



Patient Perspective On ME Research


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Patients weren't happy with service
from physicians



Conceptual breakthrough
physicians have unmet needs
Figure out what they are



Result: Canadian diagnostic and
treatment protocols



Patients aren't happy with health services

Ontario Task Force year 1 report

Lots of good stuff

But stalled in Ontario and

Not used elsewhere



Conceptual breakthrough
Task force has unmet needs
Figure out what they are



Result: Thursday afternoon workshop

Discussed what is good, what is missing,

Challenges of selecting diagnostic and treatment protocols

Challenges of developing care pathways

Task force chair, patient reps from across Canada, some health providers

Lack of Research Funding



Conceptual breakthrough
CIHR (and NIH) have unmet needs
Figure out what they are

Result: we suggest an aggressive
program based on their idea of
providing seed grants followed by
larger grants



Cause, biomarkers, subgroups

Dysfunction in many systems. Where does it start?

How does it fit together? How do we recognize it for sure? Can we measure it? Does it behave differently depending on....?

Multiple research teams possible

Clinical Diagnosis

Efficacy of screening protocol

Evaluation of current clinical diagnostic practices,
including access to testing

Awareness



Co-morbidities

Fibromyalgia, Lyme, Multiple Chemical Sensitivities,
Ehlers-Danlos Syndrome, IBS

Autism, Parkinsons, Alzheimers, ALS etc.

Depression, anxiety

Diabetes, cancer, heart disease, etc.

Treatment

Efficacy of various treatments

Evaluation of current treatment practices, including access to treatments

Awareness

Pediatrics and Youth

Prevalence

Evaluation of current tools

Awareness

Access to services and accommodations

Exertion Intolerance (Post-exertional malaise)

Awareness among health professional

Best practices, training

Awareness in public

De-stigmatization

Assessing prevalence

Canadian Community Health Survey

Special surveys

Administrative data – billing codes, ICD codes, disability systems

Patient registries

Longitudinal studies

Evolution of disease

Case histories to examine prognosis, aging, variability over time, social impact, etc.

Functional Capacity, Employment and Income Security

Evaluation of employability

Accommodations at work

Access to income support in cases of inability to work

Care Pathways

Health human resource planning

Responding to range of needs (medical and social)

Access for special populations – eg remote, housebound.

Social isolation

De-stigmatization


Role of support groups

Role of technology

Education / Awareness

- Family doctors, specialists, nurses, pharmacists, occupational therapists, physiotherapists, psychologists, counsellors, administrators and planners, home care workers, first responders, support groups leaders, families, friends, employers, teachers, etc.

Not enough research



Conceptual breakthrough
researchers have unmet needs
Figure out what they are

We are working on this

Thank you for your interest in ME/CFS

A challenging area

Innovation and science will make a big difference and will be very appreciated.



Don't underestimate the value of the
patient community!