Science, Innovation and Unmet Needs

Helping Canadians with ME/CFS
and related illnesses

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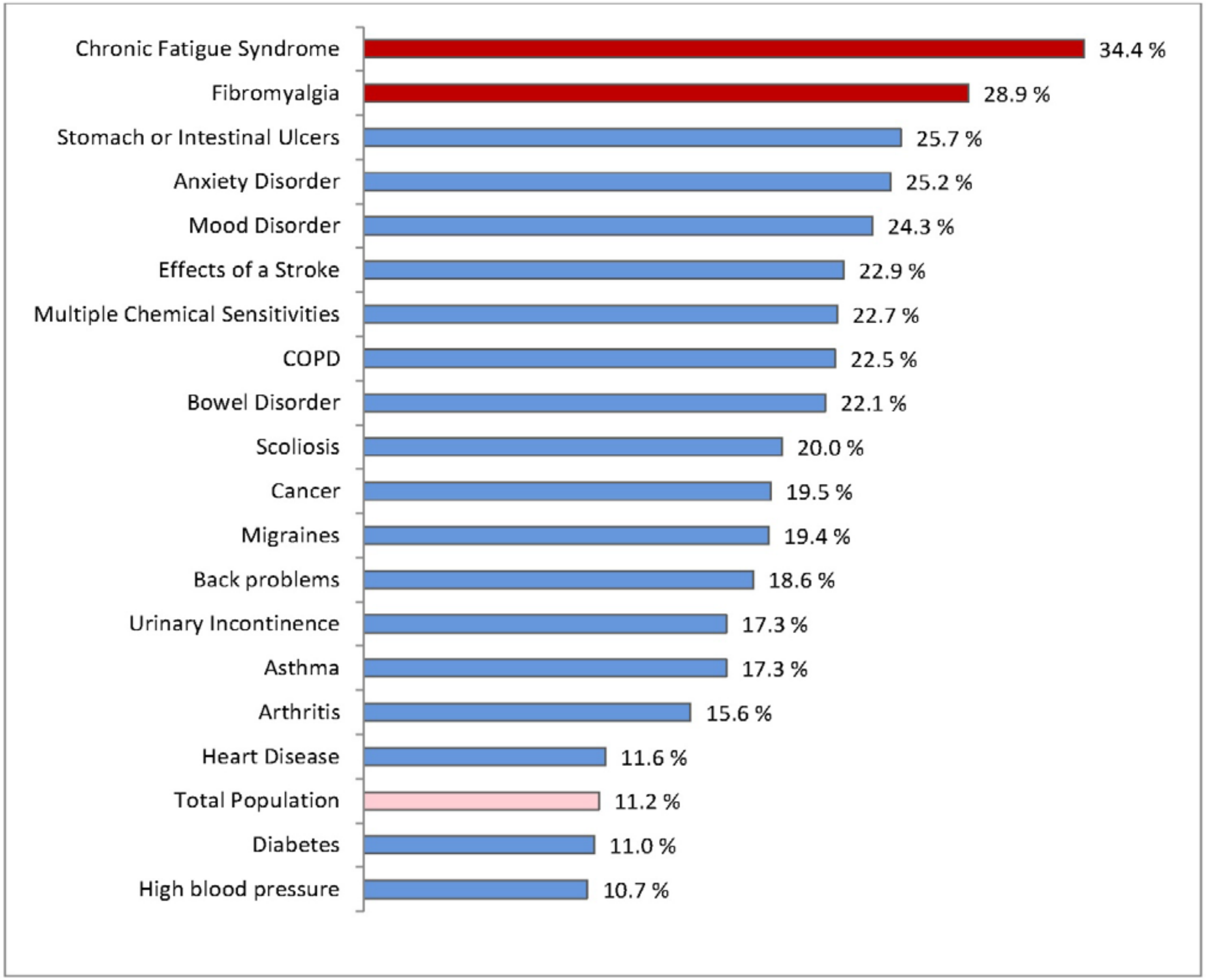
President
National ME/FM Action Network

1) Unmet needs

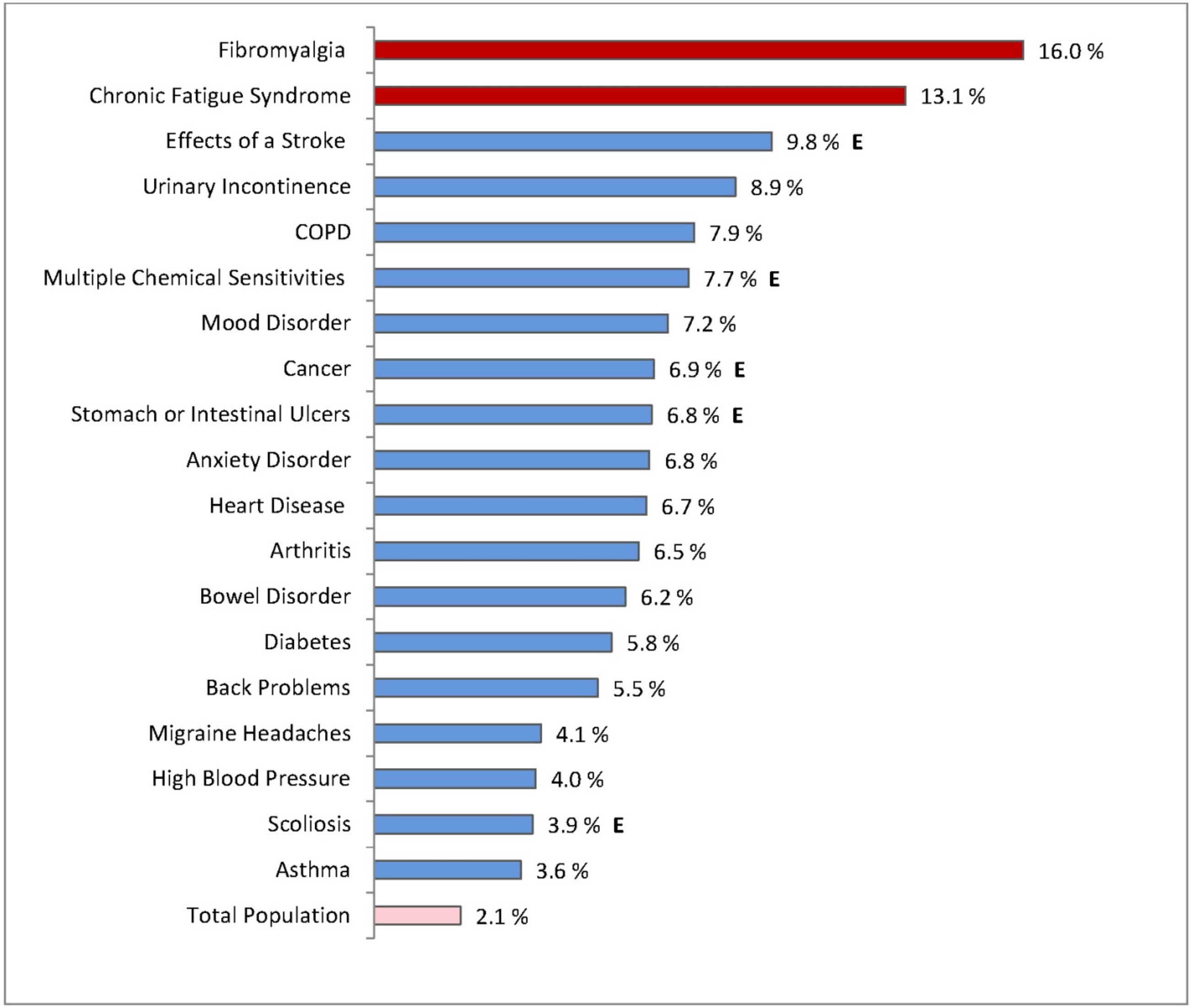
UNMET HEALTH CARE NEEDS

Canadians Aged 12 and Older Reporting Unmet Health Care Needs According to their Chronic Health Condition, 2014



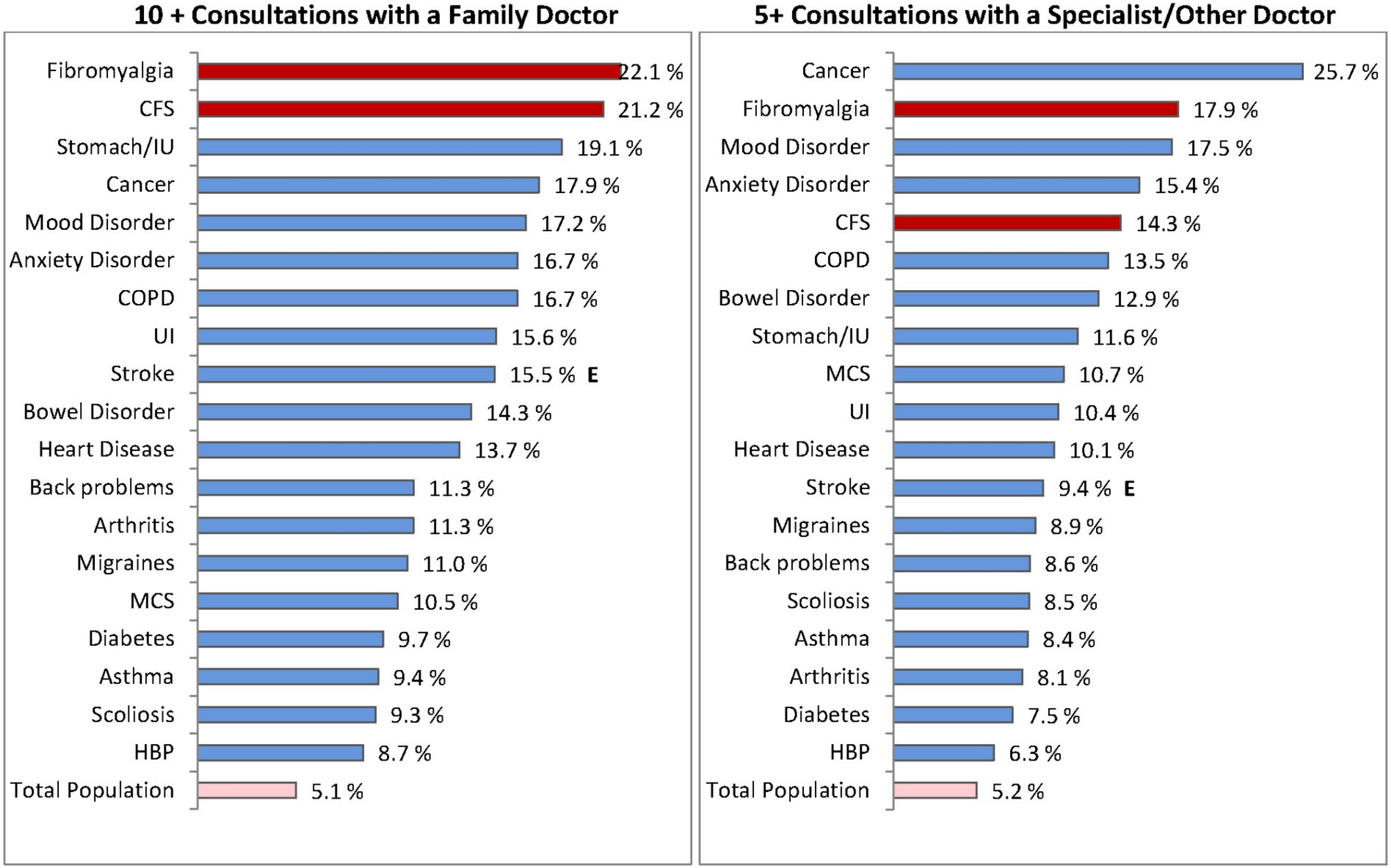
UNMET HOME CARE NEEDS

Canadians Aged 18 and Older Reporting Unmet Home Care Needs According to their Chronic Health Condition, 2014



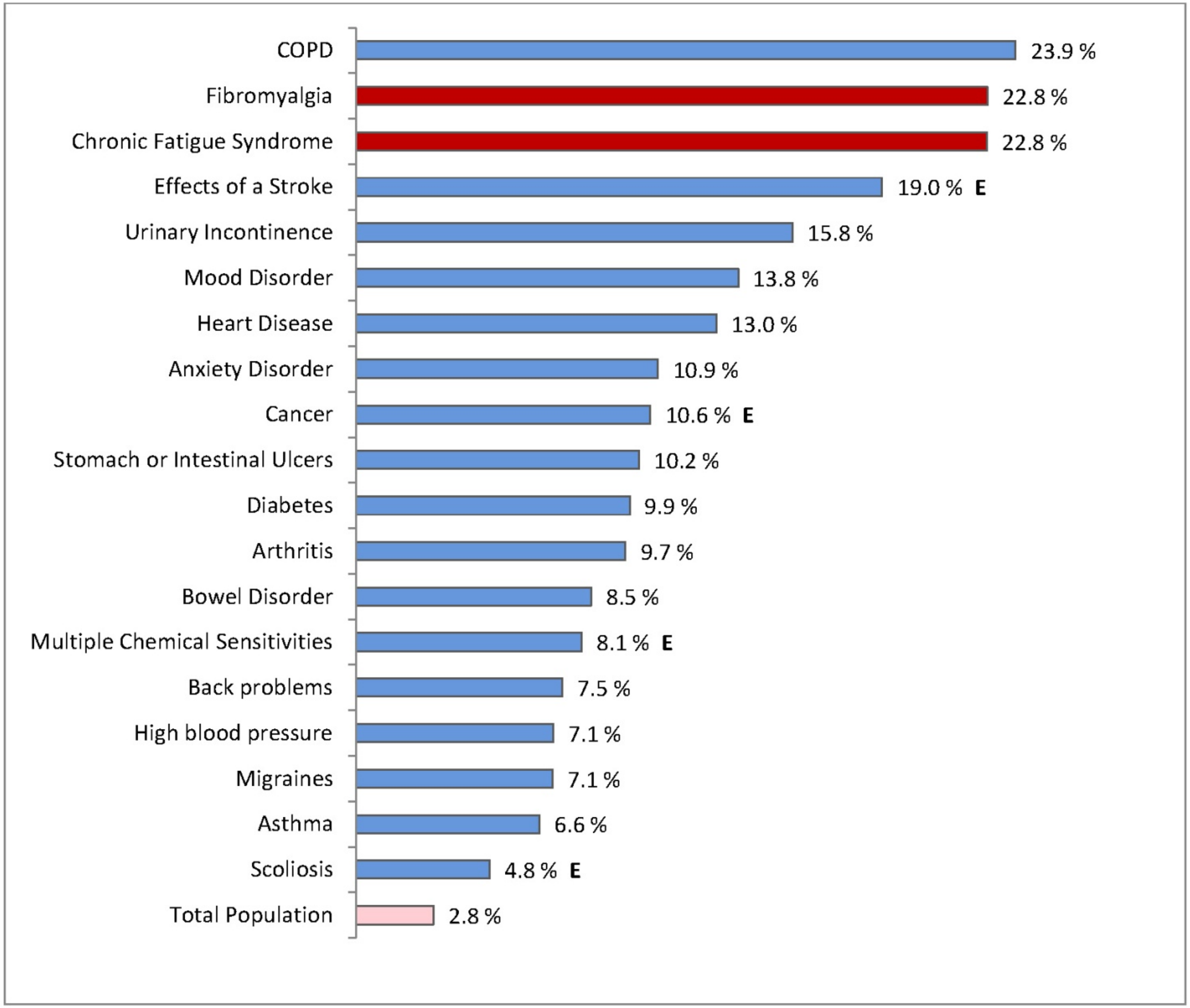
HEALTH CARE UTILIZATION

Health Care Consultations by Canadians Aged 12 and Older in the Previous 12 Months According to their Chronic Health Condition, 2014



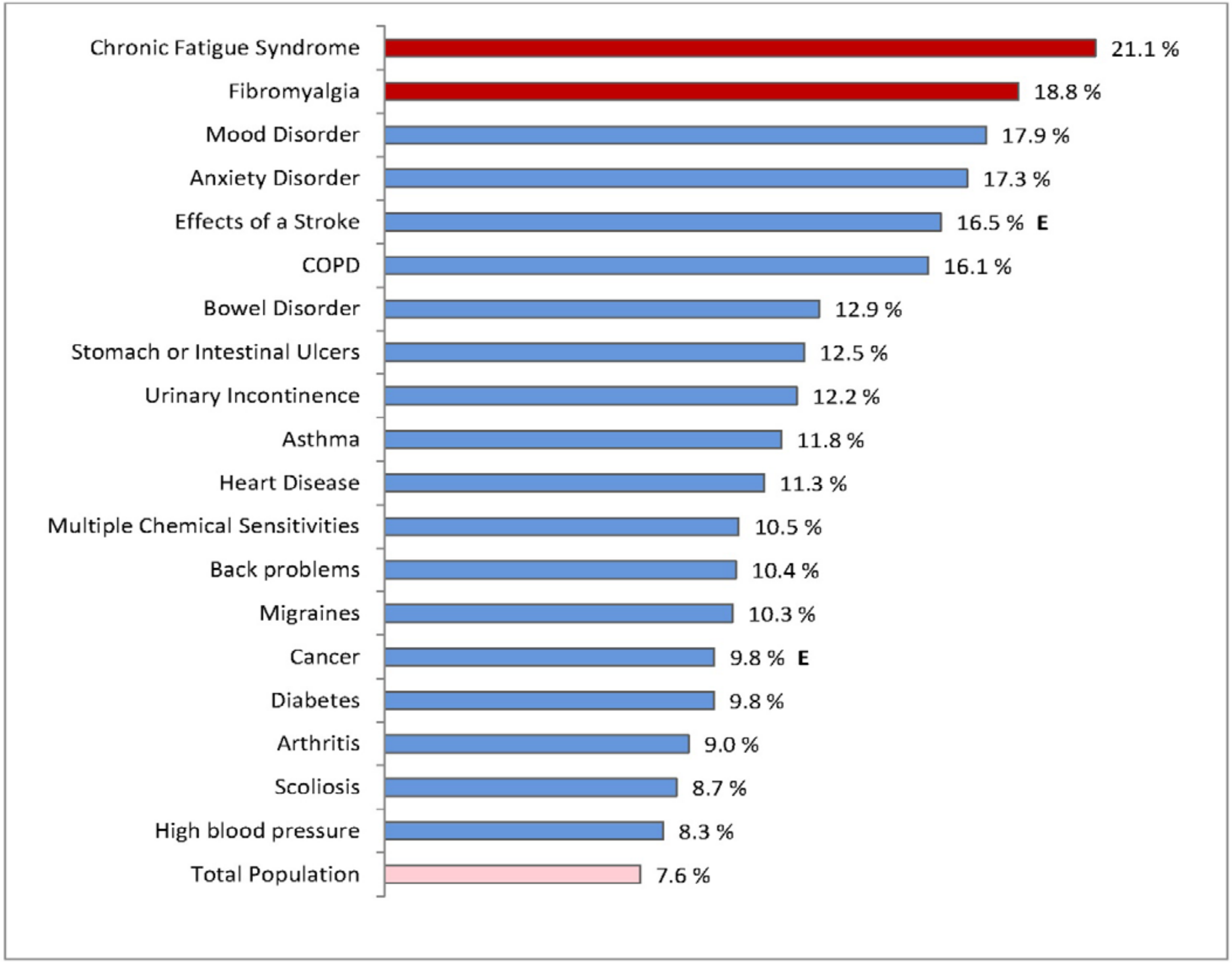
DISABILITY

Canadians Aged 18-64 who are Permanently Unable to Work According to their Chronic Health Condition, 2014



SOCIAL IMPACT

Canadians Aged 12 and Older Reporting a Very Weak Sense of Community Belonging According to their Chronic Health Condition, 2014



Goals

- Reduce unmet needs
- Reduce social isolation
- Improve health
- Prevention

Primary – stopping it in the first place

Secondary – stopping it from progressing

Tertiary – limiting the impact

- Wise use of health system resources

2) Innovation

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INACTIVISTS

Innovation

The central meaning of innovation really relates to renewal. For this renewal to take place it is necessary for people to change the way they make decisions, they must choose to do things differently, make choices outside of their norm.

Innovation generally

Current way

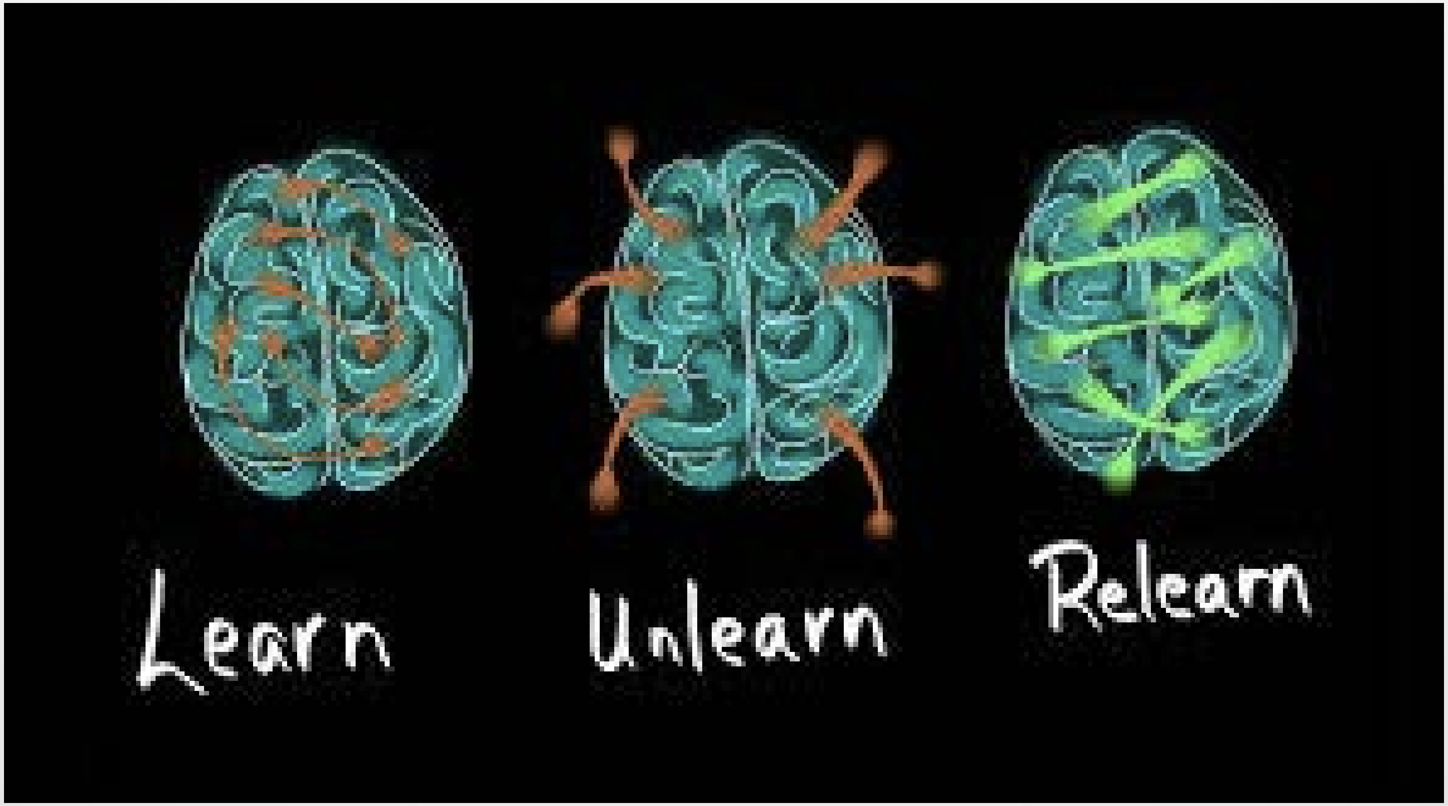
New way

Innovating ME/CFS

The psychosocial theory
Discredited

The biomedical theory
Now accepted

Innovation



3) Science

CIHR Funding Research into Chronic Conditions 2012-2015

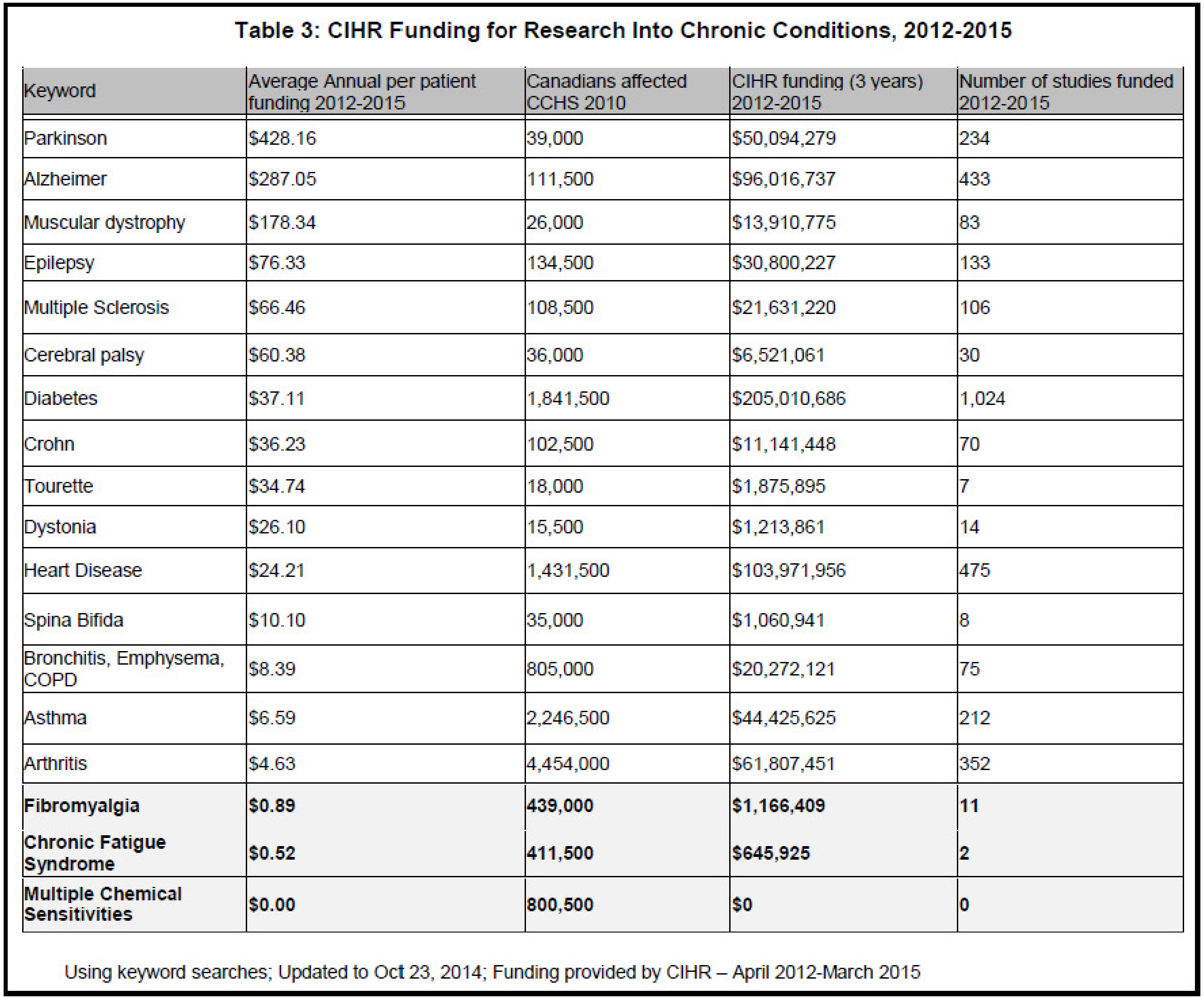
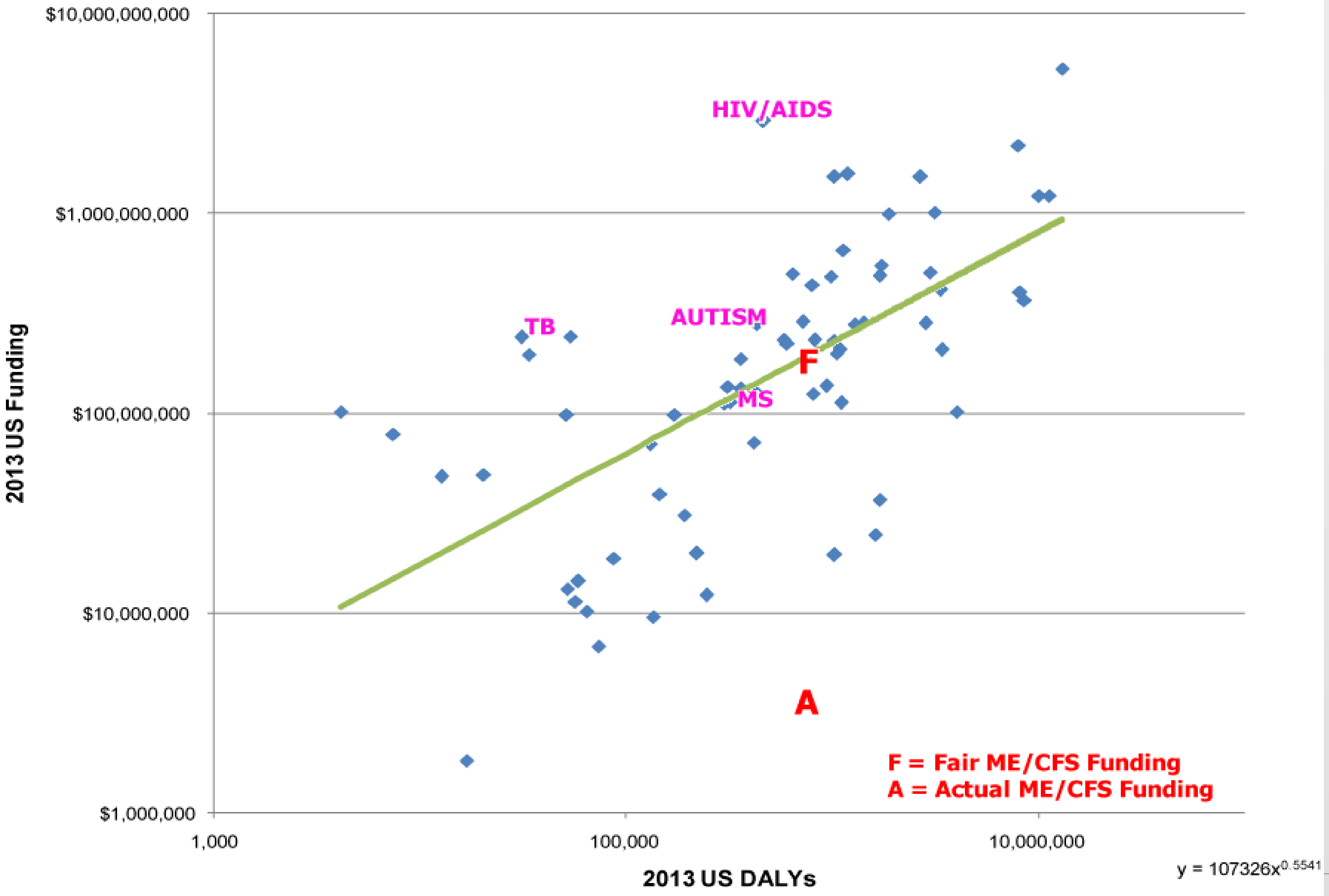


Table 3: CIHR Funding for Research Into Chronic Conditions, 2012-2015

Keyword	Average Annual per patient funding 2012-2015	Canadians affected CCHS 2010	CIHR funding (3 years) 2012-2015	Number of studies funded 2012-2015
Parkinson	$428.16	39,000	$50,094,279	234
Alzheimer	$287.05	111,500	$96,016,737	433
Muscular dystrophy	$178.34	26,000	$13,910,775	83
Epilepsy	$76.33	134,500	$30,800,227	133
Multiple Sclerosis	$66.46	108,500	$21,631,220	106
Cerebral palsy	$60.38	36,000	$6,521,061	30
Diabetes	$37.11	1,841,500	$205,010,686	1,024
Crohn	$36.23	102,500	$11,141,448	70
Tourette	$34.74	18,000	$1,875,895	7
Dystonia	$26.10	15,500	$1,213,861	14
Heart Disease	$24.21	1,431,500	$103,971,956	475
Spina Bifida	$10.10	35,000	$1,060,941	8
Bronchitis, Emphysema, COPD	$8.39	805,000	$20,272,121	75
Asthma	$6.59	2,246,500	$44,425,625	212
Arthritis	$4.63	4,454,000	$61,807,451	352
Fibromyalgia	**$0.89**	**439,000**	**$1,166,409**	**11**
Chronic Fatigue Syndrome	**$0.52**	**411,500**	**$645,925**	**2**
Multiple Chemical Sensitivities	**$0.00**	**800,500**	**$0**	**0**

Using keyword searches; Updated to Oct 23, 2014; Funding provided by CIHR – April 2012-March 2015

Funding vs US Burden of Disease - 2013



Research Teams/Networks

To generate new knowledge to improve diagnosis and treatment of ME/CFS in Canada

To facilitate and support translation and dissemination of new knowledge from bench to bedside to population in order to

- Improve patient outcomes
- Improve access to care
- Improve quality, efficiency and effectiveness of health care

Cause, biomarkers, subgroups

Dysfunction in many systems. Were 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.

Barriers to ME/CFS research

- Lack of research infrastructure
- Historically stigmatized
- Historically unfunded
- Complex, multi-system

Incentives to ME/CFS research

- Meeting unmet needs
- Opportunity for innovation
- Fascinating science

Thank you for your interest in ME/CFS

A challenging area

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