



RECOGNITION, INCLUSION AND EQUITY

Solutions for People Living in Ontario with Environmental Sensitivities/
Multiple Chemical Sensitivity (ES/MCS), Myalgic Encephalomyelitis/
Chronic Fatigue Syndrome (ME/CFS), and Fibromyalgia (FM)

**Proposal for an Ontario Centre of Excellence
in Environmental Health (OCEEH)**

*On behalf of the Steering Committee overseeing
the OCEEH Business Case Project*

October 2013

Recognition, Inclusion and Equity for people living with environmentally-linked conditions, including myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS), fibromyalgia (FM), or environmental sensitivities / multiple chemical sensitivity (ES/MCS)

Executive Summary

Business Case Plan submitted to MOHLTC

The Association of Ontario Health Centres (AOHC) and the Myalgic Encephalomyelitis Association of Ontario (MEAO) are excited to endorse an innovative and leading edge proposal aimed at providing a new integrated and innovative model of care for over 570,000 Ontarians who continue to suffer from debilitating environmentally-linked conditions. In a health care system that currently provides colossal challenges for this population in accessing primary health care as well as highly specialized services, a proposed “Hub and Spoke” model will bring together expertise and knowledge in a highly specialized centre of excellence (the Hub) that ensures the most complex and high needs patients receive quality care when they need it. This combined with innovative support by regional specialized centres (Spokes) will support building knowledge and skills in the primary care community. This proposed approach will address the needs of these clients who are not receiving the care required and will provide services as close to home as possible. They have struggled long and hard to gain equitable access to health care and social services.

AOHC and MEAO have performed an extensive current state analysis which is evidenced by the comprehensive and well researched compendiums including data analysis, architectural considerations, the state of the science and evidence, and the voices of the clients, family members and friends who have seen the effects of this condition. Strong partnerships have emerged through this process including the University of Toronto, health care providers and the community itself. These key stakeholders are driven to creating a system that is built on evidence-based comprehensive interprofessional primary health care, complimented with appropriate health and social services, and with access to trained specialists when required.

This proposal is a bold and progressive step to meeting the needs of an ever increasing demand for leading edge and compassionate care. Over the course of the past decade, there has been a dramatic increase in the incidence of environmental illnesses to the point where it now ranks third amongst all major chronic diseases. Currently, there are over 570,000 people of all ages in Ontario who have one, or more, of three environmentally-linked health conditions including ME/CFS, FM and ES/MCS.

In depth community consultation overwhelmingly expressed concern about the significant lack of primary health care supports for people struggling with these debilitating conditions. Clients with these conditions describe heart wrenching stories of feeling stigmatized and ‘invisible’ from the health care and social services systems and are often labeled as psychogenic or some form of hypochondria. Many attempts are made to access the system, frequently going from specialist to specialist trying to get help. Health care professionals often do not recognize the chronic, life-long and debilitating nature of these conditions, or lack of access to knowledge based resources on how best to provide care. Protocols and guidelines to assess, diagnose and manage these conditions are in early stages of development and there is no apparent formal education in any health professional schools for these environmentally - linked conditions.

This comprehensive provincial strategy has two broad pillars, each that will be designed and operated in a way that ensures the voice of patients and their families and friends informs the strategy and its subsequent implementation.

Pillar one is focused on developing a system of care that can meet the full range of health and social needs of individuals with these conditions – one that embraces a philosophy of people-centred care and that is integrated, coordinated, comprehensive, and provided by interprofessional teams.

Pillar two is focused on removing systemic barriers to health equity so that patients and their families can lead full and productive lives. The goal is to ensure that these conditions are recognized as chronic diseases with supports that are treated in an equitable manner to other major chronic conditions.

This strategy will be achieved through the establishment and operationalization of the Ontario Centre of Excellence in Environmental Health (OCEEH). The OCEEH will be an independent, self-governed organization, affiliated with the Dalla Lana School of Public Health and the Department of Family and Community Medicine at the University of Toronto and other academic health centres. Through partnerships, it will provide teaching, research, health promotion, and policy analysis as well as both primary and secondary clinical services for people living in Ontario with chronic, complex environment-linked illnesses. There will be a focus on, but not limited to, ES/MCS, ME/CFS and FM.

The plan is progressive in its design. To ensure a successful implementation of the proposed plan, the overall project will be phased-in over a realistic time-frame to ensure the infrastructure and skills required are systematically built to ensure success and to ensure quality services are developed/provided throughout the project implementation. The first phase has a specific set of objectives and outcomes which includes a provincial hub (in Toronto) and two initial spokes across the province. The lessons learned from these first spokes will be applied to determine the subsequent expansion of spokes to meet the demand of services across the province. Phase 1 would begin upon funding being confirmed and is anticipated to end in March 2015.

A significant investment in this plan is required to create an equitable system of care and social supports. This involves developing the continuum from primary to highly specialized care, facilitating a cultural change to acceptance as a chronic disease, building or redeveloping safe facilities, influencing social policy and supporting a research and education infrastructure. This will be offset by timely access to the right care at the right time. It is estimated that currently, well over \$150 million per year in health system costs is spent to service these patients in a fragmented unsustainable fashion. This excludes cost to society including lost wages to patients and families and other costs such as drugs, nutritional supplements, or the provision of safe housing that are borne by these patients and their families.

Key stakeholders in the field are engaged and enthusiastic about this opportunity. Recognition and momentum towards implementing innovative approaches to improve the current situation is building. The Dalla Lana School of Public Health has expressed enthusiastic support for and willingness to collaborate with OCEEH in order to provide a strong academic and research foundation for the proposed strategy. The strategy aligns well with the Excellent Care for All Act, Ontario's Action Plan for Health as well as the work of the government to ensure all Ontarians are able to contribute to the economic wellbeing of the province.

The opportunity is now. By investing today and setting up the necessary infrastructure shortly, we will have a system that:

- ***Embraces environmental conditions as a chronic disease*** - Environmental health conditions will be 'normalized' and recognized as a chronic disease with supports equitable to other major chronic conditions.
- ***Creates a Centre of Excellence*** - There will be a Centre to care for the most high needs and complex patients as well as provide leadership in the development of health and social policy, research and education of health care providers in the field and in training.
- ***Leads to informed health care providers throughout the system*** - Services being available at the right place at the right time from the right provider. All health professionals will have formal training, integrated into their foundational education, and all primary care providers will be trained to assess, diagnose and treat.
- ***Supports a "care closer to home" philosophy where appropriate*** - Management for more complex conditions will be available closer to home in facilities made safe for people living with these conditions.
- ***Creates equitable access to quality care*** - People will receive appropriate, evidence-based comprehensive interprofessional primary health care with appropriate health and social services, and with easy access to trained specialists when required.
- ***Improves the patient experience*** - Patients will not have to contend with lack of effective services, and also multiple layers of stigma.
- ***Prevents and delays serious illness and injury among those who are at the greatest risk of declining health*** - Patients will access care sooner which should improve their quality of life and prevent or delay further deterioration.
- ***Enables evidence informed care*** - Services will be provided according to and will be informed by evidence; and where evidence does not exist, research will contribute to new knowledge.
- ***Leverages recent investments in strengthening the primary health care system*** - The majority of patients will receive care from their primary care provider, who has been provided the required skills and knowledge
- ***Builds on effective and available social supports*** - Appropriate and safe housing and treatment facilities, including supportive housing, long-term care homes and hospitals, will be available.
- ***Fosters a learning environment*** - A spirit of enquiry, innovation, and evaluation will pervade.
- ***Delivers value and sustainability through efficient use of resources*** - Through prevention and appropriate care for patients with environmental conditions, it is expected that patients will not only receive better care but there will be more efficient use of resources.

Acknowledgements

The Business Case for the Ontario Centre of Excellence in Environmental Health was developed in partnership with the Association of Ontario Health Centres (AOHC) and the Myalgic Encephalomyelitis Association of Ontario (MEAO). It was funded by the Ministry of Health and Long-Term Care. This business case is the product of many people bringing together their expertise and perspectives. Four compendiums were developed in order to inform the development of this business case, and provide a wealth of background information.

Tab 1 (Highlights Report) and Tab 1a (Full Report):

Recognition Inclusion and Equity – The Time is Now. Perspective of Ontarians Living with ES/MCS, ME/CFS, and FM. (Author: Varda Burstyn)
The result of extensive community consultation, the experience of patients' organizations, literature analysis and environmental scanning, this report is about the lives and needs for care and support of people living in Ontario with ME/CFS, FM and ES/MCS. It includes the current state, service and policy recommendations and alignments with the OCEEH business case.

Tab 2:

The Quantitative Data. (Authors: Erika Halapy, Margaret Parlor)
This quantitative data report complements Recognition, Inclusion and Equity through objective analysis of data to evaluate a broad range of health-related characteristics surrounding people living with ME/CFS, FM and ES/MCS.

Tab 3:

Ontario Centre of Excellence in Environmental Health, Chronic Complex Conditions – Academic and Clinical Perspectives. (Author: Dr. John Molot)
This report includes a broad-based scoping review of scientific literature related to environmental associations with chronic complex health conditions, focused on ME/CFS, FM and ES/MCS, as well as an overview of clinical perspectives on what is required to build the OCEEH.

Tab 4:

Architectural Considerations for the Ontario Centre of Excellence in Environmental Health. (Author: David Fujiwara)
This report includes standards for the construction of environmental health centres, including planning assumptions, capital build details, space needs and estimated costs for the prototype hub and spokes of the OCEEH.

A Steering Committee oversaw the development of the OCEEH business case, with a Medical Advisory Committee providing expert feedback to the Steering Committee and consultants. The members of both of these committees are acknowledged below.

A special thanks is extended to Varda Burstyn, who worked diligently shepherding this project through multiple phases across five years dedicating countless hours as a volunteer and as a consultant. Varda's work was instrumental in the development of the model for the OCEEH that forms the foundation of this Business Case Proposal.

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Finally, the project management team consisted of Erika Halapy, Project Coordinator, Leah Stephenson and Sophie Bart, AOHC Co-Project Managers, Dr. Dona Bowers, Physician Co-Project Manager, and Wendy Banh, AOHC Administrative Assistant.