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## **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)

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

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

## 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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## **Executive Summary**

### **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)**

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. With Phase I implementation, the total operational cost is estimated to be \$25.4 million per year. One-time investments of \$1.5 million and capital investments of \$12.4 million will be required to establish the hub and six spokes. However, the initial request for operating funding for phase 1 is \$5.3M (for start-up of

hub and 2 spokes); \$.5M for one time; \$3.2 for capital for two spokes; and \$200,000 for two fellowships.

**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.

## 1. Introduction

This proposal presents an exciting opportunity to help approximately 570,000 Ontarians<sup>1</sup> living with one, or more, of three environmentally-linked health conditions.

With the investments outlined in this plan, we believe that Ontario can make substantial progress towards having a leading edge people-centred delivery system with Primary Health Care as its foundation. The system will address the needs of people of all ages with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia (FM), or environment sensitivities / multiple chemical sensitivity (ES/MCS) with dignity and compassion.

In this system:

- Environmental health conditions are ‘normalized’ and recognized as a chronic disease with supports equitable to other major chronic conditions.
- People receive appropriate, evidence-based, comprehensive, interprofessional primary health care with appropriate health and social services, and with easy access to trained specialists when required.
- Services are available at the right place at the right time from the right provider. All health professionals receive formal training, integrated into their foundational education, and all primary care providers are trained to assess, diagnose and treat/manage these conditions.
- Services are delivered using protocols and guidelines, informed by evidence and, where evidence does not exist, research will contribute to developing new knowledge.
- Management for more complex conditions is available closer to home in safe facilities.
- Appropriate and safe housing and treatment facilities, including supportive housing, long-term care homes and hospitals, are available.
- A spirit of enquiry, innovation, and evaluation pervades.

Developed by integrating a broad range of perspectives – patients, physicians, academia and health system planners – this comprehensive provincial strategy has two broad pillars. Each will be designed and operated in a way that ensures the voice of patients and their families fully informs the strategy and its subsequent implementation.

- Pillar One: Developing a System of Care:

Pillar one is focused on developing a system of care that can meet the full range of health and social needs of individuals of all ages with these conditions – one that is integrated, coordinated, comprehensive and that embraces a philosophy of people-centred care. At the foundation is an enhanced primary health care system where

providers have the knowledge and capacity to care for the majority of the patients with these conditions. Those individuals with more severe/complex needs would receive care in one of several geographically distributed “spokes” whose interprofessional team will have specialized training in ME/CFS, FM and ES/MCS. Finally, those with the most severe/complex needs will receive care in a “provincial hub”. To support ongoing evaluation and generation of new knowledge, all elements of the system would contribute to a provincial database, and the spokes and the hub would be active participants in clinical research programs. A comprehensive education program would support the translation of new knowledge into clinical practice across the system.

- Pillar Two: Removing Systemic Barriers to Health Equity:

Pillar two is focused on removing systemic barriers to health equity so that patients and their families can lead full and productive lives. To ensure that these conditions are recognized as chronic diseases with supports that are equitable to other major chronic conditions, and to remove the barriers to health equity that currently exist for individuals with these conditions, systemic level change must occur. This requires focused efforts to change health and social policies at multiple levels as well as robust education programs that will increase health professional and public awareness regarding the conditions.

This strategy will be actualized through the establishment and operationalization of the Ontario Centre of Excellence in Environmental Health – 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, that directly and through partnerships 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-associated illnesses. There will be a focus on, but not limited to, ES/MCS, ME/CFS and FM.

Recognition and momentum are building towards implementing innovative approaches to improve the current situation. The numbers are increasing and there is no time to wait. The strategy aligns well with Ontario’s Action Plan for Health, the Excellent Care for All Act and the work of the government to ensure all Ontarians are able to contribute to the economic wellbeing of the province. 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. And – equally important – the key stakeholders are aligned on a way forward.



## 2 Environmentally-Linked Health Conditions – A Context for Change

In Ontario, there are approximately 570,000 people who live with one, or more, of three environmentally-linked health conditions: myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia (FM), environmental sensitivities / multiple chemical sensitivity (ES/MCS)<sup>2</sup>. As outlined in the Compendium patients' perspectives report, 'Recognition, Inclusion, Equity: The time is now,' individuals with these chronic conditions frequently do not receive the care they need – instead they are often shunned and dismissed by poorly informed health care professionals who do not recognize the chronic, often comorbid, life long, and debilitating nature of the conditions and who do not have the knowledge about how best to provide care to them. Patients often go from specialist to specialist trying to get help – all too often being labelled as having some form of hypochondria. Other systemic issues (such as program inclusion criteria for health and social programs or the lack of access to safe spaces and safe housing) significantly compound the difficulties faced by these individuals, their families and their caregivers<sup>3</sup>.

These three serious, chronic, often comorbid, environmentally-linked health conditions have been on the rise in Ontario, and as noted in Compendium #2, now affect more Canadians than cancer, stroke and Alzheimer's combined<sup>4</sup>.

While many chronic disabling conditions are known to be associated with increasing age (e.g., cancer, heart disease and stroke) ES/MCS, FM and ME/CFS are, in contrast, most common among the middle aged. They are most likely to occur during a time in people's lives when they have the potential to be highly productive, employable and contribute to the economy and society.

It is very common for persons to have more than one of these environmentally-linked conditions at the same time. While all these conditions exist on a gradient from mild to severe (and can go completely undiagnosed until greater severity sets in), all three can produce devastating symptoms that can lead to total disability and can be life threatening at severe levels.

- Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS): Think 'toxic injury'. A diagnostic label for people who suffer multi-system illnesses as a result of contact with, or proximity to, a variety of air, food, water or consumer products-borne agents and other substances.
- Myalgic Encephalomyelitis/Chronic Fatigue

**Kate** is a 37 year old with young children who is unable to work and participate in family activities due to extreme fatigue, causing her to be bedridden. As a child she was diagnosed with asthma with many visits to the ER. While at university, following routine minor surgeries, she began experiencing severe fatigue, irritable bowel symptoms, headaches and chronic sinusitis. These conditions escalated where she had to drop out of university and was eventually unable to work or participate in family activities. Over 18 years, she doctor shopped, seeing over 15 health care professionals, desperate for a diagnosis and treatment. All ordered a battery of tests (CT, allergy testing, MRI, blood work) but nothing alleviated her symptoms. In 2012 she was assessed with ME/CFS at the Environmental Health Clinic. A prescribed regime avoiding irritating moulds, tobacco, latex paints, perfumes and detergent stabilized her asthma. That, plus recommended diet restrictions allowed her to participate in family activities. Carefully balancing her activities with rest has subsequently allowed her to return to work in a safe environment.

Syndrome (ME/CFS): Think ‘infection that does not resolve’. Debilitating fatigue, post-exertion malaise, sleep dysfunction, swollen lymph nodes, pain, and neurological dysfunction.

- Fibromyalgia (FM): Think ‘physical injury that does not resolve’. Onset of FM syndrome is often associated with a physical injury, whether past or recent. Symptoms occur on a gradient: from nuisance-type symptoms to severe pain so bad that it makes normal existence impossible, resulting in disability and severely compromised quality of life.

Ontario’s health care system is currently failing those living with these conditions. There has recently been a study that compiled patient and family perspectives of those living with the three conditions; the results are outlined in the compendium to this business case entitled “Recognition, Inclusion and Equity – The Time Is Now: Perspectives of Ontarians Living with ES/MCS, ME/CFS and FM”. The Ontario community informants consistently describe being largely ‘invisible’ to and excluded from health care and social support systems<sup>5</sup>. There are a number of inter-related factors contributing to this situation:

- Many primary care providers are poorly informed about the conditions and their treatment. Environmental health and ME/CFS, FM and/or ES/MCS are not included in the core curriculum for physicians or nurse practitioners, and while the development of Continuing Medical Education courses in environmental medicine and the three conditions is underway, few are currently available. For those primary care providers who do recognize ME/CFS, FM and/or ES/MCS, they are often unaware of diagnostic and treatment guidance to follow or that information is not readily available. Finally, some physicians incorrectly believe these conditions to be psychosomatic and thus do not assess/diagnose or treat the conditions as is required – leaving the patients without appropriate care and experiencing further stigmatization that exacerbates the individuals’ sense of exclusion and invisibility<sup>6</sup>.
- While ME/CFS, FM and/or ES/MCS fit the same description of chronic disease as that used in Ontario’s CDPM Framework<sup>7</sup>, there is limited recognition of the chronic nature of these conditions.
- The lack of recognition of these conditions is systemic in nature. Community informants identified a number of social determinants that are especially affected by their condition and the current deficits in care and support, and for which systemic solutions are necessary. These include disability (societal recognition through accommodation, law, benefits, custom); income security, employment and social status; food security; housing security; social safety support networks (personal support services, family and social inclusion/exclusion, friendships, community involvement, isolation); emotional/psychological wellbeing; gender equality; physical environment; and education. Safe housing and accommodation is a particular concern.
- The prevalence of these conditions is projected to increase over the coming years - without sufficient health human resources to meet the current demand. Assuming that these conditions continue to grow at the same rate that they did between 2005 and 2010 (29% over that period), there will be about 730,000 Ontarians with these conditions in 2015 and about 950,000 in 2020.

- There is one specialized clinic in the province and it only has a mandate for in depth assessment, diagnosis and development of treatment plans in conjunction with adult patients. Located at Women’s College Hospital, it sees approximately 240 adult clients/patients per year with a staffing complement of 0.8 FTE physician resources and part time administrative support. There is no government funded specialized center for ongoing treatment of adults, nor for the assessment, diagnosis, or treatment of children or youth in Ontario. There are a very small number of physicians in private practice doing work in ME/CFS and ES/MCS and a few that support patients with FM. A number of the patients with severe symptoms who have the financial means go to the United States for diagnosis and treatment due to the lack of services in Ontario. Others are unable to receive specialized care as they are unable to travel and there are no services provided close to home – and in some cases their local health facilities do not provide an environment safe from chemical and environmental symptom triggers. There is no assistance to help adult parents of sick children, including in negotiating accommodation in the schools system; and no assistance for children and their families to deal with the system navigation or care coordination that these patients often desperately need. All but one of the physicians at the WCH Environmental Health Clinic is close to the age of retirement and there is currently no fellowship/specialized training program to replace them, let alone meet the growing demand.
- Currently, there is a paucity of evidence based management guidelines and protocols for the three conditions. Compounding the situation is the fact that no structured mechanisms are available to evaluate the effectiveness of the care that is delivered<sup>8</sup>.
- The failure to meet the needs of those with ME/CFS, FM and/or ES/MCS is costing the health system and the economy on the whole. The lack of a coherent system for providing care to individuals with the three conditions means that exceptionally high utilization costs by people with the conditions have been noted by many observers. These include Statistics Canada, the Environmental Health Clinic (Toronto), the Nova Scotia Environmental Health Centre and U.S. scholars<sup>9</sup>. In Ontario, the EHC found that by the time patients arrived for assistance at the clinic - patients who, on average, had stopped working three years after onset of symptoms - they were consulting both specialists and family physicians at roughly eight times the rate of average Canadians. At the same time, they had received little to no help, and many had deteriorated over the time they waited for diagnosis and appropriate care.

**Molly** is a single 36 year old woman whose employment required moderate physical activity. Following an incident at work in 2008, she has suffered with chronic pain in her upper back and neck with intermittent spasms of severe pain lasting on average 2 to 3 weeks and causing numbness in her fingers. This intense pain results in nausea, exhaustion and withdrawal from any social activities. If she sits, or drives too long she will have flare-ups. She has been referred to 8 health care specialists including an orthopaedic surgeon, psychiatrist, and a rehabilitation clinic who have suggested various exercises, physiotherapy treatments, avoidance of twisting or lifting, as well as medication. She has also sought relief through 8 other health care professionals to no avail. Finally, in 2012, she was diagnosed with fibromyalgia and provided with self-management techniques. However, she has been unable to return to her original line of work. Attempts at part-time work caused flare-ups and has resulted in a forced unemployment. She is now being treated for depression in addition to this acute chronic pain and has had to move back with her parents.

Equally important, by contrast, are the instances of people who had high initial and ongoing costs, but who received timely and appropriate care plus responsive accommodation at work, and were therefore returned to productivity. Investment in such care means that individuals with these conditions were able to lead full and productive lives, contribute to the provincial economy, and experience increased quality of life.

Given the approximately 570,000 Ontarians who are living with these conditions, the aggregate economic impact is significant. Fixing the current fragmented care model, and addressing the systemic barriers to health equity for those living with these conditions could reduce the health care budget by more than \$157 million per year. Far more significant in terms of economic impact is the fact that the current situation limits patient's participation in the labour market, reducing net wages by \$4.7 billion per year across Ontario (see Appendix A). In addition, there are numerous other costs - drugs, nutritional supplements, the provision of safe housing - that are borne by these patients and their families and increase the economic burden they experience.

### **3 The Time for Change is Now – the Critical Success Factors Are in Place**

#### **3.1 The Appropriate People Have Come Together To Generate This Business Case.**

Recognition and care for these conditions has slowly been developing. There is now momentum towards accelerating the process of positive change that moves from a current state of ‘invisibility and exclusion and stigmatization/discrimination,’ to one of ‘recognition, inclusion and equity,’ or, in a word, normalization. This state would be achieved when people living with these environmentally-linked conditions receive a comparable level of services, benefits and rights as those people with health conditions of comparable severity.

This business case represents not only the perspectives of patients, providers, and experts in environmental health but also of key stakeholders. The business case is the product of a Steering Committee that brought together the perspectives of patients, providers, health organizations, and health system experts, which has been meeting regularly for over a year to put together this business case and the supporting documents. The Steering Committee was further supported by a patients’ perspective report and a Medical Advisory Committee (MAC) that included experts in the field as well as physicians from the Environmental Health Clinic and a consultant working on model of care development. In addition, advisors and potential partners were engaged as part of this process; these include experts in environmental health, funders, and potential academic partners. The support of these stakeholders is documented in letters of support that accompany the business case. (See Acknowledgements for membership of the Steering Committee and the MAC. See Appendix B for letter of support from Dalla Lana School of Public Health).

#### **3.2 The Government has an Action Plan for Health that has a Person-Centred Approach to Care**

The Ontario’s Action Plan for Health Care is focused on ensuring person-centred care that is evidence-based and supported by providing the right care, at the right time, in the right place; and keeping Ontarians healthy. This plan aligns very well with the actions that need to be taken to meet the needs of those with ME/CFS, FM and/or ES/MCS.

Ontario is also moving ahead with the introduction of Health Links to improve the quality and reduce the costs of caring for those who are frequent users of the health system. Many of the change concepts that are being applied in the Health Links – care coordination plans, utilization of chronic disease prevention and management principles, focused attention on managing the transitions of care, increasing the role of primary care in the overall care system – are equally applicable to ensuring that the full needs of individuals living with ME/CFS, FM and/or ES/MCS are met.

#### **4 Addressing the Need – A Person-Centred, Evidence-Based, Primary Care Driven System Strategy Delivered Through a Provincial Program**

By 2020, we believe that Ontario can make substantial progress towards having a leading edge people-centred delivery system with Primary Health Care as its foundation that addresses the needs of those with ME/CFS, FM and/or ES/MCS with dignity and compassion.

In this future state system:

- Environmental health conditions are ‘normalized’ and recognized as a chronic disease with supports equitable to other major chronic conditions.
- People receive appropriate, evidence-based, comprehensive, interprofessional primary health care with appropriate health and social services, and with easy access to trained specialists when required.
- Services are available at the right place at the right time from the right provider. All health professionals receive formal training, integrated into their foundational education, and all primary care providers are trained to assess, diagnose and manage these conditions.
- Services are delivered using protocols and guidelines, informed by evidence and where evidence does not exist, research will contribute to developing new knowledge.
- Management for more complex conditions is available closer to home in safe facilities.
- Appropriate and safe housing and treatment facilities, including supportive housing, long-term care homes and hospitals, are available.
- A spirit of enquiry, innovation, and evaluation pervades.

In order to achieve this vision, this business case proposes actions in two broad pillars: the first focusing on developing a system of care for individuals with these conditions, and the second focusing on removing systemic barriers to health equity so that they can lead full and productive lives.

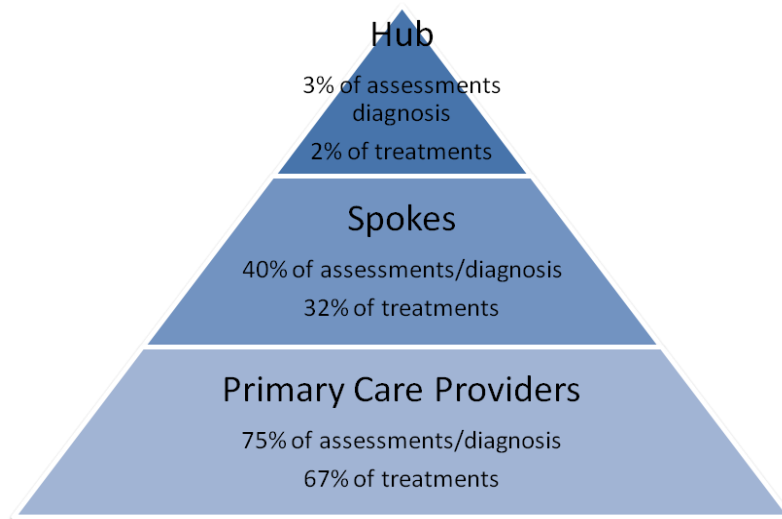
##### **4.1 The First Pillar – A System of Care with its Foundation in Primary Care**

This strategy will be based on primary care providers having the knowledge, skills, and confidence to appropriately assess/diagnose and treat those with ME/CFS, FM and/or ES/MCS. An increase in capacity of primary care providers would allow them to care for individuals living with these conditions within their practices. Those individuals with more severe/complex needs would be escalated to see physicians or nurse practitioners with specialized training in ME/CFS, FM and ES/MCS in one of a number of “spokes” that are geographically distributed to provide care closer to home. Those with the most severe/complex needs would be escalated to a “provincial hub”. Through the coordinated delivery of services at the spokes and hub, the right care will be provided at the right place and at the right time and all will apply a person-centred care model<sup>10</sup>. Through organizational affiliation agreements and individual cross appointments

with academic hospitals, the OCEEH clinical staff will be ensured access to the necessary clinical, education and research resources.

This strategy will see the majority of individuals living with one or more of ME/CFS, FM and/or ES/MCS assessed/diagnosed and treated/managed by their primary care provider; the spokes would see fewer individuals with more severe/complex needs; and the provincial hub would see a small number of individuals with the most severe/complex needs. The estimated percentage of services provided at each of these levels is outlined in the diagram below. It is of note that the percentages estimated do not add up to 100% as some individuals will require more specialized care and therefore will be referred from one level to another.

**Figure 1 System of Care with Estimated Percentage of Services Provided at Each of the Levels**



The spokes will have the necessary environmental modifications to their facilities and chemical restrictions to address the more complex/severe needs of those with ME/CFS, FM and/or ES/MCS. To meet the full range of clients' needs, the spokes will primarily be located within primary care organizations that provide a suite of wraparound services that address both clinical health needs and the social determinants of health, such as community health centres (CHCs). This will allow the interprofessional teams within the spokes to truly meet the needs of the clients. All service providers at the spokes will have specialized training in ME/CFS, FM and ES/MCS.

In order to continue to enhance the capacity of the primary care system, the spokes will complement the activities of the hub in providing education and training to primary care providers in their catchment area and participate in research and evaluation activities led by the provincial hub.

Experts in ME/CFS, FM or ES/MCS will be available at a provincial hub for those with the most severe/complex needs. Also embracing a philosophy of people-centred care, the hub will house an interprofessional team that can meet the range of health and social needs of their clients. The provincial hub will be affiliated with an academic health sciences centre to provide access to tertiary health services as needed.

The exact nature of the spokes and range of services will evolve with time and experience as they may also for the hub.

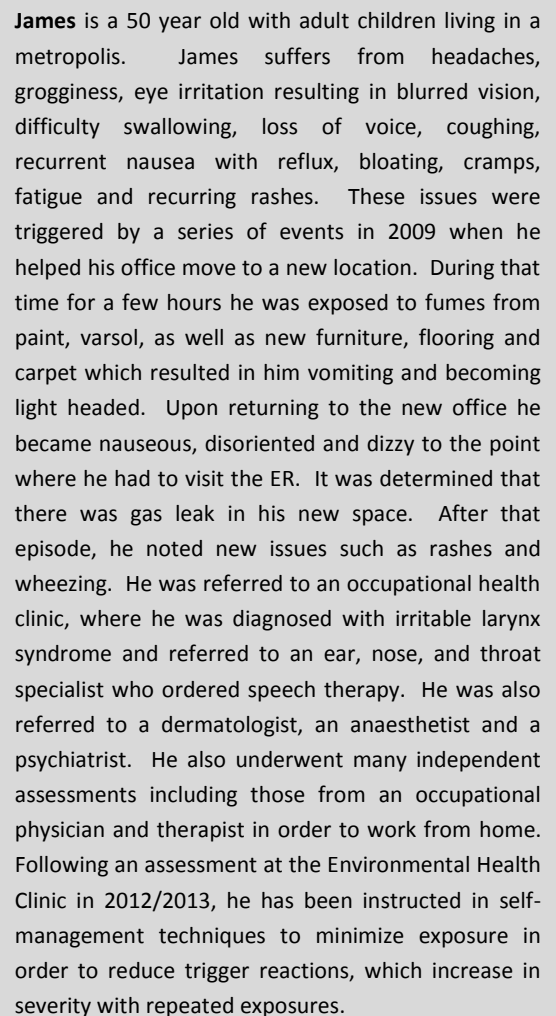
#### 4.1.1 Education and Training is an Essential Enabler

For the primary care system approach to be successful, a key function for the provincial hub is education of health and social service providers – particularly as the strategy calls for primary care providers (PCPs) to be able to assess/diagnose and provide treatment/ management for 75% of Ontarians with ME/CFS, FM and/or ES/MCS.

Continuing medical education courses will be further developed and approved for Continuing Education credits by the appropriate institutions. The provincial hub will lead an aggressive program to build the capacity of the existing primary care providers. In addition, the hub and the spokes will be expected to support local primary care providers (PCPs) through training and education on both an ongoing and one-off basis.

To address the long-term education and training needs of the system, undergraduate and post-graduate curricula will be developed in collaboration with academic institutions and these integrated in the medical and nursing schools. OCEEH will partner with the Department of Family and Community Medicine at the University of Toronto and the Division of Clinical Public Health at the Dalla Lana School of Public Health. Those spokes in proximity to medical and nursing schools will form similar partnerships to advocate for and support the integration of curricula into their programs.

The need for advanced training in ME/CFS, FM and ES/MCS will be initially addressed at the hub through two fellowship positions based in the Department of Family and Community Medicine with cross-appointments in the Division of Public Health in the Dalla Lana School of Public Health at the University of Toronto. These fellowships for family medicine graduates who wish to do an extra year of specialty training in environmental health are anticipated to begin in July 2014 in order to build the health human resource (HHR) capacity needed to assist in staffing the hub and the spokes with expert clinicians. Work has



**James** is a 50 year old with adult children living in a metropolis. James suffers from headaches, grogginess, eye irritation resulting in blurred vision, difficulty swallowing, loss of voice, coughing, recurrent nausea with reflux, bloating, cramps, fatigue and recurring rashes. These issues were triggered by a series of events in 2009 when he helped his office move to a new location. During that time for a few hours he was exposed to fumes from paint, varsol, as well as new furniture, flooring and carpet which resulted in him vomiting and becoming light headed. Upon returning to the new office he became nauseous, disoriented and dizzy to the point where he had to visit the ER. It was determined that there was gas leak in his new space. After that episode, he noted new issues such as rashes and wheezing. He was referred to an occupational health clinic, where he was diagnosed with irritable larynx syndrome and referred to an ear, nose, and throat specialist who ordered speech therapy. He was also referred to a dermatologist, an anaesthetist and a psychiatrist. He also underwent many independent assessments including those from an occupational physician and therapist in order to work from home. Following an assessment at the Environmental Health Clinic in 2012/2013, he has been instructed in self-management techniques to minimize exposure in order to reduce trigger reactions, which increase in severity with repeated exposures.



already begun to develop these fellowship positions and a separate proposal has been submitted to the MOHLTC.

Education and training of other health providers such as dietitians, social workers, psychologists, health promoters, physiotherapists, chiropractors, acupuncturists and psychologists will be provided both to existing practitioners and to those entering the professions. The hub will develop materials and support the integration of curricula in regards to ME/CFS, FM and ES/MCS and environmentally-linked conditions in the education programs for these professions. It is expected that partnerships will be formed to support this education. Additionally, the hub and the spokes will offer health professionals in their proximity, training and education on both an ongoing and one-off basis.

#### 4.1.2 Developing an Improved Understanding of These Conditions and How to Treat Them

The provincial hub will be involved in a range of research and evaluation activities that will contribute to the understanding of ME/CFS, FM and ES/MCS and the guidance for assessing and treating/managing these conditions. As a provincial resource, the hub will coordinate studies measuring the effectiveness of care; these activities will be undertaken through partnerships with service provider organizations, academic institutions, academic health sciences centres and others. In addition to partnering for education, the Dalla Lana School of Public Health will serve as a primary partner for generating research that can capitalize on the patient population of the provincial hub to address fundamental questions regarding the epidemiology and pathogenesis of ME/CFS, FM and ES/MCS, the evaluation of potential management and treatment modalities (e.g., through the conduct of randomized trials or other studies), and the health economics surrounding the impact of these conditions (see letter of support from Dalla Lana School of Public Health). Research will be important in developing evidence-based guidance for ME/CFS, FM and ES/MCS and for improving quality of care for all three conditions.

Environmental factors are estimated to cause 70 to 90% of chronic disease risk. It is accepted that pollution increases the risk for developing environmentally-linked diseases, such as allergies, autoimmune disorders, asthma, diabetes, cardiovascular disease, neuropsychological development and autism in children, and progressive neurodegenerative disorders, such as Parkinson's and Alzheimer's. Research is needed to further understand how the environment is impacting individuals with ME/CFS, FM and ES/MCS. The hub will participate, through collaborative partnerships, in projects funded through external research grants.

**Bob** was an 18 year old male, who began to experience debilitating fatigue and body aches after severe viral illnesses, saw many specialists who know nothing about CFS/FM and like others suffered a battery of tests that were not relevant. Eventually he was told that his signs and symptoms were all psychiatric. He dropped out of university due to fatigue, poor cognition and pain. Bob travelled to the USA for further assessment and spent thousands of dollars on alternative therapies. When he returned to Toronto, he was admitted to the psychiatric ward at a hospital and stayed there for one month. His physician told him he was fine although he could not digest food and was emaciated. His pain was not controlled with narcotics prescribed to him, which he reported made him feel more ill, but were prescribed anyway. Bob's situation was so severe that he sought to end his life and was successful.

## **4.2 The Second Pillar – Driving Systemic Level Change**

Focusing solely on the health care system will not create a society in which individuals with these conditions can lead full and productive lives. In order to normalize ME/CFS, FM and ES/MCS conditions, ensure that they are recognized as chronic diseases with supports that are equitable to other major chronic conditions, and to remove the barriers to health equity that currently exist for individuals with these conditions, systemic level change must occur. This requires focused efforts to change health and social policies at multiple levels as well as robust education programs that will increase health professional and public awareness regarding the conditions.

### **4.2.1 Ensuring Policies Help Those with These Conditions**

The provincial hub will be the lead on policy activities that include developing and informing legislation and regulations, fiscal policies, guidelines, and organizational policies and programs. The scope of change required spans all of the social determinants of health. While the policies of the Ministry of Health and Long-Term Care and the Ministry of Community and Social Services are key, a variety of other government ministries and stakeholders will be engaged to affect positive changes to policies and regulations such as: the Ministry of Children and Youth Services for issues affecting children; the Ministry of Labour for issues affecting social and employment policies; the Ministry of Environment and Public Health Ontario for issues affecting the environment; Ministry of the Attorney General; the Ontario Human Rights Commission; as well as a range of academic programs related to public health, occupational health, genetics and environmental health.

A special area of focus will need to be supportive safe housing. For some of these individuals living with ES/MCS, safe housing is as, or more important than, prescription medications or assistive devices are for individuals with other chronic diseases.

Given the provincial scope of the policies under consideration, the majority of policy development work will occur at the provincial hub; the spokes will also be involved through working with local municipalities – including Public Health – to apply the broad provincial policies within the local context.

### **4.2.2 Public Education and Communication**

Equally important as policy change are communications and publication to de-stigmatize ME/CFS, FM and/or ES/MCS, normalize them so that those living with these conditions are less isolated and excluded, and develop awareness to facilitate early detection and intervention. This strategy will involve ongoing public education campaigns similar to those undertaken for cancer screening, smoking cessation, stroke awareness and diabetes; the patients and their patients' organization(s) and coalitions of interest professional organizations will be included in the development of the public education program. The provincial hub, in collaboration with partners, will lead the development of this initiative.

## 5 The Ontario Centre of Excellence in Environmental Health – Implementing the Strategy

This strategy will be actualized through the establishment and operationalization of the Ontario Centre of Excellence in Environmental Health. The vision of the OCEEH is to:

*Create a leading edge, patient-centred health care delivery system for over 570,000 Ontarians with chronic, complex environment-associated illnesses\* who are currently receiving sub-optimal care while spending many times the average Ontarian’s physician utilization costs.*

*This world-class centre of excellence will be composed of a hub that will include, and expand on, the Environmental Health Clinic, and spokes delivering primary care that could begin with a patient-population-based selection of Community Health Centres.*

*The independent, self-governed hub, affiliated with the University of Toronto and other academic health centres, will provide teaching, research, health promotion, and policy analysis as well as both primary and secondary clinical services. It will operate as a referral resource for primary care providers, and support the spokes in the delivery of best and promising practices - including those for continuum of care support services - based on evidence from research and leading clinics, and from the findings of patient-centred needs assessments.*

*\* Including but not limited to environmental sensitivities-multiple chemical sensitivities (ES/MCS), myalgic encephalomyelitis-chronic fatigue syndrome (ME/CFS) and fibromyalgia (FM).*

The OCEEH will provide all of the services described in the future state through the hub and spoke model. An overview of these services and their distribution across the hub and the spokes is provided in the table below. It is also important to note that both the provincial hub and the spokes will need to maintain a number of corporate services such as partnership development and maintenance, governance and management processes, etc.

The Centre will be designed and operated in a way that ensures there is capacity to broadly engage with patients and families, so that their voice fully informs the strategy and its implementation. An important way to achieve this is to co-locate or make space available to patient voice organizations within the hub and to ensure that there is space available in spokes for such groups to engage with their members.

Figure 2 Overview of Services That Will Be Provided by OCEEH

	Hub	Spokes
Health and Social Services	<ul style="list-style-type: none"> <li>Assess/diagnose and treat the most complex/severe patients (referred by the spokes)</li> <li>Coordinate and participate in case conferences for the most complex / severe patients</li> <li>Provide e-conferences and telemedicine consults</li> <li>Assist patients with system navigation</li> <li>Provide accommodation at the Lodge for clients/families/caregivers traveling to the hub and requiring special accommodation</li> <li>Manage the lodge</li> <li>Coordinate allocation of travel grants to those requiring assistance in accessing OCEEH services</li> </ul>	<ul style="list-style-type: none"> <li>Assess/diagnose patients</li> <li>Treat patients, this includes primary care treatment, allied health treatment, and specialized services (e.g., sauna detoxification)</li> <li>Engage in telemedicine consults and e-consults with the Provincial Hub, local PCPs, and patients</li> <li>Assist patients with system navigation and advocate for them with multiple providers (e.g. CCAC, hospitals, social services)</li> </ul>
Research	<ul style="list-style-type: none"> <li>Project manage, collate, and report on epidemiological and clinical research (research to be developed conducted through partnership arrangements). Examples include research design and use of specialized medical technology and equipment (e.g. 2-day cardiopulmonary exercise tests, tilt table, capsaicin challenge tests, functional scans, etc.)</li> </ul>	<ul style="list-style-type: none"> <li>Participate in epidemiological and clinical research projects with data collection, including demographics, symptoms and function. Treatments can be evaluated with continuing case studies or under research protocols, depending on the level of available evidence.</li> </ul>
Education	<p>Professional</p> <ul style="list-style-type: none"> <li>Develop and maintain curriculum for primary care providers, allied health providers, and the spokes</li> <li>Provide professional training to the spokes and through fellowships</li> <li>Manage and provide elements of professional training for primary care providers and residents, allied health providers and undergraduates</li> </ul> <p>Public and Para Public Service</p> <ul style="list-style-type: none"> <li>Develop and maintain educational materials to support systemic change (accelerate pro-active service provision, removal of barriers, alignment of rights, benefits, polices, programs)</li> </ul> <p>General Public</p> <ul style="list-style-type: none"> <li>Lead development of major campaigns to raise awareness of the three conditions to promote recognition, accommodation and vigilance purposes</li> </ul> <p>Clients (Patients And Families)</p> <ul style="list-style-type: none"> <li>Develop and evaluate various Peer support activities (self-management, crisis peer</li> </ul>	<ul style="list-style-type: none"> <li>Attend professional training provided by the provincial hub</li> <li>Provide elements of professional training for PCPs and residents, allied health providers and undergraduates</li> <li>Provide patient and/or caregiver education</li> <li>Provide public education</li> <li>Support educational activities for service providers at regional and local levels (liaise with LHINs, public health, school system)</li> <li>Implement hub designed program, working with local partners, stakeholders, for awareness activities</li> <li>Support local community building activities</li> </ul>

	Hub	Spokes
	support, etc.) <ul style="list-style-type: none"> <li>Develop and support family support activities, for those with sick family members</li> </ul>	<ul style="list-style-type: none"> <li>Host ongoing peer-support self-management groups and family support activities;</li> <li>Develop local community building activities</li> <li>Informational outreach to alert potential clients to new services</li> </ul>
Policy Development	<ul style="list-style-type: none"> <li>Develop and inform public policy and knowledge translation to accelerate equitable provision of services and to reduce systemic barriers to health equity</li> <li>Collaborate with education efforts as indicated</li> <li>Manage communications and public education campaign</li> </ul>	<ul style="list-style-type: none"> <li>Local/regional stakeholder engagement</li> <li>Develop and maintain local/regional partnerships/affiliations</li> </ul>

## 5.1 Governance

### 5.1.1 The Provincial Hub

The provincial hub will be an independent, self-governed not-for-profit organization with a decision-making community based volunteer Board of Directors to ensure that OCEEH fulfills its mandate<sup>11</sup>. To support the person-centred, community-based approach, the Board of Directors is proposed to have at least 51% of its Directors be individuals who have experience with ME/CFS, FM and/or ES/MCS.

The provincial hub will be designated as a health service provider; would receive funding from the appropriate Local Health Integration Network (LHIN) and would be accountable to the LHIN through an applicable accountability agreement. A Medical Advisory Committee would be established and would include representatives from academic institutes such as Dalla Lana School of Public Health. Affiliation and partnership agreements would be developed with academic institutes, medical schools and academic hospitals (including one teaching hospital as a principal affiliate) in order to ensure access to clinical, research and education programs and services for the staff of OCEEH (including clinical privileges, participation in rounds, and academic cross appointments).

### 5.1.2 The Spokes

The spokes will be located within non-profit community governed primary health care organizations throughout Ontario, each of which already has a governance body and funding/accountability relationship with their LHIN.

Each spoke would have a partnership agreement with the Provincial Hub that ensures the support of provincial standards and policies, participation in clinical and epidemiological research, and other policies as appropriate. The spokes also would have affiliation and partnership agreements with local medical schools and hospitals as appropriate.

## 5.2 Service Volume

The expected assessment and treatment volumes for the provincial hub and for each “typical” spoke are outlined in the table below. In Phase One, we anticipate two spokes would be developed in addition to the provincial hub. Lessons learned from this implementation would be incorporated in the development of four additional spokes. Under the current model outlined below, approximately 23 spokes would be required to meet the 2010 demand. However, our recommendation is that initially six spokes be developed, and the lessons learned be applied to determine the appropriate expansion of spokes. These lessons will likely include an improved understanding of the optimal configuration/design for the spokes and spoke services as well as the degree to which PCPs can provide the care required.

The projected service volumes outlined below are derived using the prevalence data from the 2010 Canadian Community Health Survey, best estimates of the annual incidence of the three conditions in Ontario, the distribution of clinical activity based upon the recommended hub/spoke/primary care model, and expert opinion from the Medical Advisory Committee. Additional detail on the planning assumptions are outlined in Appendix C

**Figure 3 Expected Assessment and Treatment Volumes for the Provincial Hub and a “Typical” Spoke**

	# Delivered at the Hub	# Delivered Per Typical Spoke
Number of assessments	1,050	609
Number of Physician/NP treatment consults	5,700	4709
Number of telemedicine consults with patients (MD or NP with patient)	600	52
Number of case conferences	25	25
Number of e-consults (MD to MD)	1,800	157
Other health professional treatment consults or encounters	28,500	23,544
Number of system navigation consultations	1,425	1,178

## 5.3 Infrastructure Requirements

### 5.3.1 Information Management

The success of the strategy requires effective and efficient collection and analysis of information regarding the incidence, prevalence and treatment of environmentally-linked conditions in order to support excellent patient care, education, policy analysis and research.

- EMR. The hub and spokes will operate in a fully electronic environment. The spokes will leverage the Electronic Medical Record (EMR) of the host organization. Given that many of the spokes will be located within CHCs, this will leverage the eHealth investments made by the province through the deployment of a modern EMR across all the CHCs. The hub will use the same EMR to streamline the introduction of

documentation standards and care protocols and to ease referrals between the hub and the spokes.

- **Provincial Database.** Given that the majority of patients will receive most - if not all - of their care through primary care providers that use a range of EMRs, it will be important to develop a small provincial database that gathers - from the disparate EMR systems - a limited number of data elements about all clients living with the three conditions and the care they receive. By collecting information from across the primary care providers, the spokes and the hub, this database will be the foundation for understanding trends in the incidence of the conditions and the geographic distribution of those living with the disease. This will aid in service planning, gaining insights into the treatments that they receive which will aid in program evaluation and planning of education programs, supporting the evaluation of policy initiatives, and identifying individuals throughout the province who may be interested in participating in research. The business case includes funding to develop and operate this database, as well as the Information Management human resources needed to analyze and report on the data.
- **Telehealth.** Given the provincial nature of the program, the hub and all spokes will be equipped with OTN capabilities and will leverage these for both patient care and education purposes.

### **5.3.2 Facilities**

For individuals with ES/MCS, it is essential that the physical space at both the hub and spokes be environmentally friendly. The air in the room should be clean and fresh, fragrance-free and volatile organic compound (VOC) free. The rooms should have operating windows to provide fresh air at any time. Natural light is preferred over artificial light due to electromagnetic sensitivities. Electrical work and electronic equipment should attempt to minimize the creation of electrical or electromagnetic fields as much as possible. There are specific recommendations for the construction of walls, floors, ceilings, and cabinet work to reduce chemical exposure in Compendium #4. In addition, rooms should be minimally furnished to minimize dust and clutter. Making these facilities safe enough to accommodate staff living with ES/MCS, and providing a model of this type of accommodation, is a goal.

Facility size was determined based on the service volumes of the hub and a typical spoke, and the associated human resource requirements. The details of square footage of the hub and typical spoke, and the estimated costs for their renovation, are provided in Compendium # 4, and are summarized in the table below.

A specialized architect (David Fujiwara) was retained to develop the estimates. As this is a new model of care in Ontario, the following estimated size and cost of the hubs was derived both from applying the new model as well as drawing from experience in other jurisdictions, including the Environmental Health Centre Dallas which provides a broad range of diagnostic and therapeutic services for adults and children, the Nova Scotia Environmental Health Center which is operated by the Capital Health Region, and the Complex Chronic Disease Program at the BC Women's Hospital and Health Centre in British Columbia. Appendix D provides additional details including a list of rooms and square footage for each of the hub and a typical spoke.

**Figure 4 Estimated Facility Size and Associated Construction/Renovation Cost**

	Estimated Cost	
	Hub	Typical Spoke
Estimated Square Footage Required	10,949	6,595
Facility Construction/Renovation	\$2,682,505	\$1,615,775

## 5.4 Human Resource Requirements

The projected human resource requirements for the hub and a typical spoke are outlined in Appendix E and summarized in the table below.

**Figure 5 Estimated Human Resource Requirements for the Provincial Hub and a “Typical” Spoke**

	FTE	
	Hub	Spoke
Clinical Services	25.7	16.5
Policy, Education, Research	10	
Corporate Services	9	3
<b>FTE Total</b>	<b>40.7</b>	<b>19.5</b>

## 5.5 Other Operating Costs

There are a number of unique operating expenses that are required for the OCEEH to meet the needs of Ontarians with ME/CFS, FM and/or ES/MCS. These operating expenses directly reflect services that support the person-centred systems strategy and social determinants of health focus of the OCEEH and are aligned with the Ontario Action Plan for Health Care.

- **Travel Grants.** To further support access to care for those living with ME/CFS, FM and/or ES/MCS, by 2020 the provincial hub will oversee the distribution of travel access grants to those requiring services at the spokes or the provincial hub due to complex/severe needs, for whom travel costs are a barrier, and for whom other travel grant programs (such as the northern travel grant) are unavailable.
- **Tests and Services.** There are tests, services, and medical equipment that are included in treatment of ME/CFS, FM and/or ES/MCS, but are not covered by OHIP or personal health insurance.
- **The Lodge.** The hub will have a “lodge” that will provide accommodations to those who have to travel longer distances to access hub services, and their families/caregivers. The lodge will have the appropriate facilities for those with environmental and chemical sensitivities. The lodge will offer 10 suites.



## 5.6 Fully Operational Budget

The projected operating expenses for the OCEEH hub and a typical spoke are outlined in the table below. These expenses are provided in 2013 dollars and projected for a time when the hub and spoke are fully operational. Across the hub and the six planned spokes, the total operational costs would be \$25.4 million per year.

**Figure 6 Estimated Operating Expenses for the Provincial Hub and a “Typical” Spoke**

	Estimated Cost	
	Hub	Typical Spoke
Salaries and Benefits	5,888,265	2,191,322
Contracted Out Services	883,000	122,000
Supplies and Sundry	581,235	65,423
Educational Material Development & Production	500,000	
Building and Grounds	417,500	291,255
Lodge	260,000	
IT & Equipment	210,000	50,000
Medical Supplies	60,000	40,000
<b>Total Operational Costs</b>	<b>\$8,800,000</b>	<b>\$2,760,000</b>

Given that this is a new model of care in Ontario, the estimates was derived both from applying the new model as well as drawing from experience in other jurisdictions. Principally, the Environmental Health Centre in Dallas, which has been operating for a number of years, provides a full range of diagnostic and treatment services, is one of the few centres that cares for children as well as adults, and incorporates a residential lodge.

## 5.7 Fellowship Costs

Two fellowships, at a budget of \$199,500, are a critical enabler to enhance the supply of physicians with specialized training in this area. These fellows will be funded through University of Toronto and a separate submission has been submitted to the MOHLTC; therefore these funds are not included in the Phase 1 business case request.

## 5.8 One Time Costs

In addition to facilities costs, there are a number of one-time costs that will be required over the next several years as the hub and initial spokes are implemented. One time IT/IM related costs for EMR licences, hardware and the development of the provincial database are \$1 million. One time capital costs for clinical and other equipment are \$525,000.

## 6 Moving the Strategy Forward - A Phased Approach

A phased approach is foundational to the successful implementation of the OCEEH and it begins with intensive work in Phase 1, the first year of the OCEEH. It will leverage the collaborative process that has successfully developed this Business Case and will ensure broad involvement in the next stage of planning.

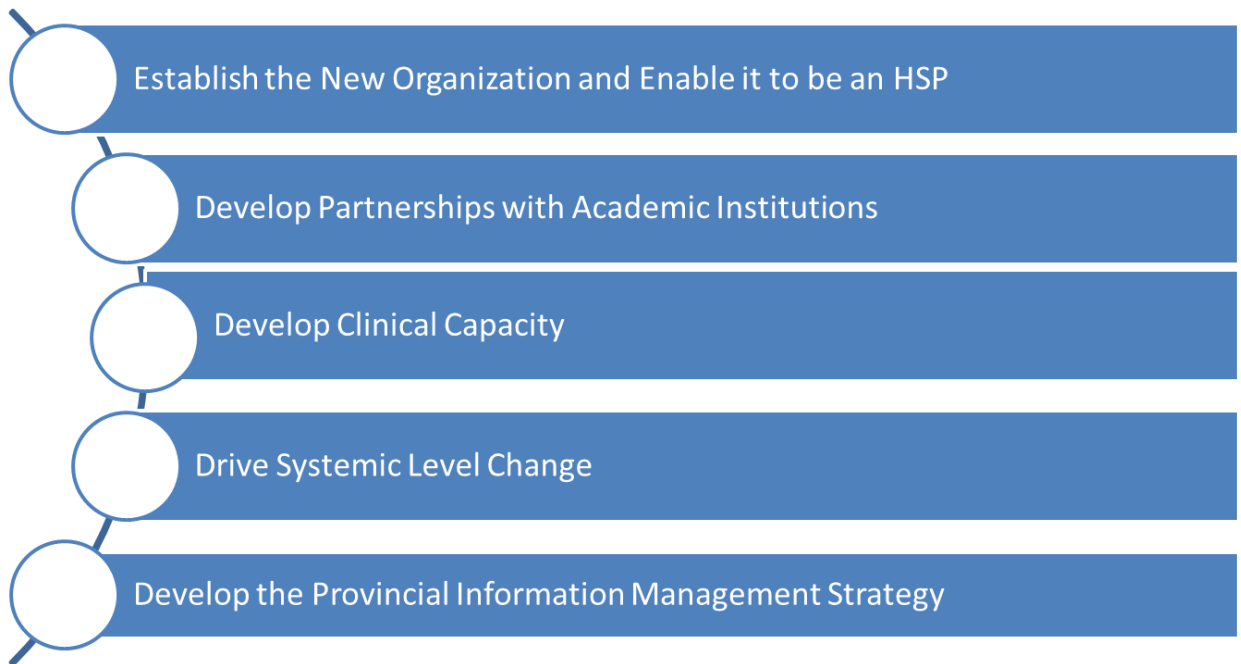
Phase 1 will build capacity at the organizational, partnership, clinical and system level. It would focus on increasing the capacity of the existing primary care providers in the province. This will be followed by the second phase which consists of implementing the clinic transition plan, fully implementing the hub and establishing a plan to roll out the other four spokes.

A diagram of the phased approach and a high level timeline is provided below.

### 6.1 Phase 1 Outcomes

Phase 1 will commence as soon as funding is confirmed and will be completed by March 2015. The following key streams will be undertaken concurrently:

Figure 7 Key Streams of Phase 1



The outcomes and objectives in each stream are outlined below:

**1 A new organization is established and designated as a Health Service Provider (HSP).**

Objectives:

- a) A new organization is incorporated as a non-profit corporation, a Board of Directors is established, a transitional CEO is hired, and the organization is designated as a HSP.
- b) A five year strategic plan and a two year operational plan / budget are developed.

**2 Partnership agreements are approved to enhance the research, academic education and clinical capacity of the OCEEH.**

Objectives:

- a) A partnership agreement with Dalla Lana School of Public Health (DLSPH) is approved, enabling a comprehensive research agenda and an organizational structure that would make world-class research possible.
- b) A partnership agreement with the University of Toronto Department of Family & Community Medicine (DFCM) is approved to ensure academic linkages are developed, including hosting two PGY3 (post-graduate year 3) fellowships in Environmental Health per year within the Centre.
- c) Academic cross appointments with the DLSPH and the DFCM are promoted for all OCEEH physicians in Toronto, and with local medical schools for the spokes' physicians.
- d) Affiliation agreements are established with one or more academic hospitals to support collaborative endeavours across clinical, education and research spheres, including hospital appointments for OCEEH physicians.

**3 Clinical capacity is enhanced.**

Objectives:

- a) A transition plan to transfer the Environmental Health Clinic (EHC) from Women's College Hospital to the new organization at the appropriate time, with the appropriate resources and affiliations (including with a teaching hospital), is developed.
- b) A multi-day expert subject forum / symposium to inform recommendations for best and promising practices (by assessing the GRADE of available evidence) and a second forum to establish evaluation strategies and to develop a longer term research agenda.
- c) A primary care provider education plan is developed and implemented to immediately enhance the capacity of the current primary care providers, including identifying and

leveraging the expertise of those currently practicing in this area and developing a toolbox of resources for primary care clinicians. Particular focus will be developing the capacity and mentoring the interprofessional teams in the spokes.

- d) Two spokes are implemented and locations for the next four spokes are identified.

#### **4 Drive Systemic Level Change.**

##### Objectives:

- a) Through working closely with organizations such as MOHLTC, Ministry of Community and Social Services (MCSS), Ontario Human Rights Commission (OHRC), and Workplace Safety and Insurance Board (WSIB), policies and initiatives that enable the recognition of environmental health conditions as chronic health disorders and as disabilities, and a plan to align services, rights and benefits accordingly are developed.
- b) To reduce stigma and enhance awareness and understanding, plans are developed for education, communication and engagement programs for:
  - i. health and social service providers and public and para-public servants
  - ii. people living with these conditions, their families and caregivers; and
  - iii. the general public.
- c) A partnership and a plan for an ES/MCS housing project(s) are developed.
- d) Working closely with MOHLTC and Ontario Hospital Association (OHA), a plan is developed to create safe spaces for the three environmental health conditions in health facilities and hospitals.

#### **5 The provincial IM strategy is developed.**

- a) An information management strategy that enables the effective and efficient collection and analysis of information regarding the incidence, prevalence and treatment of environmentally-linked conditions in order to support excellent patient care, education, policy analysis and analytical research will be developed, and the database will be developed.
- b) A provincial EMR licence will be negotiated. The EHC (hub) will transition to the new EMR from its current paper-based charts, and the spokes will be operational using that EMR from day one of opening.

## **6.2 Cost Estimate for Phase 1**

To achieve these outcomes, Phase 1 will require operational funding of approximately \$5.3 million, one-time IT/IM funding of \$0.5 million and capital funding of \$3.2 million. Note: these costs exclude those associated with the current Environmental Health Clinic at Women's College Hospital.

**Figure 8 Estimated Operating Expenses for the Provincial Hub and Two Spokes (Phase I)**

	Hub	Spokes (2)	Total
Salaries and Operating Costs	2,490,000	2,760,000 <sup>12</sup>	5,250,000
One-Time Costs - IT / IM <sup>13</sup>	500,000		500,000
Capital Costs - Facilities		3,231,550	3,231,550

The salaries and operating costs are further described below, and include 8.7 FTEs. These human resources are essential to complete the outcomes outlined above. For example, the transitional CEO will be responsible for establishing the new organization, guiding the overall execution of the strategy and ensuring a strong foundation is built for the future. The clinical director will develop the transition plan and the clinical policies and procedures for the hub and spokes.

As noted above, there is a dearth of primary care providers who are knowledgeable about these conditions, while at the same time the strategy calls for the 75% of the patients whose condition does not require them to come to the hub or a spoke to be cared for close to home. The 4 FTE educational resources will build the knowledge and skills among the more than 12,000 primary care providers in Ontario so that this gap can begin to be addressed. A budget of \$350,000 is allocated for educational material costs to develop these much needed materials in English and French.

The two policy development leads will begin the work on addressing the social determinants of health and the systemic barriers for people receiving the social supports that they require. See objectives in Section 6.1 above.

**Figure 9 Estimated FTE, Salaries, and Operating Costs of the Provincial Hub (Phase I)**

	FTE	\$	
Salaries and Operating Costs	Transitional Chief Executive Officer	0.7	150,000
	Clinical Director	1	240,000
	Education Lead , Curriculum Development Specialist and 2 Delivery Staff (note: of the 4 FTE 2 would be physician champions)	4	640,000
	Policy Development Lead & Staff	2	180,000
	Admin Assistant	1	50,000
	Legal and Consultant Services		280,000
	Education Costs (Materials, Symposium, Translation)		350,000
	General Operating Expenses		600,000
	<b>Total</b>		<b>2,490,000</b>

## **Conclusion**

This Business Case has outlined the urgency of addressing the needs of those with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia (FM), or environment sensitivities / multiple chemical sensitivity (ES/MCS) – now the third largest chronic disease in Ontario and one that is experiencing significant and worrying rates of growth.

We have also outlined a plan through which Ontario can make substantial progress towards providing the required care for these individuals using protocols and guidelines that are based on evolving knowledge and research. Equally important, our plan will contribute to reducing the systemic barriers to health equity that are experienced by these patients and their families.

The process to develop the plan was an inclusive one that integrated the perspectives of patients, clinicians, academics and health system planners. There is an engaged and supportive stakeholder community ready and waiting to support the implementation of the plan and to position Ontario as a leader in the area of environmental health.

In summary, there is an urgent need, a comprehensive solution has been described and there is a palpable readiness for change in the stakeholder community. The time for action is now.

**Endnotes**

<sup>1</sup> Source: Statistics Canada, Canadian Community Health Survey, 2005 and 2010

<sup>2</sup> As of 2010, over 568,000 Ontarians were diagnosed with one or more of the three conditions – approximately five percent of Ontario’s population. This has grown from 439,000 in 2005 as reported in the Canadian Community Health Survey (CCHS). As the survey question required there to be a diagnosis of these conditions by a health care professional, and given the stigma associated with the three conditions and the fact that lack of understanding within the health care community may lead to under-diagnosis, this number is in all likelihood an underestimate.

Condition	Number and Percent with Condition		Percent Increase
	2005	2010	2005 to 2010
ES/MCS	217,920 (2.1%)	292,660 (2.6%)	34%
FM	161,300 (1.5%)	196,800 (1.8%)	13%
ME/CFS	137,870 (1.3%)	181,110 (1.6%)	23%
One or more	439,230 (4.2%)	568,120 (5.0%)	25%
Ontario Population	10,570,000	11,260,000	6.5%

Although the CCHS does not collect information on children below age 12, cases of ES/MCS, FM and ME/CFS also occur among younger children and teenagers, and the conditions thus have the potential to impact people’s lives from a very early age. The data also clearly highlight that the majority of people with the conditions are women, a finding that has further implications regarding issues of parenting, family cohesiveness, poverty and lack of respect from health care professionals, among others.

<sup>3</sup> In addition, economic determinants were seen as major issues: loss of jobs and income due to disabling health conditions is extremely common and causes great hardship. Lack of recognition of these conditions as chronic health conditions and/or disabilities makes it very difficult to obtain workplace accommodation and disability coverage, through either private insurance or government programs.

<sup>4</sup> Indeed the environmental health conditions have many similarities with other chronic conditions. For example, 8.5% of the Canadian population has been diagnosed with asthma (2010) which has seen similar trends of increasing prevalence rates over time. Asthma can range from mild, moderate to severe and vary by person. It may flare up from time to time and triggers include environmental (including both allergic [e.g. pollen] and non-allergic [e.g. chemical and fumes]), and behavioural. Direct costs associated with asthma in Canada are estimated at \$600 million per year but do not account for indirect costs such as absenteeism and loss of productivity.

Across Canada in 2010, the number of individuals with one or more of these environmental health conditions was 1.4 million – similar to other chronic diseases such as diabetes (1.8 million), heart disease (1.4 million), and cancer (0.55 million). Interestingly, the prevalence rate for diabetes has declined in recent years according to the Canadian Diabetes Association, while the rate of the environmental health conditions continues to climb.

Chronic condition	No. with Condition
Diabetes	1,841,500
Heart disease	1,431,500
One or more ES/MCS, FM, ME/CFS	1,415,000
ES/MCS	800,500
Cancer	553,500
FM	439,000
ME/CFS	411,500

Effects of a stroke	312,500
Alzheimer's or other dementia	111,500
Multiple Sclerosis	108,500
Parkinson's disease	39,000

Being permanently unable to work is a well-known measure indicating level of disability. Those with chronic conditions in general experience higher levels of being permanently unable to work than the total population. Although there are overlaps among the chronic conditions groupings, when evaluating the proportion of Canadians permanently unable to work according to their chronic health condition, the results are telling. Canadians with ME/CFS in particular experience high levels of being permanently unable to work (24.0%), which is similar to the finding for those living with the effects of a stroke (23.6%). Those with FM also have a high rate and followed closely behind (20.6%). Further, those with ES/MCS have a similar level to those with cancer and diabetes.

Chronic Condition	% Permanently Unable to Work
ME/CFS	24.0
Effects of a stroke <sup>§</sup>	23.6
FM	20.6
Heart disease <sup>§</sup>	12.0
Cancer <sup>§</sup>	9.8
ES/MCS	9.7
Diabetes <sup>§</sup>	9.1
Total population <sup>§</sup>	2.7

When individuals are afflicted with many other chronic diseases, they are readily assessed and can access a range of services from the health system as well as the broader social services when needed. In addition, since their conditions are well known, issues of support/accommodation at work are recognized and supports for treatments through insurance can be obtained.

However, as noted in the compendium 'Recognition, Inclusion and Equity', being diagnosed with one of the three conditions is often the start of a long journey that can often lead to hardship on individuals and their families. Obtaining a clear assessment is challenging as these conditions are not well understood and often individuals are characterized as having psychiatric issues. When these conditions are diagnosed, treatment is even more challenging as these conditions are not readily understood so access to CCAC services and supports are frequently not provided. Further, treatments which may include prescription drugs, nutritional supplements, massages and assistive devices such as water purifiers must be paid for out of pocket and this places an additional burden on individuals and their families. Access to social supports such as disability supports or social and supportive housing is not appropriately geared to address those with these conditions who may have very specific needs.

Further accommodation and/or resolution of work issues to support those with these conditions is often challenging due to the lack of awareness of these issues and the severe consequences they entail. These issues need to be addressed at the individual employer as well as systemically through WSIB. This route has been challenging for those with these conditions, often resulting in no accommodation, which may force them out of work entirely and with limited or no access to disability. As a result individuals who are in their prime economic earning period of their life – often have to drop out of the workforce which has both an individual and societal impact. All of these items taken together have a devastating impact upon individuals and their families as they have nowhere to seek relief, help and support.

<sup>5</sup> Worse, they described being frequently stigmatized by health and social service provider, and by family and friends, thanks to erroneous beliefs about the nature of their conditions. The vast majority of health



professionals encountered by community informants knew little to nothing about the three conditions. This often resulted in late or missed diagnosis, deterioration, and poor to no treatment and support.

<sup>6</sup> As a result, most PCPs do not assess/diagnose or treat ME/CFS, FM or ES/MCS, many patients report symptoms for long periods of time before they are diagnosed, and patients often seek help from a number of physicians and specialists before they are diagnosed or treated, increasing the cost to the health system.

<sup>7</sup> Ontario's CDPM Framework recognizes that chronic disease:

- Is ongoing, and therefore warrants pro-active, planned, integrated care within a system that clients can easily navigate
- Involves clients living indefinitely with the disease and its symptoms, requiring them to be active partners in managing their condition, rather than passive recipients of care
- Requires multi-faceted care which calls for clinicians and non-clinicians from multiple disciplines to work closely together, to meet the wide range of needs of the chronically ill
- Can be prevented and therefore warrants health promotion and disease prevention strategies targeted to the whole population, especially those at high risk for chronic disease.

<sup>8</sup> A second compendium entitled "Academic and Clinical Perspectives for the Ontario Centre Of Excellence In Environmental Health: Chronic Complex Conditions" is enclosed with this business case and provides a broad-based review of the scientific literature related to environmental associations with chronic complex health conditions, with particular focus on the three conditions.

It notes that there are many gaps in knowledge in environmental health. The pathology of ME/CFS, FM and ES/MCS is still not well understood. While a strong similarity exists between the three conditions (ME/CFS, FM and ES/MCS) and other chronic diseases in terms of overlapping symptoms and patient profiles, the upstream etiology and "branches" of mechanistic pathways that ultimately result in the common symptoms remain unclear but is a critical area of research.

We do not have the ability to measure the impact of our lifetime chemical and psychosocial exposures from uterus to old age. Developing this ability is key to unravelling the major causes of chronic diseases. Research is required to develop mechanistic etiological understanding, diagnostic markers and treatments.

Currently, there is also a paucity of evidence based treatment guidelines and protocols for the three conditions. Compounding the situation is the fact that there are few clinical trials undertaken and no structured mechanisms to evaluate the effectiveness of the care that is delivered.

However, it is clear that there are numerous facilities and practices that have been achieving positive outcomes. In addition, at least for ME/CFS and FM there are practice guidelines by specialists that await incorporation into the mainstream. A process to derive guidelines for ES/MCS as well as the two other conditions, and, if need be, to implement these under experimental protocols, is planned. Because the patient study revealed that where patients have sought specialized help from trained physicians they have reported great improvement, in a spirit of innovation and patient-centred care, the OCEEH will seek to bring these guidelines and practices into its network and then rigorously evaluate them over time.

<sup>9</sup> New initiatives to create care facilities are taking place in the UK, in Europe, and in Canada. There are currently two other clinics in Canada that provide services for individuals with environmental health related conditions: the Complex Chronic Disease Program (CCDP) at the BC Women's Hospital and Health Centre in Vancouver, British Columbia and the Nova Scotia Environmental Health Centre (NSEHC) in Fall River, Nova Scotia.

The CCDP opened in 2012 to provide services to individuals with FM, ME/CFS, and tick borne illnesses such as Lyme disease. The clinic provides clinical care, research and surveillance, education and health promotion, and scientific evidence synthesis and knowledge transfer. The clinic was provided funding of approximately \$2M by the BC Ministry of Health to establish the program and related research activities. The NSEHC was opened in 1996 and provides clinical care and research; it is now known as the Integrated Chronic Care Service (ICCS). The ICCS provides services for individuals with ME/CFS, chronic pain conditions, environmental illnesses, FM/ES, MCS, multiple chronic conditions, and functional neurologic and gastrointestinal syndromes. It serves a population of approximately 54,500 who are living with one or more of ME/CFS, FM and/or ES/MCS, has an annual operating budget of approximately \$1.3M and recorded 5,386 visits in 2011.

<sup>10</sup> “People-centred care: care in which individuals, families and communities are served by, and are able to participate in, trusted health systems that respond to their needs in humane and holistic ways.” (WHO 2007). The term ‘people-centred health care’ is not to be confused with patient-centred health care. People-centred health care is an umbrella term which better encapsulates the foremost consideration of the patient across all levels of health systems. Therefore, this term would cover patient-centred health care.

<sup>11</sup> This model is consistent with the funding proposal to develop this business case that was jointly submitted to the MOHLTC in April 2012 and funded in October 2012

<sup>12</sup> This represents 50% of the annual operating costs for each of the two spokes; full operating costs will be required in subsequent years

<sup>13</sup> Budget amount is a portion of the one-time costs identified in section 5.8.

## Appendix A: Summary of the Economic Analysis

<b>Medical Costs</b>	<b>Case 1</b>	<b>Case 2</b>	<b>Case 3</b>
1 year of treatment (average cost)	\$ 1,327	\$ 1,193	\$ 632
<b>Typical treatment course</b>			
Lower estimate	\$ 3,988	\$ 3,584	\$ 1,898
Upper estimate	\$ 5,322	\$ 4,784	\$ 2,533
<b>Treatment through EHC</b>			
Treatment through EHC	\$ 1,453	\$ 1,453	\$ 1,453
<b>Savings per patient</b>			
Lower estimate	\$ 2,535	\$ 2,131	\$ 445
Upper estimate	\$ 3,869	\$ 3,331	\$ 1,080
<b>Assumptions</b>			
(1) Lower estimate is based on 3 years of treatment.			
(2) Upper estimate is based on 5 years of treatment.			
(3) In estimating treatment costs for future years (years 2-5 of treatment), costs are inflated using the average growth rate of the Ontario Health Services CPI (Statistics Canada CANSIM Table 326-0020) and then a 3% discount rate is applied.			
	<b>Case 1</b>	<b>Case 2</b>	
Annual Salary, 2013	\$ 35,000	\$ 45,000	
NPV of Lost Wages, 10 years	\$ 335,098	\$ 430,840	
Less: EI Claimed	<u>\$ 11,846</u>	<u>\$ 13,911</u>	
Net Lost Wages	<u>\$ 323,252</u>	<u>\$ 416,929</u>	
<b>Assumptions</b>			
(1) Salaries are inflated at the rate of inflation for 10 years and then discounted at 3%.			
(2) EI is assumed to be at the maximum rate (55% of salary up to a maximum of \$47,400) for 32 weeks.			
(3) Salaries and EI payments are assumed to happen in a lump sum at the end of the year (for ease of NPV calculation).			
<b>Aggregate Costs</b>			
Aggregate estimates are derived from the following assumptions:			
(1) For health system savings, the 570,000 individuals diagnosed with one or more of the three conditions would be represented by an average of the three vignettes. Savings accrue over ten years.			
(2) For lost wages, 50% of those diagnosed with ES/MCS and 25% of those diagnosed with the other two conditions would be represented by the vignettes.			

## Appendix B: Letter of Support



UNIVERSITY OF TORONTO  
DALLA LANA SCHOOL OF PUBLIC HEALTH

Howard Hu, M.D., M.P.H., Sc.D.

*Dean*

*Professor of Environmental Health, Epidemiology and Global Health*

*Professor of Medicine*

October 23, 2013

Ministry of Health and Long-Term Care

Re: The Ontario Centre of Excellence in Environmental Health

Dear Colleagues,

I am pleased to provide this enthusiastic letter of support for and willingness to collaborate with the proposed Ontario Centre of Excellence in Environmental Health (OCEEH).

First, as a board-certified academic internist and occupational medicine physician, I can vouch for the importance of myalgic encephalomyelitis-chronic fatigue syndrome (ME-CFS), fibromyalgia (FM), and multiple chemical sensitivities (ES-MCS) as a set of chronic illnesses that remain poorly served by standard approaches in both primary and specialty care. The large and growing pool of patients who carry these diagnoses desperately need a coordinated and centralized approach in terms of diagnosis and management, and for this reason alone, the proposed OCEEH carries great promise for meeting the needs of this patient population, promoting education on the best evidence-based strategies for evaluating and managing these patients, and, ultimately, reducing suffering and costs.

Second, as the Dean of the Dalla Lana School of Public Health (DLSPH), the largest and strongest School of its kind in Canada, I am very pleased to express the willingness of our School and its associate faculty to partner with the OCEEH on research on these conditions. The DLSPH understands that research is NOT within the purview of the OCEEH proposal. However, the creation of OCEEH would also create the foundation of patients, clinicians, standardized protocols for diagnosis, and an organization structure that would make world-class research possible. Such research is critical to understanding the mechanisms underlying the development of these conditions, which, in turn, is absolutely essential to the development of promising therapeutic approaches. Research is also critical to fully understanding the patient and economic burden associated with these diseases, and randomized clinical trials will ultimately be needed to test the true efficacy of therapeutic approaches that are developed. Should the proposal be funded and created, we will work with the OCEEH to establish and secure additional external funding to create a leading research program on the epidemiology and pathogenesis of ME-CFS, FM and ES/MCS, the evaluation of potential management and treatment modalities (e.g., through the conduct of randomized trials), and the health economics surrounding the impact of these conditions.

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Finally, as a Professor with a long history of externally-funded and leading research on the environmental and molecular epidemiology of toxicant-induced illness (see biosketch appended), including research on EC-MCS (Hu et al., 1999a, 1999b, Wolfe et al., 2002), I am pleased to note that I would be personally interested in helping to co-lead the research effort discussed above.

I wish this application success and would be glad to respond to any inquiries or questions regarding what this letter describes.

Sincerely,



Howard Hu, M.D., M.P.H., Sc.D.

Dean and Professor of Environmental Health, Epidemiology, and Global Health

#### REFERENCES

Hu H, Stern A, Rotnitzky A, Schlesinger L, Proctor S, Wolfe J. Development of a brief questionnaire for screening for multiple chemical sensitivity syndrome. *Toxicol Ind Health*. 1999 Oct;15(6):582-8. PubMed PMID: 10560136.

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Wolfe J, Proctor SP, Erickson DJ, Hu H. Risk factors for multisymptom illness in US Army veterans of the Gulf War. *J Occup Environ Med*. 2002 Mar;44(3):271-81. PubMed PMID: 11911029.

**BIOGRAPHICAL SKETCH**

NAME

Hu, Howard

POSITION TITLE

Dean and Professor, Dalla Lana School of  
Public Health at the University of Toronto

INSTITUTION AND LOCATION	DEGREE (if applicable)	MMYY	FIELD OF STUDY
Brown University, Providence, RI	BSc	06/76	Biology
Albert Einstein College of Medicine, Bronx, NY	MD	06/82	Medicine
Harvard School of Public Health, Boston, MA	MPH	06/82	Occupational Health
Boston City Hospital, Boston, MA	Residency	06/85	Internal Medicine
Harvard School of Public Health, Boston, MA	Residency	06/87	Occupational Medicine
Harvard School of Public Health, Boston, MA	ScD	06/90	Epidemiology

**A. Personal Statement**

*Background:* My entire career has been spent as a physician scientist engaging in research and training related to environmental epidemiology and environmental medicine. I started as an Assistant Professor at the Harvard School of Public Health and received my first NIEHS R01 grant as PI in 1991. I was promoted to Associate Professor in 1994 and full Professor with tenure in 2002. In 2006, I was recruited to the University of Michigan School as Chair of the Department of Environmental Health Sciences in the School of Public Health and Professor of Environmental Health, Epidemiology and Internal Medicine (the latter in the School of Medicine). In January of 2009, I became the first occupant of the NSF International Endowed Chair at the School of Public Health. In terms of science, in 1991 I began the Metals Epidemiology Research Group (MERG), a multidisciplinary group of scientists bridging Harvard institutions and eventually including research experts in physics, chemistry, epidemiology, pediatrics, internal medicine, neurology and neuroscience, genetics, and statistics. MERG grew to encompass a large portfolio of NIEHS-supported grants. Of these, I have been the PI of 7 NIEHS-funded 5-year R01 projects (1991-current), 6 P42 projects of the Harvard Superfund P-42 (1992-2006), PI of the Harvard P01 Center for Children's Environmental Health and Disease Prevention Research (2004-2006; stepped down when I moved to the University of Michigan), and PI of many pilot projects funded by the Harvard-NIEHS P30 Core Center. MERG has generated over 200 publications related to environmental impacts on health and continues as a Michigan-Harvard/Harvard-Michigan collaboration (see: [http://sitemaker.umich.edu/merg/emerg\\_home](http://sitemaker.umich.edu/merg/emerg_home)).

I was the founding PI and Director of the current UM NIEHS P30 Core Center (2011-2015), the culmination of a 3 year planning effort with the cultivation of major partnerships and investments throughout the University. I also served as co-PI of the Bloodspot Environmental Epidemiology Project (BLEEP), an effort involving the University of Michigan, Michigan State University, and Wayne State University to use the archived bloodspots taken on all neonates in Michigan since 1984 for environmental epidemiology research.

On July 1, 2012, I transitioned from the University of Michigan to the University of Toronto as the inaugural Dean of the Dalla Lana School of Public Health and Professor. I continue my research collaborations at around 20% effort (unpaid; salary is fully supported by the U of Toronto) and continue publishing cross-disciplinary translational research on the subject of environmental impacts on health, with most papers specifically addressing early life exposures, biomarkers, disease outcomes, and/or the role of epigenetics (see publication list). I have a current R01 grant (2012-2017) on the potential impacts of early life exposure to fluoride on offspring neurobehavioral development. I served as Co-Leader and Center Physician Scientist for

the Administrative Core of the UM NIEHS P20 Children's Center, which recently been renewed as a full P01 Children's Center (PI: Karen Peterson), and am co-I on several R01's or P42 Projects.

## **B. Positions and Honors**

### **Positions and Employment (abbreviated)**

1988-1997 Instructor in Medicine/Assistant Prof in Medicine, Harvard Medical School, Boston, MA

1988-2006 Assoc Phys, Channing Laboratory, Dept Medicine, Brigham & Women's Hospital, Boston, MA

1990-1992 Fellow, Agency for Toxic Subst Disease Registry Clinical Environmental Medicine Program

1990-2002 Assistant/Associate Professor of Occupational Medicine, Harvard School of Public Health

1995-2006 Associate, Center for Health and the Global Environment, Harvard Medical School, Boston, MA

1996-2006 Director, Occ& Environ Medicine Residency Pgm, Harvard Sch Public Health, Boston, MA

1997-2006 Associate Professor of Medicine, Harvard Medical School

2002-2006 Professor of Occupational and Environmental Medicine, Harvard School of Public Health

2002-2006 Associate Director, Harvard-NIEHS Center for Environmental Sciences

2004-2009 Director, PI (co-PI after 2006), Harvard Children's Ctr Env Hlth & Dis Prev Res, Boston, MA

2006-2012 Chair and Professor of Environ Health Sciences (NSF International Endowed Chair beginning in 2009), U Michigan Sch Public Health, Ann Arbor, MI

2006-2012 Director, Occupational/Environmental Epidemiology Core, University of Michigan NIOSH Education and Research Center, Ann Arbor, MI (PI: Thomas Robins)

2006-2009 Adjunct Professor of Occ & Environ Medicine, Harvard School of Public Health, Boston, M

2007-2012 Professor of Epid & Int Med, Univ Mich Schools of Public Health & Medicine, Ann Arbor, MI

2007-2012 Associate Physician, Division of General Internal Medicine (specialty: Occupational/ Environmental Medicine), University of Michigan Health System, Ann Arbor, MI

2009-2011 Director and PI, NIA T32 Training Grant on Aging & Public Health Research, University of Michigan School of Public Health

2012-Present Dean & Professor, Dalla Lana School of Public Health, University of Toronto

2012-Present Professor & Associate Physician, St. Michael's Hospital, University of Toronto School of Medicine

### **Other Experience and Professional Memberships**

1985 Diplomat, American Board of Internal Medicine

1987 Diplomat, American Board of Preventive Medicine (Occupational Medicine Specialty)

1987-Present Member, American College of Occupational and Environmental Medicine

- 1990-Present Member, International Society for Environmental Epidemiology
- 1998-Present (Founding) Medical Editor (until 2004); Associate Medical Editor, Environ Health Persp (NIEHS)
- 2000-2001 Senior Fulbright Scholar (in India)
- 2004-Present Member, Editorial Board, American Journal of Industrial Medicine
- 2007-2010 Member, Board of Population Health and Public Health Practice, Institutes of Medicine
- 2007 Member, Ad Hoc Study Section, Special Emphasis Panel/Scientific Review Group  
2007/05 ZES1 JAB-C (DI) (NIEHS Discover Centers)
- 2007 Special Consultant, Ad Hoc Study Section, Special Emphasis Panel/Scientific Review Group  
2008/01 ZAR1 CHW-G (NIAMS Arthritis Centers)
- 2009-Present Board of Environmental Studies and Toxicology, National Research Council
- 2009-2011 Chair, Committee on Global Health, University of Michigan School of Public Health
- 2009-Present Member, Society for Toxicology
- 2009 Reviewer, NIH Challenge Grants, Special Emphasis Panel/Scientific Review Group  
2009/10 ZRG1 GGG-F
- 2012-Present Member, NIEHS Council

### **Honors**

- 1994 Will Solimene Award of Excellence, American Medical Writers Association
- 1998 First Prize for Best Infant Nutrition Research, Instituto Danone, Mexico
- 1999 NIEHS, Progress and Achievement Award of the Year
- 2001 Hoopes Prize, Faculty Mentorship of Research, Harvard University
- 2005 Adolph Kammer Merit in Authorship Award, American College Occup/Environ Medicine
- 2006 Teacher of the Year Award, Occupational/Environmental Medicine Residents, Harvard School of Public Health
- 2006 Harriett Hardy Award, New England College of Occupational and Environmental Medicine
- 2009 Linus Pauling Lifetime Achievement Award, Am Coll Adv Med.
- 2011 Award of Excellence, American Public Health Association



**C. Selected peer-reviewed publications** (from over 260 original reports and 70 other publications; emphasis on recent publications, early life exposures, environmental epigenetics).

1. Cantonwine D, Hu H, Sanchez BN, Lamadrid-Figueroa H, Smith D, Ettinger AS, Mercado-Garcia A, Hernandez-Avila M, Wright RO, Tellez-Rojo MM. Critical Windows of Fetal Lead Exposure: Adverse Impacts on Length of Gestation and Risk of Premature Delivery. *J Occup Environ Med*. 2010 Nov;52(11):1106-11. PubMed PMID: 21063188; PubMed Central PMCID: PMC3003442.
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3. Palaniappan K, Roy A, Balakrishnan K, Gopalakrishnan L, Mukherjee B, **Hu H**, Bellinger DC. Lead exposure and visual-motor abilities in children from Chennai, India. *Neurotoxicology*. 2011 Aug;32(4):465-70. Epub 2011 Apr 8. PubMed PMID: 21510976; PubMed Central PMCID: PMC3115626.
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7. Peters JL, Kubzansky LD, Ikeda A, Spiro III A, Wright RO, Weisskopf MG, Kim D, Sparrow D, Nie H, **Hu H**, Schwartz J. Childhood and adult socioeconomic position, cumulative lead levels and pessimism in later life: The VA Normative Aging Study. *Am J Epidemiol* (in press).
8. Hicken M, Gragg R, **Hu H**. Both social and environmental factors play a role in racial health disparities: The case of lead and hypertension. *Health Affairs* (in press).
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**D. Research Support:**  
**ONGOING**

NIH 1R01ES021446-01 (PI: Hu)

6/1/2012-3/30/2017

University of Toronto

*Prenatal and Childhood Exposure to Fluoride and Neurodevelopment*

This project will capitalize on the archived biological samples and neurobehavioral tests from the "Early Life Exposures in Mexico to Environmental Toxicants" (ELEMENT) cohort to test the hypothesis that prenatal and/or postnatal exposure to fluoride is a risk factor for impaired neurobehavioral development. It will conduct a household and individual exposure assessment study to investigate major sources of fluoride exposure amongst the study subjects. Role: PI

NIEHS P30ES017885 (PI: Hu, 2011-2012; Loch-Carusio, 2012-2015)

4/15/11-4/14/15

University of Michigan

*The Univ of Michigan P30 Core Center in Environmental Health ("Lifestage Exposures and Adult Disease")*

The University of Michigan-NIEHS Center is a new entity that will bring together basic and translational scientists from multiple disciplines into a partnership focused on the theme of "Lifestage Exposures and Adult Disease". Our overall mission is to promote new translational research using novel multi-disciplinary approaches to better understand the impact of environmental exposures on risk of adult chronic disease through mechanisms involving epigenetic modifications during vulnerable stages of life. Role: founding PI; *now a consultant*.

NIEHS R01ES013744 (PI: Wright)

4/1/12-3/30/17

Mt Sinai School of Medicine

*Stress-Lead Interactions and Child Development*

In this ViCTER grant, the investigators integrate animal toxicology research with human epidemiologic research on the same neurotoxicant-manganese (Mn). They are measuring the same functional domains in animals and humans and to use dental Mn measures to reduce exposure misclassification in humans. Their results will be critical for informing clinical and public policy decision making and could be a model for future studies that combine animal and human research to assess chemical neurotoxicity. Role: *Consultant*.

K01 ES016587 (PI: Park)

01/15/09-01/15/14

University of Michigan

*Environment, Novel Aging Outcomes, and Genetics*

The goal of this Development Award is to support the Principal Investigator to gain the research knowledge, skills and experience to conduct environmental, gerontological and genetic epidemiology studies.

Role: original Principal Mentor; *now continuing as a co-mentor.*

NIH P42 ES017198-01, Project 3 (PI: Meeker)

04/01/10-03/31/15

University of Michigan

*Phthalate Exposure and Mechanistic Pathway Markers in Preterm Birth among Women in Puerto Rico* The rising rate of preterm births in the U.S. represents a significant public health challenge. The problem is even more urgent in Puerto Rico, where preterm births have increased sharply since 1990 to now account for nearly one in every five births on the island. This epidemiological project will use state-of-the-art methods to provide much needed information on environmental, genetic, demographic, and behavioral factors that contribute to preterm birth risk in Puerto Rico to facilitate effective prevention strategies. Role: original Co-inv; *now a consultant.*

NIEHS/EPA P01ES022844 (PI: Peterson)

4/1/13-3/31/18

University of Michigan

*Lifecourse Exposures & Diet: Epigenetics, Maturation & Metabolic Syndrome.*

The major goal of this NIEHS/EPA Children's Environmental Health and Disease Prevention Center is to conduct three Projects examining the complex interactions among perinatal environmental exposures, epigenetic regulation, childhood growth and the development of obesity and the tempo of sexual maturation. Role: *Consultant-Co-Investigator.*

NIEHS K01 ES019909 (PI: Somers)  
06/30/16

07/1/11-

University of Michigan

*Immune dysfunction associated with early life heavy metal exposure*

The overarching goal of this K01 proposal is for the candidate to acquire the expertise necessary to lead a research program in environmental epidemiology applied to immune-mediated disorders. Role: original Principal Mentor; *now a co-Mentor.*

Bloodspot Environmental Epidemiology Project (BLEEP; PI: Hu) 7/1/11-6/30/14

University Research Corridor

The overall mission of this project involving University of Michigan, Michigan State University and Wayne State University is to promote transdisciplinary and translational research that generates insights into the impact of prenatal environmental exposures on adverse health outcomes. It takes advantage of the availability of the neonatal blood spots that are available on every individual born in the state of Michigan since 1984, Role: Original co-PI; *now a co-investigator.*

**Appendix C: Service Volumes Planning Assumptions**

	Hub		Spokes		
	Planning Assumption	Volume	Planning Assumption	Volume for all Spokes	Volume for a "Typical" Spoke
Number of assessments /diagnoses	Total number of assessments diagnoses per year in Ontario (35,000) x Percentage that will be delivered at the hub (3%)	1,050	Total number of assessments diagnoses per year in Ontario (35,000) x Percentage that will be delivered at the spokes (40%)	14,000	609
Number of Physician/NP treatment consults	Total prevalence (570,000) x percentage that will have a consult in a given year at the hub (.25%) x number of consults per year for those that do have consults (4)	5,700	Total prevalence (570,000) x percentage that will have a consult in a given year at the hub (4.75%) x number of consults per year for those that do have consults (4)	108,300	4,709
Other health professional treatment consults or encounters	Number of Physician/NP consults (5,700) x number of other health professional consults per physician/NP consult (5)	28,500	Number of Physician/NP consults (108,300) x number of other health professional consults per physician/NP consult (5)	541,500	23,544
Number of telemedicine consults with patients (MD or NP with patient)	Expected volume of telemedicine consults (1,500) x percentage that will involve the hub (40%)	600	Expected volume of telemedicine consults (1,500) x percentage that will involve the spokes (80%)	1,200	52
Number of case conferences	Expected volume of case conferences (25) x percentage that will involve the hub (100%)	25	Expected volume of case conferences (25) x percentage that will involve the spoke (100%). Note: all spokes will be involved so total for typical spoke and all spokes is the same	25	25
Number of e-consults (MD to MD)	Expected volume of e-consults (3,600) x percentage that will involve the hub (50%)	1,800	Expected volume of e-consults (3,600) x percentage that will involve the spoke (100%)	3,600	157
Number of system navigation consultations	For planning purposes, equivalent to number of patients having physician/NP consults	1,425	For planning purposes, equivalent to number of patients having physician/NP consults	27,075	1,178

## Appendix D: Space Planning Budget for the Hub & Spoke

### ENVIRONMENTAL HEALTH CLINIC

#### IDEAL PROTOTYPE - CENTRAL HUB FACILITY

#### Space Planning and Speculative Construction Budget

ROOM	DESCRIPTION	AREA sq.ft.
Waiting Room	Chairs, for 8 people, display space	210
Reception/Admin	Counter, workstations, mail	130
File Room/ Print Room	Charts, cabinets, computer hub, print/copy/scan, supplies	150
Office 1, Chief Executive	Private, workstation, 3 chairs, table	140
Office 2, Clinical Service Dir.	Private, workstation, 2 chairs	110
Office 3, Corporate Services	Private, workstation, 2 chairs	110
Office 4, Policy & Ed. Dir.	Private, workstation, 2 chairs	110
Shared Office 1, managers	5 workstations, modular, open plan	400
Shared Office 2, admin, IM/IT	4 workstations, modular, open plan	400
Shared Office 3, medical assistants	4 workstations, modular, open plan	400
Shared Office 4, physicians	6 workstations, modular, open plan	400
Shared Office 5, nurses	6 workstations, modular, open plan	400
Shared Office 6, therapeutic	6 workstations, modular, open plan	400
Shared Office 7, policy ed, residents	5 workstations, modular, open plan	400
Exam/Consultation Room 1	Exam Table, counter, sinks, equipment	115
Exam/Consultation Room 2	Exam Table, counter, sinks, equipment	115
Exam/Consultation Room 3	Exam Table, counter, sinks, equipment	115
Exam/Consultation Room 4	Exam Table, counter, sinks, equipment	115
Exam/Consultation Room 5	Exam Table, counter, sinks, equipment	115
Exam/Treatment Room 1	Exam Table, chair, bed, vial trays, counter, sinks	130
Exam/Treatment Room 2	Exam Table, chair, bed, vial trays, counter, sinks	130
Exam/Treatment Room 3	Exam Table, chair, bed, vial trays, counter, sinks	130
IV Therapy Room 1	Chair, counter, sinks, bio-waste	75
IV Therapy Room 2	Chair, counter, sinks, bio-waste	75
IV Therapy Room 3	Chair, counter, sinks, bio-waste	75
Sauna/ Shower	Infra-red dry equipment, bench, shower stall	70
Quiet Room	Couch, chair	80
Counselling Room 1	Table, 3 chairs	90
Counselling Room 2	Table, 3 chairs	90
Meeting Room	tables, 12 chairs	215
Interview Room 1	table, 2 chairs, spare chair	70

Interview Room 2	table, 2 chairs, spare chair	70
Multipurpose Room	Groups, education, exercise, physio for 15, meeting for 25	800
Storage Room	Tables, chairs, plinths, equipment	120
Staff Room	Tables, chairs for 30, kitchen counter, sink, fridge	800
Client Sitting Room	Table, 3 chairs, kitchenette counter, sink, mini fridge	150
WC 1, waiting room	WC, unisex, accessible	70
WC 2, clinical	Men's WC, accessible	75
WC 3, clinical	Women's WC	75
WC 4, group rm	WC, unisex, accessible	70
WC-5, men staff	2 wc's, 2 urinals, accessible	110
WC-6, women staff	3 wc's, accessible	120
Coat Closet	Guest coats	15
Janitor Room	Slop sink, equipment	20
Bio-waste Closet	Bin	20
Garbage/Recycling Room	Bins, sink	30
Circulation, walls	Hallways, interior/exterior wall thickness, 35% factor	2839
<b>Total Area</b>		<b>10,949</b>

**ENVIRONMENTAL HEALTH CLINIC**  
**IDEAL PROTOTYPE - REGIONAL SPOKE FACILITY**

Space Planning and Speculative Construction Budget

<b>ROOM</b>	<b>DESCRIPTION</b>	<b>AREA sq.ft.</b>
Waiting Room	Chairs, for 6 people, display space	200
Reception/Admin	Counter, workstations, mail	120
File Room/ Print Room	Charts, cabinets, computer hub, print/copy/scan, supplies	150
Shared Office 1, admin	3 workstations, file cabinets, bookshelves	300
Meeting/ Counselling Room	Table, 3 chairs	100
Meeting/ Counselling Room	Table, 6 chairs	170
Shared Office 2, medical staff	4 workstations, modular desk system, open plan	400
Shared Office 3, nurses	5 workstations, modular desk system, open plan	400
Shared Office 4, therapeutic	5 workstations, modular desk system, open plan	400
Exam/Consultation Room 1	Exam Table, counter, sink, equipment, chair	115
Exam/Consultation Room 2	Exam Table, counter, sink, equipment, chair	115
Exam/Consultation Room 3	Exam Table, counter, sink, equipment, chair	115
Exam/Treatment Room 1	Exam Table, chair, bed, vial trays, counter, sinks	130
IV Therapy Room 1	Chair, counter, sinks, bio-waste	75
IV Therapy Room 2	Chair, counter, sinks, bio-waste	75
Sauna/ Shower	Infra-red dry equipment, bench, shower stall	70
Quiet Room	Couch, chair	80
Counselling Room	Table, 3 chairs	90
Multipurpose Room	Groups, education, exercise, physio for 15, meeting for 20	700
Storage Room	Tables, chairs, plinths, equipment	120
Staff Room	Tables, chairs for 18, kitchen counter, sink, fridge	475
Client Sitting Room	Table, chairs, kitchenette counter, sink, mini fridge	110
WC 1, waiting room	WC, unisex, accessible	70
WC 2, clinical	Men's WC, accessible	70
WC 3, clinical	Women's WC, accessible	70
WC 4, staff	WC, unisex, accessible	70
Coat Closet	Guest coats	15
Janitor Room	Slop sink, equipment	30
Bio-waste Closet	Bin	20
Garbage/Recycling Room	Bins, sink	30
Circulation, walls	Hallways, interior/exterior wall thickness, 35% factor	1710
<b>Total Area</b>		<b>6,595</b>



## Appendix E: Planned Staffing Within the Hub and Spoke

	Role	FTE	
		Hub	Spoke
Clinical Services	Director, Clinical Services & Research	1	1
	Manager, Clinical Services	1	-
	Medical Office Assistant	4	2
	Physician	4	2
	Nurse Practitioner	3	1
	Nursing (RN, RPN)	2.5	2.5
	Psychologist	1.2	1
	Therapeutic Staff	5	5
	Other Health Staff	2	2
	Resident Fellows (PGY3)	2	-
Policy, Education, Research	Director, Policy, Education, Communications & Stakeholder Relations	1	-
	Research and Evaluation Lead	1	-
	Policy Lead & Staff	3	-
	Communication Specialist	1	
	Primary Care Professional Education Lead & Staff	3	
	Stakeholder Relations	1	-
Corporate Services	Chief Executive Officer	1	-
	Director, Corporate Services	1	-
	Manager, IM/IT/IS	1	-
	Provincial Decision Support Analyst	1	-
	IM/IT Staff	2	1
	Executive Assistant	1	-
	Administrative Support Staff	2	2
<b>FTE Total</b>		<b>44.7</b>	<b>19.5</b>

- (1) Consistent with a person-centred approach, the hubs and spokes will have an interprofessional team including clinical providers such as physicians, nurse practitioners, psychologists, and nurses. In addition, the recommended treatment services for ME/CFS, FM and/or ES/MCS may include such providers as social workers, dietitians, physiotherapists, massage therapist, psychologists and acupuncturists. Finally, to ensure that the needs related to the social determinants of health of those living with ME/CFS, FM and/or ES/MCS are addressed, individuals require services such as system navigation and health education provided by social workers and health promoters (described as 'other health staff' in this document) who will work with CCACs and other organizations to ensure that services such as personal support work (health, hygiene, food preparation, cleaning, laundry, dwelling searches and transportation are available for the patients of the hub and spokes.
- (2) To address the second pillar of the strategy – a focus on removing systemic barriers to health equity – the provincial hub will have policy analysts that can undertake a broad range of policy activities across the range of social determinants of health. The spokes will have policy capacity to apply the broad provincial policies within the local context.

The education function will be supported by staff that can develop and implement education programs for four broad groups: health professionals, public and para-public servants, patients and their families/caregivers (patient education materials, developing peer support activities such as self-management, crisis peer support, etc.), and the general public.

Through the activities of a dedicated resource, the hub will facilitate research activities such as clinical trials, will coordinate these trials across the spokes and will partner with other organizations to support other research endeavors. Establishment of the OCEEH will create a platform on which researchers led by the Dalla Lana School of Public Health (DLSPH), including the Dean, Dr. Howard Hu, an occupational/environmental medicine physician expert with research expertise in ES/MCS, will be able to apply for external funding to support research on the epidemiology and pathogenesis of ME/CFS, FM and ES/MCS, the evaluation of potential management and treatment modalities (e.g., through the conduct of randomized trials), and the health economics surrounding the impact of these conditions (see letter of support). This will be made possible by the DLSPH's position as the largest and strongest School of Public Health in Canada, with deep bench strength in core areas that will be required for this kind of research (epidemiology, biostatistics, occupational & environmental health, social & behavioural health sciences, and health policy and health economics). DLSPH also contains an innovative Division of Clinical Public Health, which is the home of Canada's largest Public Health & Preventive Medicine Residency and a large cadre of clinical-scientist scholars; and it is also a major partner of the Institute for Health Policy Management and Evaluation, which is one of the world's foremost centers for clinical epidemiology.

- (3) The hub will house a small corporate services team to provide overall direction and – through partnership and other agreements – ensure the vision that has been articulated is brought to life throughout the province. The team includes a CEO and administrative supports as well as an information management group that will develop and maintaining the provincial database and provide provincial decision support and analysis.

It is expected that the spokes will leverage the corporate support services of the organizations within which they are housed, but will require some management and administrative supports.