the continuum of care as a stand-alone, one mission organization

	Option 1 - A department within a parent health service provider organization, e.g., an academic health sciences centre or a hospital	Option 2 - An independent structure with its own funding but located within a host health service provider e.g., an academic health sciences centre or a hospital	Option 3 – An independent single-mission organization located in a stand-alone facility
Capital/Operating Cost	Less capital/operating cost than Option 2	Less capital/operating cost than Option 3	Highest cost option from a capital and operating cost perspective
Success factors	Important for parent organization to be committed to the overall purpose of the department and for the new structure and parent organization to find the relationship mutually beneficial	Purchase agreements - Funding goes to the new structure and it purchases back office and other services from the host organization through a purchase service agreement or in-kind support	Interim solutions will be required as it will take significant time to implement. Significant funding needed to make this a viable option

Recommended Structure for Environmental Conditions Organization and Leadership Model

Based on the comparison chart above, **Option 2** for the ECO is recommended -- an independent organization with dedicated funding, located within or adjacent to a host organization such as an academic health sciences centre. Initially the Leadership of the ECO would report to the senior leadership of the host organization.

The new structure and leadership model should be supported by a Provincial Community Advisory Committee for Environmental Health Conditions (PCAC-EHC).

This committee would be made up of advocates, people with lived experience and those who care for people living with these conditions, physicians specializing in environmental health, primary care and community providers. The committee would advise the new leadership and act as a resource to other committees as required.

The goal of the ECO is to become a unified hub for environmental health conditions for the province.

The new structure's leadership team will develop an effective vision, a strategic direction, implement the initial action plan and plan for the implementation of the remaining deliverables. The team will also need to evaluate and develop a plan for other outstanding issues identified through this process.

Proposed Organizational Chart for the ECO [Appendix C].

ECO Financials, Including Staffing, One-Time Costs and Ongoing Operational Costs [Appendix D].

Recommendations for Prompt Action for Environmental Conditions Organization (ECO) for Ontario

TFEH Recommendation #8

Establish an overarching Environmental Conditions Organization (ECO) and leadership model that is both cost-effective and aligned with the evolving health care system for the purposes of improving health outcomes for people with ME/CFS, FM and ES/MCS.

1.1 The ECO will implement the remainder of the Initial Action Plan and assess and sequence the balance of the 2018 Care Now recommendation.

1.2 The ECO will be scalable from a start-up to a mature organization that will oversee programs for environmental health conditions across Ontario, creating opportunities for future growth (potentially scalable to a Centre of Excellence for ME/CFS, FM and ES/MCS care, education, research and policy development).

1.3 The Leadership of the ECO will establish three main advisory committees to include a community voice and to advise on Primary Care/Clinical Guidelines and Tools and Research and Evaluation Plans.

1.4 The ECO will monitor implementation of the Action Plan and address organizational risk and performance.

1.5 The ECO will develop a monitoring framework to measure the success of the implementation of the Initial Action Plan

Cost–Effective - Option 2 (the ECO as an independent structure located within a host organization) is the preferred option from both a cost-effective and flexibility perspective. Although Option 1 (a department within a parent health service provider) has similar set-up costs, Option 2 with its own dedicated funding and purchase service agreements offers more flexibility, independence and scalability in an evolving model. Option 3 (a stand-alone facility) requires significant planning and a substantial capital outlay.

II. Develop a Primary Care Plan

In accordance with the Minister's request, an emphasis was placed on primary care in the Initial Action Plan.

The second recommendation is for the newly-established ECO to develop a primary care plan for people living with one or more of ME/CFS, FM and ES/MCS, with practical and concise guidelines and tools for the management of these conditions. With input from primary care providers the plan can incorporate not only their perspective but also their preferred format and technology. The guidelines and tools can fit within the existing Family Physician (FP) care models, and FPs and nurse practitioners will benefit greatly from the opportunity to consult directly with environmental health experts and specialists in rheumatology, neurology, internal medicine, rehabilitation medicine and cardiology in person or virtually. Involvement from other health professionals includes physiotherapists, occupational therapists, chiropractors, naturopaths, acupuncturists, massage therapists, psychological support professionals with knowledge and experience in treating patients with these conditions is also necessary for quality care.

Throughout the consultations, one of the key messages conveyed by people living with ME/CFS, FM and ES/MCS was that they need access to evidence-based, comprehensive, inter-professional primary health care close to where they live and work. As Primary Care Providers (PCPs) are generally patients' first contact with the health care system in local communities, the importance of implementing an effective primary care plan cannot be overstated. Patients rely on PCPs in their local communities; they are responsible for their overarching care, ensuring follow-up and facilitating transitions of care and/or referrals when required.

According to a 2018 Ipsos Public Affairs Qualitative Report, specialists and family physicians want to help these patients but lack the necessary knowledge.[1]

Community Health Centres (CHCs), Nurse Practitioner-Led Clinics (NPLCs), Aboriginal Health Access Centres (AHACs), Indigenous Interprofessional Primary Care Teams (IIPCTs) and Family Health Teams (FHTs) which are built on an interprofessional team model and are located across Ontario, are well suited to care for people with these conditions. These organizations can provide quality care for people living with these conditions close to home anywhere in Ontario using a team approach.

Nurse Practitioners (NPs) and NPLCs offer an alternate approach to treating patients with these complex chronic conditions in many communities. The approximately 4,000 NPs of which 3,200 are primary care NPs, who are most likely to work in FHTs, CHCs and NPLCs with various teams across Ontario, are important to treating patients with complex chronic environmental conditions.[6] Of note according to the to the Nurse Practitioner Association of Ontario, the NPLCs in Ontario serve over 100,000 patients, mostly in rural and underserviced areas in more than 20 communities across Ontario.

People living with these complex, chronic conditions need access to interprofessional teams as noted above. It is therefore important to design programs for the 70-75% of FPs who do not practice in funded

team-based models in order that they can care for these patients, especially those patients receiving care in remote areas.

Feedback from Consultations re: Development of a Primary Care Plan:

- **People with lived experience want to be treated with competence, compassion and dignity** -- They want these conditions to be de-stigmatized and to receive the same types of care and support services available to people with illnesses and disabilities of comparable severity.

- **Need to ensure diversity, inclusivity and equity** –For example, Indigenous Primary Care Teams such as Aboriginal Health Access Centres (AHACs) and Indigenous Interprofessional Primary Care Teams (IIPCTs) along with a range of providers such as First Nations Traditional Healers will be important partners.

- **The misconception of psychogenesis** -- Changing the mindset of health care providers through increasing awareness and providing clinical guidelines will go a long way to dismissing this misconception and improving the wellbeing of people living with these conditions.

- **There are many considerations to take into account when treating these patients, who suffer from multisystem disease** – For example, a growing number of ME/CFS patients (along with Long COVID patients) are experiencing adverse effects following exercise therapy, known as post-exertional malaise (PEM).[7]

- **People living with these conditions need access to safe, efficient and appropriate psychological supports** -- Patients with these conditions need help coping with their impact on daily life. Beyond the physical burden of becoming sick and disabled, these conditions bring with them immense emotional, social, financial and employment and career-related fallout.

- **Many patients experienced the safety of phone/virtual consultations during the COVID-19 pandemic** -- For many chemically-sensitive patients, in particular those living with ES/MCS, telephone/virtual consultations were the first time they felt safe accessing care.

- **Practical, simple and easy to use clinical tools and information to support diagnosis and treatment --** Currently, diagnosis typically consists of assessing patients' symptoms and ordering diagnostic tests to rule out other conditions. This leads PCPs to a reasonable "index of suspicion" that the patient has one or more of these conditions. Clinical tools and information should be readily available and easy to access while patients are in their offices.

- **Support tools need to fit into existing technology or medical record systems** -- For example, FPs and NPs would prefer a module that supports these conditions being included as part of the existing Electronic Medical Records (EMRs).

- **A cadre of PCPs across the province should be trained** -- To ensure access to care across the province, it is important to build a system of PCPs trained in caring for patients with these conditions. A recent example is the approach taken to ensure availability of transgender care

across the province. In this model, PCPs in CHCs and FHTs received education and training on transgender care enabling access to care in local communities across the province.

- **PCPs require access to interprofessional teams** -- FPs range from solo practitioners who work alone and are not part of a group practice to FP groups who work in group practices but don't have access to interprofessional teams within their offices. Some of the FPs also work in CHCs and FHTs with access to interprofessional teams.

- **Strategies or alternate approaches are needed to fit patients living with these conditions in with FPs' busy offices and typically-short appointment schedules** -- Due to the volume of patients seeking care through FPs' offices, short appointments do not offer sufficient time to assess and provide comprehensive care to patients living with these complex, chronic conditions.

- **PCPs need access to timely support from specialists** – FPs and NPs would benefit greatly from the opportunity to have greater access to specialists for referring these patients, including specialists in environmental health conditions and specialists in rheumatology, neurology, internal medicine, rehabilitation medicine and cardiology. This includes a potential referral to a centre of excellence in environmental health or other specialties and the use of virtual consults such as the eConsult program in Ontario. Expanding the eConsult program to include more environmental health specialty referrals would be an important step forward. In addition to improving patient care, FPs and NPs would feel less overwhelmed and/or reluctant to treat patients with these conditions.

- **Patients need access to an integrated system, including case management, system navigation and advocacy to achieve integrated care** -- It is a challenge to access PCPs and specialists who are educated and trained in the diagnosis and treatment of these conditions. Patients need help accessing those who are receptive, educated and trained.

- **Care for these conditions should be integrated into Ontario Health Teams (OHTs) as tools and guidelines are developed** -- There is a need to leverage the evolving infrastructure of the OHTs; and the Primary Care Collaborative (PCC) should be involved to help move this initiative forward. The PCC[a] has representatives from the Alliance for Healthier Communities, Indigenous Primary Health Care Council, NPLC Association, the Ontario Medical Association (OMA) Section on General and Family Practice, Association of Family Health Teams of Ontario (AFHTO) and Ontario College of Family Physicians (OCFP).

[a] A coalition of primary care organizations collectively representing 14,000 family doctors, 1,000+ primary care nurse practitioners, 286 primary care teams, 28 Indigenous primary care teams, including northern, rural, and remote teams. This alliance of comprehensive primary care organizations joined together by common purpose to build on the collaborative work during the COVID-19 pandemic as they move towards recovery in a time of health system transformation. The PCC provides a collective and cohesive voice with the purpose of advancing equitable person-centred primary care in Ontario and is focused on influencing policy by creating a unified voice towards resolving barriers or challenges that prevent comprehensive primary care from being the foundation of the health system.[8]

- **A Community of Practice should be organized to educate PCPs and increase awareness** -- Communities of Practice are an effective way to educate PCPs on the latest diagnosis and treatment modalities as well as to increase their general awareness of these conditions.

- **There is a need for more awareness with respect to these conditions, including ongoing Education and Training programs, e.g., Continuing Medical Education** -- Beyond giving FPs and NPs strong evidence-based guidelines and care pathways, greater awareness is needed, including ongoing education about the conditions and the most current diagnosis and treatment options.

- **Patients suffering from these conditions report a better experience and improve quality of life with Integrative Medicine**[b] -- Patients in general, and especially patients with ME/CFS, FM and ES/MCS, are turning to integrative medicine in increasing numbers as an alternative to conventional medicine in order to address complex medical problems involving multiple systems. Many patients believe integrative physicians are better informed to care for people living with these conditions. They report having more autonomy and control over their health care decisions, and access to alternate therapies that are more personal and effective.

    - Education and training programs should be developed considering assessments and treatments being conducted outside the health care system -- With the widespread use of integrative medicine practitioners, FPs find it challenging to coordinate care and keep track of and/or understand all the treatments and testing undertaken in other settings, including outside of Canada. The need to know what these tests mean from a care perspective and what treatments are required creates even more of a challenge for PCPs in Ontario.

- **Ongoing research and evaluation of therapies is required (see Section IV)** -- To be effective in the long run, there needs to be an ongoing set of work to advance clinical understanding of these conditions and to continuously improve diagnosis and treatment.

- **Long COVID patients should be included** -- Some COVID-19 patients who no longer test positive continue to have symptoms similar to ME/CFS. PCPs will likely play a key role in the recovery of these Long COVID patients, but lack the necessary information to assist and manage them. Awareness, along with information and tools, will be required to assist in the management of post-acute COVID-19. There may be opportunities to apply research and clinical tools developed for post-COVID-19 conditions to inform care for a subset of individuals with ME/CFS, and vice-versa.

[b] **Integrative Medicine defined by the JAMA** – The goal of "integrative medicine" is to provide creative and competent care that is based upon the individual's body, mind, and spirit. *Integrative Medicine* "is a very practical text that takes account of the best available scientific evidence as well as the accumulated experience of practitioners of many different systems of treatment."[9]

Provincial Professional Health Advisory Committee for Environmental Health Conditions (PPHAC-EHC)

The ECO should establish a Provincial Professional Health Advisory Committee for Environmental Health Conditions (PPHAC-EHC) to develop a Primary Care Plan.

This committee reporting to the ECO's leadership will:

- Advise on the Primary Care Plan for Ontario considering the entire health care system, with a focus on patients as well as PCPs.
- Produce best-practice documents that are evidence-informed to assist PCPs with improving quality of care, as well as patient safety. The committee will focus on and promote the highest standards of primary medical care for all three conditions: ME/CFS, FM and ES/MCS.
- Collaborate with the Primary Care partners including regulatory bodies.
- Include active participation of patient partners.

This committee will be comprised of representatives of the following stakeholder groups:

Scientific experts; clinical/health care experts in interprofessional, community and primary care who are academic, knowledgeable and experienced in providing care to patients with these conditions; patient partners; and members of OCFP, AFHTO, the Alliance for Healthier Communities, Ontario Medical Association (OMA) and the Nurse Practitioners' Association of Ontario (NPAO), to ensure information is relevant to their practices. An opportunity also exist to engage the Primary Care Collaborative (PCC).

Patient partners need to be selected based on their in-depth knowledge/expertise acquired while living with these conditions and there will need to adequate training in working with health care providers and researchers, to understand the healthcare system and to be clear on their role in the decision making processes.

Benefits:

- Develops internal expertise
- Begins to establish the ECO as the readily-identifiable "trusted source" for information about these conditions
- Draws together a network of primary care expertise that is already experienced in the implementation of such programs across the province such as the Primary care Collaborative.
- Establishes relationships with government, Ministries and educational bodies, including the University Departments of Family and Community Medicine.

As described in the next section, this committee will also be responsible for the development of Clinical Guidelines and Tools.

Recommendations for Prompt Action Related to the Primary Care Plan

TFEH Recommendations #1.3, #3, #3.1, #4

The ECO will develop a Primary Care Plan for Primary Care Providers (PCPs) providing care to people living with one or more of ME/CFS, FM and ES/MCS.

2.1 The ECO will create a structure and process for developing a Primary Care Plan to increase awareness of these conditions in the primary care setting.

2.2 The ECO will create a process for the dissemination and adoption of Clinical Guidelines and Tools for PCPs.

2.3 The ECO in its Primary Care Plan will include a strategy to support a cadre of PCPs skilled in managing ME/CFS, FM and ES/MCS and establish a community of practice to provide training and support a network of PCPs across the province. (please see below)

Table 3: Details of Prompt Actions Related to Recommendation 2.3

1. Create a cadre of Primary Care Providers (PCPs) initially.	2. Develop strategies to help Family Physicians (FPs) manage their patients with these conditions that fit with their practice model.	3. Facilitate access to environmental health experts trained to manage these conditions.
An initial cadre of PCPs skilled in managing ME/CFS, FM and ES/MCS established across the province with the longer term plan to provide training and education to all PCP through various approaches. The first cohort to be trained to provide specialized care to these patients and have access to Communities of Practice. 1. CHCs, NPLC and AHACs that have existing interprofessional teams are well-suited to initially take on the care of patients not	These patients have a constellation of multisystem disorders, a wide range of symptoms and functional challenges, which requires a paradigm shift in how they are assessed and treated. They are complex conditions with no simple solution and require a different approach by FPs. The potential exists for FPs to address identified patient symptoms on a sequential basis over several appointments, for example, the first appointment could include reviewing a	This can be achieved by opportunities to consult directly with environmental health experts and the expansion of the existing eConsult program in Ontario. Ontario eConsult is a secure web-based tool that allows physicians and nurse practitioners timely access to specialist advice for all patients and often eliminates the need for an in-person specialist visit – only about one third of eConsults result in patients

1. Create a cadre of Primary Care Providers (PCPs) initially.	2. Develop strategies to help Family Physicians (FPs) manage their patients with these conditions that fit with their practice model.	3. Facilitate access to environmental health experts trained to manage these conditions.
receiving care for these conditions. CHCs provide primary health care, social and community outreach services. They do so by meaningfully engaging clients and communities, ensuring equitable access to primary health care, and by delivering quality care through a range of evidence informed programs, services and approaches. 2. The next step is to engage well-established and interested FHTs. Part of the process will be to enroll patients in the FHTs which are built on a multi-disciplinary team concept. 3. The next step is to provide support to FPs who do not have access to interprofessional teams. Give FPs and those practising in group practices without interprofessional teams, access to other health professionals, for example, the Team Care* program. 4. Training and education to be offered to PCPs across the province.	patient completed questionnaire and validating the patient's condition. As these patients are already fatigued and require easy, practical steps to follow, depending on the patient's presenting symptoms and their severity, FPs could plan a multiple visit approach to help manage patients one major clinical issue at a time e.g., sleep, stress, diet, pain or any other concerns. Strategies to facilitate longer visits for all three conditions need to be considered to accommodate these patients.	needing to see a specialist face-to-face. OTNhub.ca provides FPs and NPs access to over 100 specialties, including Environment Health.[10] The current Environmental Health eConsult group can be accessed for questions related to testing/medications, conditions such as ME/CFS, FM and ES/MCS and patients with other complex chronic conditions.

*A platform called Team Care gives PCPs streamlined access to inter-professional teams for their clinically and socially complex patients and real-time access to specialists for secondary and tertiary care. Registration provides PCPs with a single, centralized point of access that is easy to use and ensures on-going coordination and collaboration. Patients with complex medical and psychosocial issues receive increased and seamless access in the community, and complex patients receive the most appropriate and supportive community-based services and resources. The program helps physicians collaboratively manage their complex patients through the services, resources and multi-disciplinary teams based at CHC's -- they receive increased access and utilization of those CHC

services -- and it helps build the CHC's community profile through new relationships with PCPs.[11] https://www.allianceon.org/TeamCare .

** Ontario eConsult is fully funded by the Ministry of Health and is available at no cost to the patient or the provider through www.OTNhub.ca . Where applicable, family physicians can bill OHIP using the K738 fee code. Specialists providing services on eConsult are paid an hourly rate, pro-rated based on the length of time it takes to complete an eConsult directly by the Ontario eConsult Centre of Excellence.

Cost-Effective – Creating structures and processes internal to the ECO; utilizing partnerships such as the Primary Care Collaborative; using existing platforms like eConsult Ontario; and integrating care into existing primary and community care delivery models, enables the creation of a Primary Care Delivery Plan for people living with these conditions in a cost-effective manner.

III. Development of Clinical Guidelines and Informational Resources

The third recommendation is for the newly-established ECO to create a structure and processes for the development and dissemination of clinical definitions, guidelines and easy-to-use practical tools for PCPs. This includes the evaluation of peer-reviewed research and existing national and international guidelines, and the involvement of clinical experts and patients. This will be achieved by including this responsibility in the deliverables of the proposed Provincial Professional Health Advisory Committee for Environmental Health Conditions (PPHAC-EHC). The Committee will provide advice to the leadership of ECO on clinical definitions, guidelines and tools necessary to promote the highest standards of medical care for all three conditions (ME/CFS, FM and ES/MCS).

According to a 2018 Ipsos report, many physicians in Ontario have patients with one or more of ME/CFS, FM and ES/MCS and want more information and tools to help them provide the necessary care.[1] PHO's consultations confirmed there is a need to provide PCPs in Ontario with more information and practical and easy-to-use clinical tools to assist at the point of care for people living with these conditions.

Clinical guidelines and tools are necessary to build a Primary Care Plan that is practical for use in primary care provider settings as well as designing levels of care, recommending evidence-informed tests and treatments and developing education and training programs, including Continuing Medical Education (CME) for physicians, nurse practitioners and other health professionals.

PCPs require the latest science in the form of evidence-based, best practice guidelines. This includes evidence-based practice (rigorous scientific research) and practice-based evidence (knowledge that comes from clinical experience), combined with the patients' perspective. The emergence of the Long COVID patients, the approximately 10% of COVID-19 patients who exhibit prolonged illness which may include symptoms "highly suggestive" of ME/CFS, has reinforced this pressing need, as this large new patient group is at risk for chronic ailments and may become incapacitated.[3] As more information becomes known about this condition, health care providers will need to be kept informed.

Peer-reviewed research is considered the most reliable science to inform standards and guidelines; however, there is a dearth of peer-reviewed research for these conditions.[1] Nevertheless, there are numerous sources of information for these conditions for which there is good clinical experience, including multiple guidelines and promising practices.[c]

The evaluation of existing peer-reviewed research, existing national and international guidelines and the assessment and monitoring of safe promising practices underpin the creation of up-to-date, robust clinical guidelines and tools. Research and promising practices need to be translated for health care providers in a format that is practical and easy to use, in a language understood by PCPs. This can be

[c] **A Promising Practice** is defined as an intervention, program, service, or strategy that shows potential (or "promise") for developing into a best practice. Promising practices are often in the earlier stages of implementation, and as such, do not show the high level of impact, adaptability, and quality of evidence as best practices. However, their potential is based on a strong theoretical underpinning to the intervention."[12,13]

best achieved by involving family physicians, including clinical experts in environmental health, nurse practitioners and other health professional as users of the tools and information, and those with lived experience who are well-versed in the care and treatment of these conditions. The Primary care Collaborative will include invaluable contributors and partners in both guidelines development and dissemination.

There is currently a move to develop definitions, clinical guidelines and tools for ME/CFS that are consistent Canada-wide. In the interim, many provinces have developed their own definitions, clinical guidelines and other relevant information. Ontario will do so as well, with the intent to participate in the national process as it unfolds. Hopefully, this national process can be replicated for FM and ES/MCS.

There is also an opportunity for an international exchange of knowledge to help develop Ontario's clinical guidelines; there are recognized experts concerning the treatment and diagnosis of these conditions around the globe. Opportunities to collaborate internationally include hosting international conferences and/or hosting or joining international professional groups, thereby establishing new connections and networks. These forums will facilitate information exchange with the aim of disseminating advanced research for the purposes of training and education and discussing and deliberating on ground-breaking technology and innovation among the professionals in the field.

Once clinical definitions, guidelines, tools and care pathways for Ontario are developed, this knowledge will need to be transferred to PCPs. Beyond simply improving care for people living with these conditions, the simple dissemination of practical information from an authoritative source will improve awareness of these conditions among PCPs and help dispel historical misconceptions about their origins.

Locally, communities of practices could be organized to disseminate this information to those providing care including PCPs.

The clinical guidelines and tools need to be continuously updated. Guidelines and tools will be created with the best available knowledge at the time, but current research-based knowledge is limited; they will need to change as these conditions become better understood. Some promising practices have been proven ineffective or harmful in the past, and therefore there is a need to be cautious when introducing new therapies. In light of the nature of the treatment, and where there is a lack of evidence and/or scientific reasoning to support its use, issues surrounding these therapies will need to be reconciled with regulatory authorities' standards of practice to ensure patient safety, quality of care and informed consent, while respecting patient needs, autonomy and choice.

Feedback from Consultations re: Developing Clinical Guidelines and Informational Resources:

- **Do not "reinvent the wheel"** -- There is already an abundance of information concerning these conditions, including clinical definitions, guidelines and tools developed locally, nationally and internationally by experts in the field. This information is readily available on multiple websites as well as from organizations focusing on environmental conditions.

- **Partner with people with lived experience** -- Patient partners will provide essential input and add credibility to the process.

- **Successful development and implementation requires buy-in from PCPs, particularly Family Physicians (FPs) and Nurse Practitioners (NPs)** -- Many of the more than 15,000 FPs and the 4,000 NPs in Ontario will see the majority of patients with these conditions;[14] therefore, they should be involved in the development of clear guidelines, tools and training modules. More work is required to improve both the patient and provider experiences, including a focus on maintaining a respectful clinical approach with patients. Involving FPs and NPs from the outset will help ensure the success of the rollout of the clinical definitions, guidelines and tools, and facilitate their adoption.

    - Streamlined clinical guidelines and tools in a language understood by PCPs -- Physicians have large patient volumes and a short amount of time to treat patients; they need practical, streamlined, patient-centric guidelines and tools, plus the ability to consult, including by accessing medical experts through virtual consultations. This combined with longer visits for ME/CFS and ES/MCS patients similar to FM would enhance care.

    - It is important that OCFP and NPAO be consulted to ensure the clinical guidelines and tools are developed with FP and NP perspectives.

- **A "trusted source" of information**-- An organization or group consisting of clinical experts known to PCPs and others who have the necessary skills of bridging research and knowledge to clinical practice should produce the guidelines and tools. This trusted source needs to be part of a knowledge transfer centre that provides up-to-date, accurate and unbiased information, connecting health care and community-based service providers with the latest science and promoting good practices for the diagnosis and treatment of these conditions. There are a variety of examples of "trusted sources" for other conditions, including: CATIE (Community AIDS Treatment Information Exchange) or Ontario Health: Health Quality Ontario and Cancer Care Ontario.

- **Evidence-based research is the starting point** -- Peer-reviewed, evidence-based research papers are considered the best information upon which to develop guidelines. Randomized controlled trials are the gold standard, and the ECO's goal should be to support more evidence-based research.[15]

- **Clinical expertise will play a pivotal role** -- Clinical experts who understand and have extensive experience with these conditions are a crucial source of information and should also play a major role in developing clinical guidelines and tools. Multiple national and international guidelines have been developed with a combination of evidence based research, clinical experience and the patient perspective.

- **Assess promising practices from a risk benefit perspective to ensure patient safety** – It is essential that patients get new, timely promising treatments, while being carefully monitored to help manage risks. A rigorous process is needed to evaluate promising practices, monitor them on an ongoing basis and/or conduct research trials.

Integrative Medicine has an important role to play in treating these conditions -- Patients insist many of these interventions are life-saving and improve outcomes. Often they are supported by preliminary evidence or scientific reasoning and pose little risk of harm. Therefore, consulting care providers with clinical expertise in treating these patients using integrative medicine is critical in creating clinical guidelines for these conditions. It will be important to monitor these interventions to prevent serious risk of harm and/or exploitation.

- **Technology should be used to the fullest** -- Technological assistance is critical to helping PCPs manage these conditions from their offices. For example, Electronic Medical Records (EMRs) may be the best way to disseminate information to PCPs.
- **Disseminating information requires a multi-pronged approach** -- A multi-pronged awareness program with recurrent, intermittent and updated information will increase awareness amongst PCPs, including: incorporating the clinical guidelines and tools in the EMR or a similar platform; disseminating the information at conferences or in undergraduate programs at colleges or universities; and expanding the Family Medicine Fellowship Program in Environmental Health within the Department of Family and Community Medicine, University of Toronto currently housed at Women's College Hospital. More research and involving thought leaders and experts will change minds and get buy-in.
- **Adoption of clinical guidelines by PCPs will be enhanced by***:*
    - Demonstrating Ministry of Health support.
    - Having them reviewed and endorsed by OCFP, OMA, AFHTO, and NPAO. Opportunities also exist to engage the PCC.
    - Making the guidelines accessible on the OCFP and other professional groups' websites.
    - Including these clinical guidelines as part of Medical School curriculum for undergraduates.
    - As a large number of physicians and other providers in Ontario are trained in other jurisdictions, varied approaches may be needed to disseminate the guideline and tools to ensure adoption.
    - Formalizing CME and educational approaches targeting practicing physicians using available programs such as the Foundation for Medical Practice Education at McMaster University, which offers a Practice Based Small Group (PBSG) Learning Program. This program brings family physicians together in small groups to discuss their individual practice gaps in a safe space. NP participate in this program as well.
    - Publicizing the tool/guideline through articles in Canadian-based medical journals such as the Canadian Medical Association Journal (CMAJ) and Canadian Family Physician (CFP), through Continuing Medical Education (CME) programs, seminars, etc.
    - Publishing information in the media in order to target a larger audience.

Options for a Committee charged with development of Clinical Guidelines and Informational Resources:

There are several models to draw from with regards to the infrastructure required to develop and disseminate clinical evidence-based guidelines, tools and informational resources. Programs for dissemination include the Program in Evidence-Based Care (PEBC) at McMaster University, Ontario Health's internationally-recognized guideline development program. Others include the approach used by CATIE (see above) and PHO's Provincial Infectious Diseases Advisory Committee on Infection Prevention and Control (PIDAC-IPC).

A highly-relevant approach to the delivery of best practices for these conditions is exemplified by PIDAC-IPC, which is an interprofessional committee of health care professionals with expertise and experience in Infection Prevention and Control. The committee advises PHO on the prevention and control of health care-associated infections, considering the entire health care system, with a focus on clients, patients and residents, as well as health care providers. This Committee produces best practice documents that are evidence-based, to the largest extent possible, to assist health care organizations in improving quality of care, as well as client, patient and resident safety.

The Provincial Professional Health Advisory Committee for Environmental Health Conditions (PPHAC-EHC) should be tasked to advise on development and dissemination of Clinical Guidelines and Informational Resources:

As described in the Primary Care Section above, in addition to the Primary Care Plan, the Provincial Professional Health Advisory Committee for Environmental Health Conditions (PPHAC-EHC) reporting to the leadership of the ECO will advise on the development of definitions, clinical guidelines and tools for Ontario. It will produce best-practice documents that are evidence-based, to the largest extent possible, to assist health care organizations in improving quality of care, as well as patient safety. The PPHAC-EHC will focus on and promote the highest standards of medical care for all three conditions (ME/CFS, FM and ES/MCS).

When developing clinical guidelines, tools and informational resources for these conditions, for which there is a preponderance of promising practices over rigorous evidence-based research, decisions involve assessing limited available research and also evaluating both promising practices and existing clinical guidelines developed by experts in the field. The assessment and evaluation itself also needs to involve those who treat environmental health conditions, PCPs, specialists, academics, researchers, professional associations/regulatory bodies -- and critically, patients living with these conditions and caregivers as partners, to ensure their experiences with accessing care and living with these conditions.

Figure 3: Development of Clinical Guidelines

Options for the Provincial Professional Health Advisory Committee for Environmental Health Conditions (PPHAC-EHC) with Respect to Development of Clinical Guidelines and Informational Resources

Option 1 - Internal: Become a component of the new ECO and leadership model.
In addition to developing a Primary Care Plan, this committee reporting to the leadership of the ECO will advise on the development of definitions, guidelines and tools. The PPHAC-EHC will focus on and promote the highest standards of medical care for all three conditions (ME/CFS, FM and ES/MCS). Patient partners will be active participants.

Benefits:

- Develops internal expertise.
- Begins to establish the ECO as the readily-identifiable "trusted source" for information about these conditions.
- Establishes relationships with experts in the development of clinical guidelines and tools, scientists, patient partners and providers who are knowledgeable and experienced in treating patients with these conditions.
- Establishes relationships with government, regulatory bodies (CPSO and OCFP) and educational entities, including the University Departments of Family and Community Medicine.

Option 2 – Outsource: Capitalize on the expertise of an existing organization that specializes in developing clinical definitions, guidelines and tools for primary care. There are several organizations involved with developing standards, guidelines and tools based on existing peer-reviewed literature and consensus-building processes, such as the Delphi. This may involve the purchase of services with defined expectations such participation of patient partners along with specific deliverables.

Benefits:

- Recognized as a trusted source of information
- Established expertise and a track record for delivery of the final product
- Faster turn-around time as an established organization with systems and processes in place

Challenges for both Option 1 and 2:

Outsourcing would not contribute to establishing the ECO as the readily-identifiable "trusted source" for information about these conditions

Recommendation re: the Creation of a Provincial Professional Health Advisory Committee for Environmental Health Conditions (PPHAC-EHC) for the development of Clinical Guidelines and Information: Option 1 is recommended, which is to have the **Provincial Professional Health Advisory Committee for Environmental Health Conditions (PPHAC-EHC)** develop clinical guidelines and information.

Recommendations for Prompt Action Related to the Development of Clinical Guidelines and Informational Resources:

TFEH Recommendation #2

The ECO will develop a plan for Clinical Guidelines and Tools.

3.1 ECO will create a structure and processes for bringing together key stakeholders with expertise pertaining to these conditions and those with lived experience to develop clinical tools (e.g., definitions, guidelines, and critical pathways) to support evidence-informed treatment and management of ME/CFS, FM and ES/MCS.

3.2 The ECO will organize medical education to facilitate adoption of the guidelines and tools in partnership with academic health sciences centres, patient partners, primary care experts, professional associations and regulatory bodies.

Cost-Effective – Creating structures and processes internal to the ECO, bringing together key stakeholders with expertise pertaining to these conditions; using existing education and training structures and building on existing guidelines and tools, enables the creation of Clinical Guidelines and Information in a cost-effective manner.

IV. Develop a Research and Evaluation Component

In accordance with PHO's mandate, a particular emphasis was placed on primary care in the Initial Action Plan.

The fourth recommendation is for the ECO to develop an initial Research Plan, working with the proposed Provincial Research and Evaluation Committee for Environmental Health Conditions (PREC-EHC). This will include an initial structure for the development of the research and evaluation component, establish partnerships and connections with researchers locally, nationally and internationally and promote research on a comprehensive scale.

Throughout the consultations, it became apparent that more research about ME/CFS, FM and ES/MCS is needed to improve their management and the health outcomes of affected Ontarians. These conditions are not well-recognized in the medical community; they are under-researched and poorly understood. Often they are misdiagnosed or diagnosed late and/or are poorly managed.

Research is needed to better identify the underlying causes of these conditions, to guide clinical practice, and to continuously improve diagnostic methods. Epidemiological and bench research are needed to explore the biological mechanisms behind these conditions. Currently, there is a dearth of peer-reviewed literature, and a short-term need to coordinate research;[1] without this crucial information, care for these patients cannot be optimized.

Just as importantly, further research is needed to dispel the widespread misperception that these conditions are psychological, and to address the prevalent culture among health care practitioners of treating patients' medically-unexplained physical symptoms as being psychosomatic. This stigmatization permeates Ontario's healthcare system and has led to an ever-increasing trust gap between providers and people living with these conditions. Patients report experiencing continuous trauma from repeated exposure to medical marginalization,[d] impeding their safe access to care and negatively impacting their overall quality of life.[17]

This unaddressed medical marginalization of these conditions has also impeded research and research funding, creating knowledge gaps and hindering access to safe and appropriate health care.

Included within this opportunity is a chance to address historical gender bias inherent in the healthcare system that is adversely affecting people living with these conditions. These conditions appear to predominate among women and it has been argued that the failure to demonstrate a specific etiology has led to a shift in research perspectives -- that "female illnesses" may evoke medical reactions which entail an over focus on psychological and psychosocial factors to the detriment of adequate attention to phenomena occurring at the biomedical level.[18]

[d] Health Canada defines underserved individuals as having "increased likelihood [to] experience difficulties in obtaining needed care, receive less care or a lower standard of care, experience different treatment by healthcare providers, receive treatment that does not adequately meet their needs, or be less satisfied with healthcare services than the general population".[16]

Of note is that for these complex conditions, traditional rigorous peer-reviewed research is not as prevalent as emerging, best and promising practices. Often the evidence is practice-based, anecdotal or extrapolated from clinical experience; clinicians rely on their critical thinking and clinical judgment to devise practice plans and monitor their effectiveness and safety for better outcomes for their patients. The challenge without a gold standard of randomized controlled study-based research is that not all emerging best practices have been definitively proven effective and may not be recognized by regulatory bodies. Therefore it is necessary to invest in rigorous and objective multi-year biomedical research to assess and determine the effectiveness of emerging, best and promising practices, create evidenced-informed standards of practice and bring innovation to clinical practice.

Feedback from Consultations re: Developing a Research and Evaluation Component

- **Research funding is a critical factor** -- Given the prevalence of these conditions and their high health care and social costs, research funding needs to be a priority, including rigorous research to evaluate promising practices where appropriate.
    - **Act as a catalyst and establish funding sources for more rigorous research pertaining to these conditions** -- If more research is to be undertaken related to these conditions, there is a need to focus resources aimed at leveraging health system research funds such as the Canadian Institute of Health Research (CIHR) and the U.S. National Institutes of Health (NIH), with the goal of elevating the importance of research related to these conditions.
    - **Researchers expressed that there may be opportunities to capitalize on new research related to Coronavirus Disease 2019 (COVID-19), including the Long COVID patients** -- For example, the Government of Canada, in its continued efforts to address challenges of the COVID-19 pandemic, has recently funded research through CIHR entitled, “Emerging COVID-19 Research Gaps and Priorities Funding” in the amount of $ 119M.[19]
    - **There is a need for sustainable research in Canada for these conditions** – While developing a sustainable research infrastructure is important, so is building the talent necessary to enhance research capacity, fill existing gaps in research, stimulate new discoveries and sustain excellence in research. Without a better understanding about causes/pathophysiology, diagnosis and treatment, the stigma around these conditions is perpetuated and care is not optimized.
- **There is a need for a framework to evaluate the efficacy and safety of current and emerging promising practices** – Ultimately rigorous and controlled studies of promising treatment modalities can be conducted to inform and expand the body of knowledge and further integrate the management of these conditions into evidence-based practice.
- **Partner with people with lived experience in the research process** -- Having patient partners work collaboratively with researchers adds credibility to the process, improves methodology and ultimately contributes towards improved health outcomes.[20] As equal partners in health care decisions, they help pave the way for the successful translation of new treatment modalities into approved therapies.

Provincial Research and Evaluation Committee for Environmental Health Conditions (PREC-EHC)

The next key deliverable of the Environmental Conditions Organization (ECO) is to create an initial structure and processes for the development of a research component. This can be achieved under the leadership of a Medical Director leading the proposed Provincial Research and Evaluation Committee for Environmental Health Conditions (PREC-EHC) once established. Under the leadership of a Medical Director and supported by a Research Coordinator, the new PREC-EHC will act as a catalyst, encouraging research pertaining to ME/CFS, FM and ES/MCS and establishing partnerships and connections with local, national and international researchers, promoting research on a comprehensive scale.

It will set the stage for the ECO becoming a knowledge-transfer centre that provides up-to-date, accurate and unbiased information, connecting health care and community-based service providers with the latest science and promoting good practices for the diagnosis and treatment of these conditions. It will not only contribute to new knowledge and increased awareness and scientific evidence in the hands of providers, but it will also improve care and allow these conditions to be normalized and recognized throughout Ontario's healthcare system. This will promote a paradigm shift in how these patients with multisystem disease receive care and how they are perceived in the medical community. As rigorous research is the key to this type of change, establishing a spirit of inquiry and a culture of innovation is important.

Options for Creating a Provincial Research and Evaluation Committee for Environmental Health Conditions (PREC-EHC)

Option 1 – Internal: Become a Component of the new ECO and leadership model

Benefits:

- Achieve a deeper understanding of the conditions
- Develops internal expertise - Talent management
- Is typically less costly
- Begins to establish the ECO as the readily-identifiable "trusted source" for information about these conditions
- Draws together a network of research expertise across the province focused on these conditions
- Provides more latitude for the direction of research
- Has a strong community voice
- May achieve greater buy-in

Challenges:

- Requires more time to become a functioning committee
- May struggle to find the right medical and research experts who are in high demand
- Will have minimal support available to manage the committee

Option 2 – Outsource: Capitalize on a well-established and credible research function within a host organization.

Benefits:

- Will already be recognized as part of a credible and well-established research institute with experience in building a research program
- Will benefit from established relationships with universities and colleges and research funding organizations
- Will have greater access to experienced/trained medical and research experts who are in high demand
- Will have highly-regarded research and ethics processes in place
- The new ECO can focus on other business

Challenges:

- May have conflicting priorities
- Less control over the agenda
- The ECO will have less control over research direction and processes

Recommendation re: the Creation of a Provincial Research and Evaluation Committee for Environmental Health Conditions (PREC-EHC):

Option #1 is recommended: establishing an internal committee in partnership/collaboration with a recognized research program. If not feasible initially, then Option 2 is acceptable.

Recommendations for Prompt Action related to the Research and Evaluation Component:

TFEH Recommendation # 7

The next key deliverable of the Environmental Conditions Organization (ECO) is to develop an initial Research and Evaluation Component. This includes determining the right approach and implementing a Provincial Research and Evaluation Committee for Environmental Health Conditions. Initial action for the research component will be:

4.1 Conduct an environmental scan to get a sense of the research landscape for these conditions in Ontario, Canada and internationally.

4.2 Collaborate with research partners locally, nationally and internationally and capitalize on relationships with well-known research leaders

4.3 Work with research funding organizations to create a spirit of enquiry, innovation, and evaluation.

4.4 Develop a process to Identify and closely monitor new research and promising practices to ensure information is readily available to inform evidence-based, best practice guidelines and tools.

Cost-Effective – Creating structures and processes internal to the ECO; partnering with academics and existing research organizations and working with and accessing research funding agencies, enables the creation of an initial research component in a cost-effective manner.

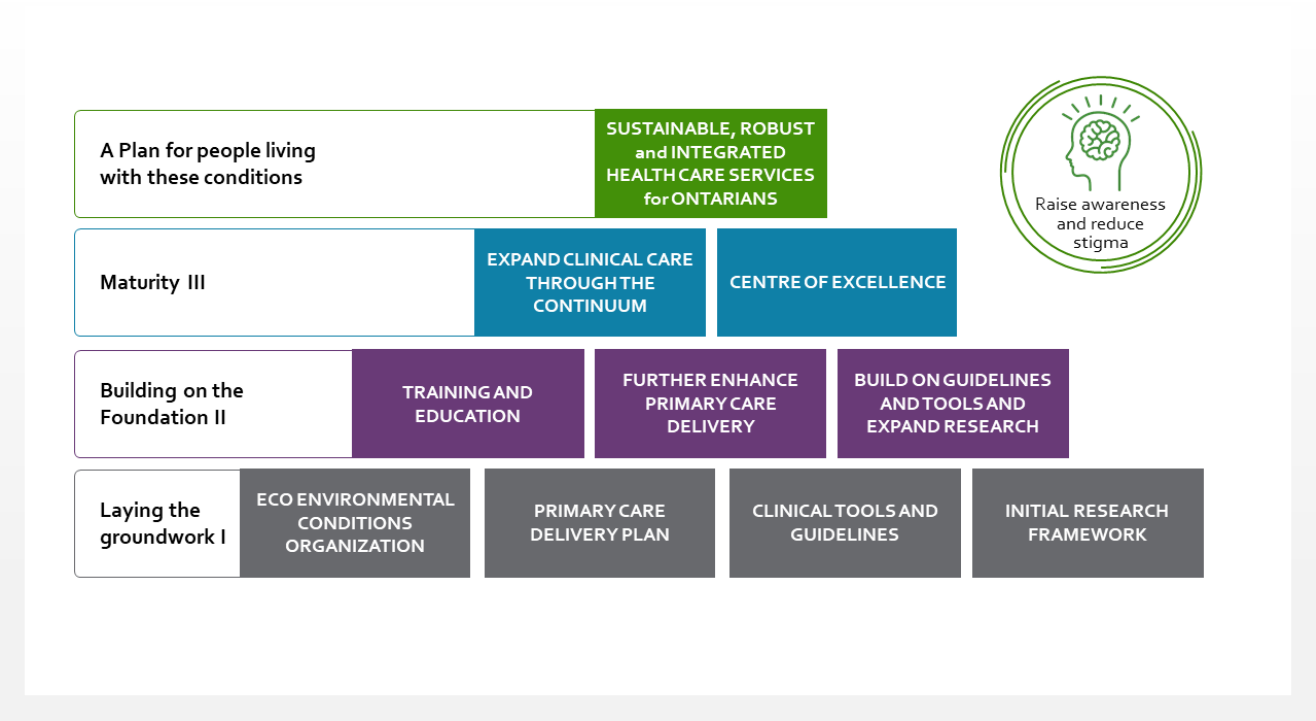
Sequencing of Remaining Deliverables from the "Care Now" Report

As mentioned previously, this proposed Initial Action Plan is a direct response to the Minister's request and is also based on feedback from the consultation process indicating that a solid foundation is needed upon which to build a robust, sustainable and integrated healthcare system for Ontarians living with ME/CFS, FM and ES/MCS. By working in partnership with people living with these conditions to lay the groundwork to build a system of care that will last, they will begin to receive the medical treatment they need and deserve.

The Initial Action Plan is not intended to in any way minimize the remainder of the recommendations/ deliverables from the 2018 TFEH "Care Now" Final Report [Appendix B]. Rather, with the foundation set, the remaining deliverables may be addressed and sequenced in a stepwise fashion. The newly-established ECO may determine that some do not have to wait until the Initial Action Plan is complete, and others may be deferred.

Figure 4 shows a proposed future state with the essential building blocks beginning with, and supported by laying the groundwork:

Figure 4: Building blocks to create sustainable, robust and integrated health care service for Ontarians



Based on consultations, the future deliverables may be sequenced as follows:

1. Raise Awareness and Reduce Stigma (TFEH Recommendation #1)
2. Next Steps on Primary Care Plan (TFEH Recommendations #1,#3 #4)
3. Build on Clinical Guidelines and Tools (TFEH Recommendation # 2)
4. Expand Research Plan (TFEH Recommendation #7)
5. A Training and Education Plan (TFEH Recommendation #3)
6. Expanding Clinical Care through the continuum and establish a Centre of Excellence (TFEH Recommendation #8)
7. Shared Care Planning Tool - defer to the leadership of the new structure (TFEH Recommendation #5)
8. OHIP Billing - defer to Ministry of Health as OHIP billing is not part of this mandate (TFEH Recommendation #6)

Priority 1 – Raise Awareness and Reduce Stigma

Stigma is major issue with these conditions, which has been attributed to a lack of awareness in society at large and a lack of recognition that they are real physical illnesses. The 2018 TFEH "Care Now" Final Report recommended three targets for an awareness campaign: (1) educate the general public, (2) target health care facilities and services (including hospitals, long term care homes and key home care providers), and (3) engage primary care.[1]

Essential components of an awareness program can be achieved through multiple strategies as communicated during stakeholder consultation.

Feedback from Consultations:

- **Have the Provincial Government communicate its agenda/plan for these conditions** -- This will greatly impact their acceptance by the general public and within the health care system.
- **Engage professional bodies such as OCFP, NPAO and AFHTO to help accelerate the adoption of new definitions, guidelines and tools** -- This includes helping to identify members for provincial committees, facilitating/organizing educational forums and assisting with the dissemination and acceptance of informational resources.
- **Reduce barriers for people living with these conditions by implementing a comprehensive awareness program** -- The general public, families, health care providers and others are expected to be more accommodating and receptive as they become more familiar with these conditions.
- **Promote the need for safe environments** -- People living with these conditions, in particular ES/MCS, need safe environments to access health care without incurring additional risks to their

health. While fragrance-free programs and policies, for example, exist in some Ontario health care facilities, updated rules may be required in the wake of the COVID-19 pandemic with the widespread use of hand sanitizers and disinfectants. New health care facilities (especially hospitals, long-term care homes and home care) should be designed so as to be conducive to care for people with environmentally-sensitive conditions.

Proposed approach:

1. An awareness program in collaboration with the Provincial Community Advisory Committee – Environmental Health (PCAC-EH) with a focus on the general public, health care facilities and providers.

2. Knowledge translation services to transfer information such as research to practice and to connect healthcare and community based service providers with the latest science and promote best practices in the care of people living with these conditions.[21] The goal is to improve care, accelerate the equitable provision of services, reduce systemic barriers to health equity, and influence policy, e.g., a scent-free policy for public health care facilities.

3. Web-based solutions, that may include: an online directory to connect patients with health care and social service providers who have expressed a commitment to welcoming people living with these conditions and providing competent care; online system navigation information for community members facing particular challenges when accessing health care; online learning platforms for remote training opportunities for PCPs that are easily accessible from anywhere in Ontario.

4. An emphasis on understanding the need for an environment that is conducive for people living with these conditions, including fragrance-free, volatile organic compound free policy and safe facilities specifications. This includes all health service providers, including home care providers.

Priority 2 – Next Steps on Primary Care Plan

A strong primary care plan is essential to create an integrated health care system for people living with ME/CFS, FM and ES/MCS.

While the initial Primary Care Plan focused on getting care to all parts of the province by utilizing the services of the CHCs, NPLCs and AHACs and interested FHTs and FPs without interprofessional teams by using the Team Care prototype (refer to **Page 27**), the next step is to continue to build primary care capacity.

See also Feedback from Consultations re: Develop a Primary Care Plan

Proposed approach:

1. **Use technological enablers by integrating guidelines and tools into existing systems, e.g., the Electronic Medical Record (EMR)** -- This has been used to improve care for people living with diabetes, where it has been shown that use of an outpatient EMR is associated with a reduction of emergency room visits and hospitalizations.[22]

A similar tool embedded in the EMR could help manage patients living with ME/CFS, FM and ES/MCS, and potentially Long COVID patients. PCPs, who generally prefer to incorporate clinical guidelines and screening tools into existing platforms, would have quick, easy access to clinical information on the diagnosis, treatment and follow-up of patients in their office. They would have a defined plan to carry out over multiple sequential visits, dovetailing with FPs' busy office schedules and typically-short appointments, and potentially reducing the propensity to refer people living with these conditions to a specialist. It would also increase awareness of these conditions among health care providers -- and the simple act of acknowledging their conditions and validating that their issues are real would be a great first step forward for patients. Overall, it should also help PCPs feel less overwhelmed and be more willing to take on these patients.

2. **Learn from programs that support FPs, including OCFP's "Practising Well" program** --

   One example of a successful strategy to support FPs is the Ontario College of Family Physicians' "Practising Well" mentoring program, intended to provide family doctors with access to credible information, knowledge, and experts to support them in providing the best care possible for their patients with their mental health, substance use disorders and chronic pain.[23] The program is made up of three elements: (1) Practising Well Community of Practice: a space created by and for FPs to connect in real time with, and learn from, others who are working with patients to address their mental health, substance use disorders and chronic pain. Anchored by live online calls scheduled once a month, featuring topics and speakers of interest to the community, it will expand to an online discussion board to continue the conversation. (2) Practising Well Information Exchange: an online self-guided resource intended to give FPs the information they need, including connection to complementary programs like ECHO (Extension for Community Healthcare Outcomes) and eConsult. (3) Practising Well Peer to Peer Connect: provides FPs the opportunity to partner with another family physician in a one-on-one setting, and share experiences and best practices in the treatment of mental health, substance use disorders and chronic pain.

   This model could be adapted for FPs diagnosing and treating patients with ME/CFS, FM and ES/MCS.[23]

Priority 3 – Next Steps on Clinical Guidelines and Tools

Comprehensive patient-centred clinical guidelines and tools underpin the primary care plan. However, once created and approved, an ongoing review process is needed to update clinical guidelines and tools with the latest information.

See also Feedback from Consultations re: Developing and Disseminating Clinical Guidelines and Informational Resources

Proposed approach:

1. Clinical, epidemiological and bench research are continuously translated into safe clinical practice to inform updates to the clinical guidelines and tools.

2. The newly-established ECO functions as a knowledge exchange hub for Ontario to promote awareness and disseminate information related to best practice for these conditions, including Long COVID patients.

Priority 4 – Next Steps on Research Plan

After establishing the Provincial Research and Evaluation Committee and developing the initial Research Plan, the next step is initiating the remaining relevant research activities to grow capacity and identifying opportunities, with the aim of filling knowledge gaps and enhancing quality of care through leading-edge research.

Creating Research Networks on a National Basis:

Partnering with organizations that already do this work can accelerate progress on the ECO's research goals.

One promising potential partner may be the Interdisciplinary Canadian Collaborative Myalgic Encephalomyelitis Research Network (ICanCME), the first of its kind in Canada for these conditions. The network is funded by the Canadian Institutes of Health Research (CIHR). The activities of the ICanCME network are centred on three strategic pillars: (1) building a catalyst-accelerator program to fill existing gaps in ME research, stimulate new discoveries and sustain excellence in ME research in Canada; (2) developing a sustainable research infrastructure for ME and implement the integration and standardization of databases and bio-banking procedures; and (3) developing talent to enhance ME research capacity and excellence in research. The ICanCME model could be considered as an approach for the other environmental conditions (http://www.icancme.ca/page.asp?ID=6).[24]

ICanCME includes representation from Ontario in the form of environmental health clinicians and researchers (including physicians from Environmental Health Clinic- Women's College Hospital) who participate in the various working groups of ICanCME. ICanCME is ahead of the province of Ontario in developing a research infrastructure and building a medical education program, and in partnering and connecting with well-known, international experts. Therefore, a partnership might accelerate research and medical education, provide access to experts for eConsults, and offer international relationships that could be leveraged. For instance, ICanCME interacts regularly with international experts who already have educational and training programs in all environmental conditions who could design educational materials for PCPs in a more-timely manner. With respect to research, ICanCME has the capacity and ability to manage the entire process, including peer reviews, open calls, receipt of applications and rank research proposals.

One option may be a purchased service arrangement to acquire services from ICanCME.

See also Feedback from Consultations re: Developing a Research and Evaluation Component

Proposed approach:

1. A strategic research plan to identify short and long-term priorities leading to the discovery of new knowledge that has the potential to improve the lives of people living with these conditions and Long COVID patients in Ontario.

2. Collaborative research partnerships to keep abreast of research and emerging evidence-based practices related to these conditions and Long COVID patients in the province of Ontario.

3. Advance research through funding opportunities, including the Canadian Institutes of Health Research (CIHR) and the US National institutes of Health (NIH) to promote and support funding research projects.

4. Advance research through funds made available through the ECO to seed research initiatives related to these conditions.

Priority 5 – A Training and Education Plan

A training and education plan is needed to improve care for people living with ME/CFS, FM and ES/MCS, including Long COVID patients. Interacting with a trained and knowledgeable health care workforce early in the treatment process will result in better experiences for both patients/caregivers and health care providers.

Providing safe primary care is a priority, and recognizing the paucity of accessible information on these conditions in the primary care setting, well-coordinated training modules for PCPs will lead to safer and higher-quality care.

The aim of training modules is to provide a compendium of information and tools on key issues pertaining to diagnosis and treatment for all of these conditions. It does not propose a "one size fits all approach", as PCPs are organized under different models across the province.

Essential components of a training and education program can be achieved through multiple strategies as communicated during stakeholder consultation.

Feedback from Consultations:

- **PCP training is a priority** -- Successfully implementing the Primary Care Plan is contingent upon having a well-coordinated education and training plan. Continuing Medical Education (CME) is a key component of the education strategy to reduce stigma and communicate evolving evidence.

- **Develop CME modules for specialist physicians** -- Patients report being referred to specialists who were not knowledgeable or comfortable treating ME/CFS, FM and ES/MCS. CME modules can help them recognize and understand these conditions and accept and provide the necessary care.

- **Train frontline staff** -- Training current health care and social service providers will demonstrate and contribute to a system-wide commitment to improved care for people living with these conditions.

- **Work with colleges and universities to integrate education and training about these conditions into their curriculum** -- This will further build a workforce that is skilled in managing patients with these conditions.

- **Support training of more providers with a specialization in environmental health conditions** -- This will increase the pool of specialized providers with expertise in these conditions and those

providing interdisciplinary care. Continuing the Enhanced Skill Program in Clinical and Environmental Health at Women's College Hospital under the auspices of the Department of Family and Community Medicine, University of Toronto and funded by the Ministry of Health is an opportunity to build clinical knowledge of these conditions in the field. The Centre of Excellence will be a rich environment to train specialized providers in the future.

Proposed Approach:

1. Collaborate with colleges and universities along with clinical experts in environmental health to develop and deliver education and training programs to future health care providers.

2. Create Continuing Medical Education (CME) programs with the assistance of the OCFP, NPAO, OMA, AFHTO and other related health care professional bodies.

3. Partner with ICanCME to accelerate the development of medical education programs for primary care providers.

4. Work with the Foundation for Medical Practice Education at McMaster University, which offers a Practice Based Small Group (PBSG) Learning Program which brings family physicians together in small groups to discuss their individual practice gaps in a safe and trusted space.

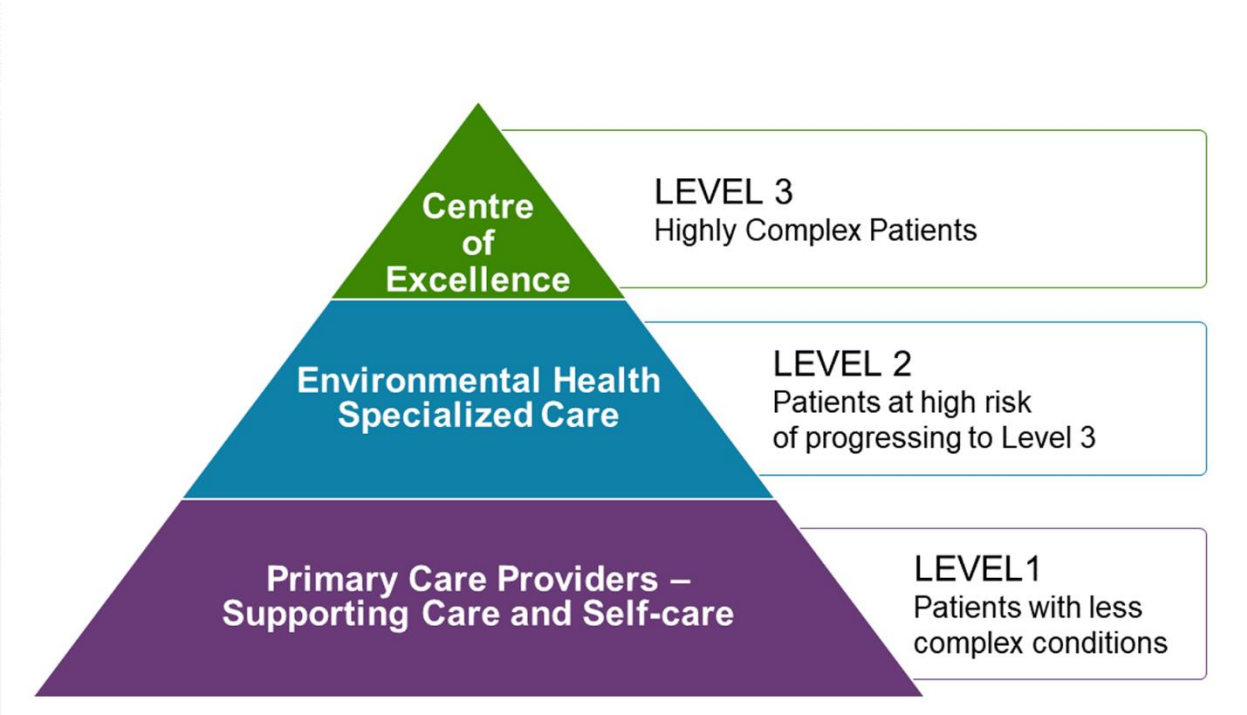
5. Expand the Clinical Fellowship program currently provided at Women's College Hospital under the auspices of the Department of Family Medicine at the University of Toronto.

Priority 6 – Centre of Excellence

Stakeholder feedback and the TFEH "Care Now" Final Report (Recommendation #8) both indicated that a Centre of Excellence (CoE) is required to add a tertiary care component for people living with the most severe or highly-complex cases of ME/CFS, FM and ES/MCS.

In expanding the continuum of care, this highly-specialized hub would provide assessment/diagnosis and treatment for those patients and support the decentralized primary care delivery system and other providers. It would also build expertise with a focus on tertiary care. From a network perspective, the centre would include system-level coordination, quality and service standards, performance and evaluation.

Figure 5: Levels of Care



Based on the Kaiser Permanente model, the top of the pyramid (Level 3) typically represents the most complex and severely affected 5% of patients. For these conditions, this would require significant increased capacity within a proposed CoE. Levels 1 and 2 will need to be well developed in order to curb the growth in level 3 patients so as not to overwhelm the system from both a quality of care and cost perspective.[25]

Once the Initial Action Plan has been implemented, the newly-established ECO should explore potential options for (and the feasibility of) adding a tertiary care component/Centre of Excellence, including through evolution of the ECO itself.

As per recommendation 1.1 of the Initial Action Plan, the ECO will be scalable from a start-up to a mature organization that will oversee programs for environmental health conditions across Ontario, creating opportunities for future growth (potentially scalable to a CoE for ME/CFS, FM and ES/MCS care, education, research and policy development).

See also Feedback from Consultations re: Establishment of ECO and Leadership Model

Proposed Approach for Creating a Centre of Excellence:

1. To develop robust and integrated clinical services for the CoE as part of a comprehensive care model, it is important to consult with leading global organizations for both content and delivery systems. Much can be learned from organizations with experience and proven success in diagnosing and treating these conditions, as well as in disseminating information and educating health care providers.

2. Similarly, it is important to consult with existing organizations in Ontario and build on local expertise, e.g. Women's College Hospital.

3. The CoE should be integrated into Ontario's evolving health care system in alignment with Ontario Health Teams (OHTs).

4. Based on feedback from consultations, a CoE would be well-positioned to advance evidence-informed Integrative Medicine.

Priority 7 – Work with Government to develop a Shared Care Planning Tool

The 2018 TFEH "Care Now" Final Report recommends a shared care planning tool to help patients and their caregivers communicate, coordinate their needs and navigate the health care system. This recommendation was listed as a Government initiative and therefore is not addressed in this report.

Priority 8 – Use the OHIP fee codes to include all three conditions and to help gather data on prevalence.

The 2018 TFEH "Care Now" Final Report recommended the Ministry re-initiate the process to modernize the Ontario Health Insurance Program (OHIP) fee code K037 in collaboration with physicians and patient experts. This recommendation is directed towards the Government and therefore is not addressed in this report.

Further Issues Identified Through Consultations

1. **Electromagnetic Hypersensitivity Syndrome (EHS)**

   Patients indicated a desire to have EHS included with ME/CFS, FM and ES/MCS on the list of environmental conditions.[26]

2. **A Plan for Children Living with these Conditions**

   The OCEEH (2013) business case strongly recommended that a plan for children living with these conditions be included as a future deliverable with a Centre of Excellence.[2]

Developing a Monitoring Framework

The vision for care of patients living with these conditions is to create sustainable, robust and integrated health care services for Ontarians with ME/CFS, FM and ES/MCS: a healthcare system that is clinically and fiscally accountable for delivering a full and coordinated continuum of care for people with this patient population. The project will be successful when it can be demonstrated that those living with these conditions are better off than before.

As with all successful project implementations, evaluation is a critical component. There is a need to assess the degree to which the Initial Action Plan meets its ultimate goal of improving the lives of people living with these conditions. An ongoing evaluation of the initial and remaining deliverables will help to identify areas for continuous quality improvement, ensure the effective programs are maintained, maximize utilization of resources, and ultimately help in better meeting the needs of this population. The evaluation will measure program effects on the target population by assessing the progress towards the outcomes that the program is meant to address.

The selected evaluation tool is to be grounded in the Quadruple Aim approach, an internationally-recognized framework that designs and delivers an effective healthcare system, which is in turn consistent with Ontario Health's approach. Its goal is to improve both the patient care and the clinical care experiences along with the health of a population, and reduce per capita health care costs (see Figure 6). Moreover, without an improved clinical experience on the provider side, the three other patient-centric aspects won't reach their full potential.

Evaluation will help the ECO's leadership understand where there are gaps in the Initial Action Plan, identify research opportunities and come up with innovative solutions or course corrections. Program evaluation is also a tool with which to demonstrate accountability to an array of stakeholders that may include the provincial government, other funders, policymakers, and environmental health leaders in the community, as well as to inform and help formulate policies and updated guidelines and tools related to these conditions.

Feedback from Consultations re: Developing an Evaluation Framework

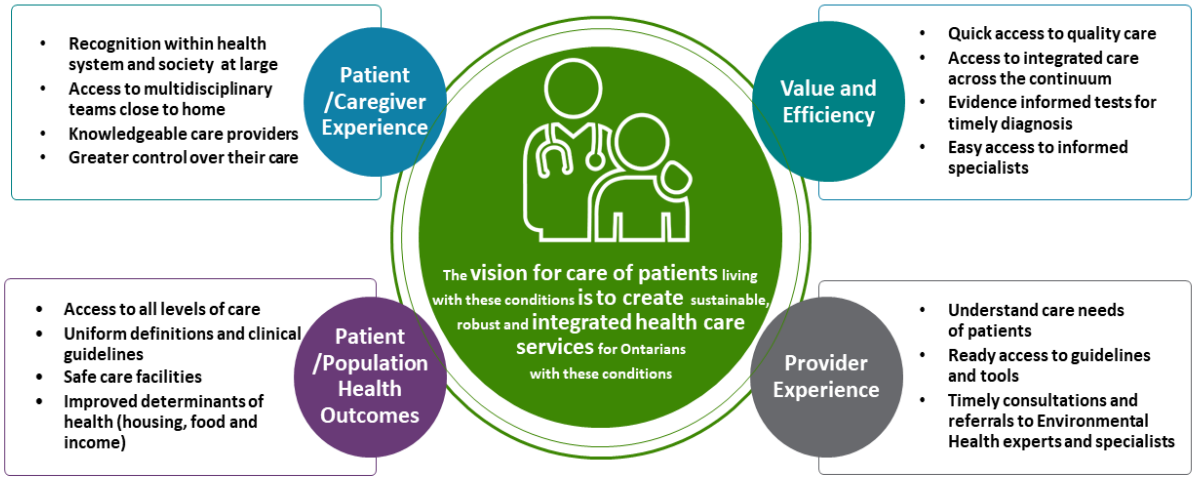
- **Develop a tool to measure the impact of the Action Plan** -- In order to assess the improvement of care and to ensure equitable access for people in Ontario living with these conditions, metrics are needed to measure the effectiveness of the initial and future deliverables of the action plan. Examples of performance metrics suggested by stakeholders include: recognition by health care providers and the healthcare system of these conditions; improvement in quality of life; reduced unmet health care needs; reduced unmet home care needs; less social isolation; less poverty; less food insecurity; better housing; more employment; improved awareness and education of health professionals; and increased recognition of ME, FM and MCS in the medical community and for research.

- **Patient Reported Outcomes Measures (PROMs) and Choosing Wisely** -- Health system experts in performance measurement and evaluation described these programs as being particularly relevant for this patient population based on patients' needs and challenges and could potentially be a future approach.

Integrated System of Care for These Conditions:

Based on the consultations with both patients living with these conditions and providers, the following performance indicators grounded in the Quadruple Aim approach are proposed. The goal is to measure patient and caregiver experience, the overall health of this patient population; the reduction in health care cost through faster access to quality and equitable care while enhancing provider experience through ready access to clinical guidelines, tools and information.

Figure 6: An Integrated System of Care



Potential Future Approaches:

Patient Reported Outcome Measures (PROMs)

Patient Reported Outcome Measures (PROMs) capture patient perspectives on aspects of their health status that are not typically captured by standard diagnostic tools. PROMs are measurement tools that patients use to provide information on aspects of their health status that are relevant to their quality of life, including symptoms, functionality, and physical, mental and social health.

PROMs are used to assess a patient's health status at a particular point in time. PROMs tools can be completed either during an illness or while treating a health condition. In some cases, using pre- and post-event PROMs can help measure the impact of an intervention.

Who uses PROMs?

- Patients and clinicians — to inform clinical care, and to improve patient–provider communication and patient involvement in decision-making.
- Health system decision-makers — to inform health services programming, planning and policies, as well as for performance measurement and quality improvement initiatives.
- Researchers and policy-makers — to conduct comparative and cost-effectiveness analyses, as well as to answer other research questions.

Health systems in many countries such as Canada, England, USA and Sweden are increasingly recognizing the value of PROMs. As PROMs collection expands, Ontario will be able to compare with other Canadian jurisdictions and internationally.

PROMs can also complement traditional sources of data, such as information derived from clinical administrative data, to inform policies, programs and value-based health care delivery. They are essential to understanding whether health care services and procedures make a difference to patients' health status and quality of life. PROMs tools can be condition-specific (used to assess outcomes that are specific or unique to particular diseases or sectors of care such as people living with these conditions).

With support from Canadian Institute for Health Information (CIHI) and the Ministry, Ontario Health - Cancer Care Ontario is adapting its electronic PROMs collection tool for the hip and knee replacement population.[27]

Choosing Wisely

The mission of Choosing Wisely is to promote conversations between clinicians and patients by helping patients choose care that is supported by evidence, not duplicative of other tests or procedures already received, free from harm and truly necessary. It encourages conversations between physicians and patients to improve care, to ensure high quality, cost-effective care to patients. As there are no specific tests approved in the diagnosis of these conditions in Ontario, patients with these conditions are often sent to multiple specialists and undergo multiple tests to rule out other conditions. By identifying diagnostic tests and treatments most appropriate for these conditions, and to rule out other conditions (on the basis of clinical care guidelines), there is an opportunity to improve care while significantly reducing health care costs.

> **The ECO leadership should collaborate with Government and other experts to implement the evaluation framework.**

Financial Summary

A comprehensive budget for the Environmental Conditions Organization (ECO) and Leadership Model within a host organization - Option 2 is presented. This includes compensation and non-compensation annual operating costs as well as one-time costs listed in the chart below. This proposed funding includes the necessary resources to start-up and operationalize the ECO and leadership model as well as to deliver on the Primary Care, the Clinical Guidelines and Information, and the Research and Evaluation Plans.

As the timing of a funding announcement is unknown, the initial costs are estimated for the first 15 months after a funding announcement. With an understanding that the start date for implementation is subject to change, this proposal assumes that funding will start in the last quarter of Fiscal 2021.

Detailed Financials for the ECO – **[Appendix D]**

Table 4 Base Funding: The following chart is an estimate of the base funding compensation and non-compensation costs for F21/22 and F22/23.

Description	F21/22 (Q3/Q4)	F22/23
Non-compensation Operating Cost	$190,000	$760,000
Compensation Operating Costs (14FTEs)	$450,000	$1,800,000
Total Cost	**$640,000**	**$2,560,000**
Total annual funding with 2% ongoing base increase commencing in F23/24 - $2,611,000.		

Budget Assumptions:

- Compensation operating costs are estimates based on a total staffing complement of 14 FTEs and a benefit cost of 27%
- Purchase Service costs are estimated at 7% of the ECO budget
- Lease costs are estimated based on a $50 CSF (cost per square foot)
- Inflation is calculated at 2% per year; requiring an adjustment to base funding on an annual basis

Table 5 Initial One-time Funding: The following chart is an estimate of the one-time funding required over the last two quarters of F21/22 and the first quarter of F22/23.

Description	F21/22 (Q3/Q4)	F22/23
One-time cost	$290,000	$160,000
Total One-time Cost	$290,000	$160,000
Total one-time funding is $450,000 over F21/22 and F22/23		

Monitoring the Implementation of the Action Plan

In order to monitor the progress of the initial Action Plan, a monitoring tool has been developed. This template titled, “Work Plan for Monitoring Initial Deliverables of the Action Plan” will be submitted under separate cover directly to the Ministry of Health.

Monitoring the implementation of the action plan deliverables may be best achieved by an organization focused on the integrated delivery of care across the evolving healthcare system.

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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.

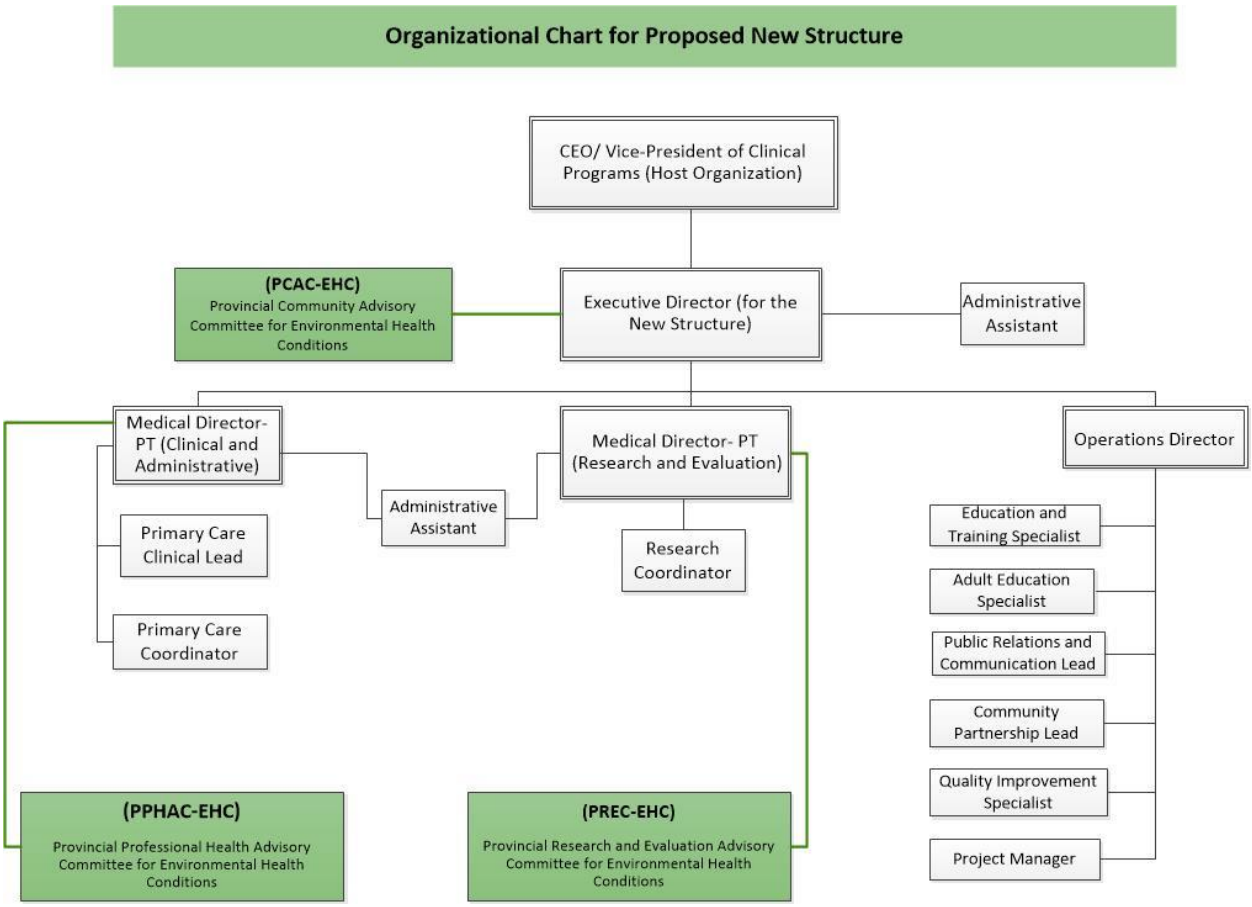
Rec #8 - Create a centre of excellence in ME/CFS, FM and ES/MCS care, education and research in Ontario.

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.

Appendix C – Proposed Organization Chart for the Environmental Health Organization (ECO)

Figure 7: Organizational Chart for Proposed New Structure



Appendix D – Financial Details

Environmental Conditions Organization (ECO) and Leadership Model Funding Summary

Environmental Conditions Organization and Leadership Model within a Host Organization (Option2) - Ongoing Operating Costs

Table 1a: Ongoing Non-Compensation Operating Costs

Non-Compensation Operating Costs (Base Funded)	Estimated Annual Budget	Quarterly Cost	2021-22 Impact (Q3/Q4)	2022-23 Impact
Annual Lease	$200,000	$50,000	$50,000	$200,000
Supplies and Other expenses	$50,000	$12,500	$12,500	$50,000
Multifunctional devices (Lease) @$250/mo.	$10,000	$2,500	$2,500	$10,000
Back Office Purchase Agreement (from Host Organization)	$160,000	$40,000	$40,000	$160,000
Public relations and Communications (Awareness)	$100,000	$25,000	$25,000	$100,000
Travel Costs	$10,000	$2,500	$2,500	$10,000
Consultants	$40,000	$10,000	$10,000	$40,000
Committee Meeting Costs	$40,000	$10,000	$10,000	$40,000
Primary Care Education & Training	$150,000	$37,500	$37,500	$150,000
Non-Compensation Operating Costs - Total	**$760,000**	**$190,000**	**$190,000**	**$760,000**

Table 1b Ongoing Compensation Operating Costs

Compensation Operating Costs (Base Funding)	FTE	Estimated Budget	Quarterly Cost	2021-22 Impact (Q3/Q4)	2022-23 Impact
Executive Director	1.00	$150,000	$37,500	$37,500	$150,000
Medical Director, Clinical and Administration	0.50	$125,000	$31,250	$31,250	$125,000
Medical Director, Research and Evaluation	0.25	$62,500	$15,625	$15,625	$62,500
Operations Director	1.00	$120,000	$30,000	$30,000	$120,000
Administrative Assistants	2.00	$110,000	$27,500	$27,500	$110,000
Research and Evaluation					
Research Coordinator	1.00	$60,000	$15,000	$15,000	$60,000
Quality Improvement Specialist	1.00	$90,000	$22,500	$22,500	$90,000
Primary Care					
Primary Care Clinical Lead	0.25	$30,000	$7,500	$7,500	$30,000
Primary Care Coordinator	1.00	$80,000	$20,000	$20,000	$80,000
Knowledge Mobilization					
Education and Training Specialist	1.00	$90,000	$22,500	$22,500	$90,000
Adult Education Specialist	1.00	$70,000	$17,500	$17,500	$70,000
Operations					
Community Partnership Lead	1.00	$100,000	$25,000	$25,000	$100,000
Public Relations/Communications Lead	1.00	$115,000	$28,750	$28,750	$ 115,000
Event Coordinator	1.00	$65,000	$16,250	$16,250	$65,000
Project Manager	1.00	$124,000	$31,000	$31,000	$124,000

Compensation Operating Costs (Base Funding)	FTE	Estimated Budget	Quarterly Cost	2021-22 Impact (Q3/Q4)	2022-23 Impact
Salaries Subtotal	n/a	$1,391,500	$347,875	$347,875	$1,391,500
Benefits @ 27%	n/a	$375,705	$93,926	$93,926	$375,705
Compensation Operating Costs – Total	**n/a**	$1,767,205 **≈$1,800,000**	$441,801 **≈$450,000**	$441,801 **≈$450,000**	$1,767,205 **≈$1,800,000**
Total Compensation & Non-Compensation Operating Costs	**14.00**	**$2,560,000**	**$640,000**	**$640,000**	**$2,560,000**

Environmental Conditions Organization (ECO) – One Time Costs

Table 1c One-Time Costs

One Time Cost Description	Total One-time Costs	2021-2022 Impact Q3/Q4	2022-2023 Impact Q1	Total One-Time Costs
Office/infrastructure set-up (workstation)	$70,000	$70,000		$70,000
IT and Equipment Set up	$50,000	$50,000		$50,000
Computers	$30,000	$30,000		$30,000
Telecommunication Equipment	$10,000	$10,000		$10,000
Telephones and headsets	$10,000	$10,000		$10,000
Recruitment Costs	$180,000	$70,000	$110,000	$180,000
Other Consultancy Costs	$100,000	$50,000	$50,000	$100,000
TOTAL ONE TIME BUDGET	**$450,000**	**$290,000**	**$160,000**	**$450,000**

Total One-Time Funding (over 2 fiscal years) - $450,000

Table 1d Total Full-Time Equivalents (FTE)

Position	FTEs
Senior Management Positions	2.75
Staff Level Positions	11.25
Total Number of FTE - Initial Staffing Complement	**14.00**

Table 1e Financial Summary Chart

Summary Chart	Total Budget	2021/22 Impact	2022/23 Impact
Operating Costs	$760,000	$190,000	$760,000
Staffing Costs including Benefits	$1,800,000	$450,000	$1,800,000
Total Operating Costs	**$2,560,000**	**$640,000**	**$2,560,000**
Total One-time Costs	**$450,000**	**$290,000**	**$160,000**
Total Funding (Operating and One-time)		**$930,000**	**$2,720,000**
Ongoing Annual Base Funding	$2,560,000		
Inflation at 2% per annum	$51,000		
Total Annual Funding	**$2,611,000**		

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