NATIONAL ME/FM ACTION NETWORK

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Submission Regarding
Canadian Research and Development Classification
by National ME/FM Action Network
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The issue

The Canadian economy spent $34B on Research and Development (R&D) last year. There is very little information available on where the money came from or how the money was used. We agree with the need for developing this area and thank you for the opportunity provide input into your initiative.

The proposed Canadian Research and Development Classification (CRDC) will have three parts: the type, field and purpose of research. The field of research classification reflects how academia and research are currently organized (chemistry, physics, clinical medicine, sociology...) It would provide information on the background and skills of people who are involved in research, but not on what they are researching. That is the role of the purpose of research classification which has not been fully developed.

In this submission, we explain why this initiative is very important to us and talk about moving the CRDC forward.

Who we are

The National ME/FM Action Network is a user of health research data. We represent Canadians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) or both. The 2014 Canadian Community Health Survey showed that there were over 800,000 Canadians with one or both diagnoses. These Canadians had high levels of disability, social isolation, food insecurity, unemployment, poverty, health system usage, unmet health care needs and unmet home care needs. http://mefmaction.com/docs/CCHS_Stats_2014.pdf

Multiple Chemical Sensitivities frequently overlaps with ME/CFS and FM. Around 1M Canadians have a MCS diagnosis. The three specialty clinics in Canada (BC, Ontario and Nova Scotia) deal with all three conditions, as did a recent Ontario government task force.

Action is desperately needed around all three conditions and research is an important part of this action.

Current information on funding by federal agencies

We have conducted numerous searches on the CIHR database and we have looked at the NSERC and SSHRC databases occasionally. We have used the searches to monitor research into ME, FM and MCS as well as comparator conditions.

We have concerns about the consistency and quality of individual study descriptions on the database.

We note that we can do searches around health conditions with distinctive names (eg multiple sclerosis or diabetes) but it is more challenging to search health conditions with generic names (eg stroke or anxiety) or multiple names (eg depression and mood disorders). We see value in consistently used keywords.

We also note that the funding agencies do not have the same search engine features, adding complexity to multi-agency searches.

We should not have to compile comparative figures across illnesses ourselves. This should be done by public officials as is done by NIH. NIH provides the information annually. We would like to see the information provided in real time.

Describing the purpose of research

Developing a purpose of research classification for health will be important and difficult. The difficulty arises because the purpose of government health funding is to serve the public interest, which is not exactly what is happening in the US, Canada, or many other countries.

This issue is discussed in a 2012 US article on disease politics and medical research funding. The author found that disease interest groups, as opposed to researcher interests or the public interest, have influenced health research funding in recent years. Well-organized and well-regarded diseases have done much better than less-organized and stigmatized diseases. ME/CFS, FM and MCS fall into the latter category. https://journals.sagepub.com/doi/10.1177/0003122412458509.

The US addressed the issue of the purpose of research funding in the late 1990's. The NIH described a five factor test for funding in 1997. That test was generally endorsed by the Institute of Medicine the following year:

1. public health need, as judged by the incidence, severity, and cost of specific disorders
2. the scientific merit of individual research proposals
3. the potential for scientific advancement in different fields
4. the desire to maintain some research in a broad range of areas “because we cannot predict discoveries or anticipate the opportunities fresh discoveries will produce”
5. the infrastructure and training programs that are needed to support current and future research

It is important to review those factors and to apply them to the Canadian context, starting with factor 1, public health need, also referred to as burden of illness.

A study on disease burden of a range of illness, graphed against their NIH funding, has already been published by NIH. https://report.nih.gov/info_disease_burden.aspx ME/CFS, FM and MCS were not included in the NIH study. A study on the burden of ME/CFS in the US was subsequently published. The authors calculated the burden of ME/CFS, matched it with NIH funding for ME/CFS, added the point to the graph and calculated a regression line for equitable funding. The results showed serious under-funding of ME/CFS research in the US. https://oatext.com/Estimating-the-disease-burden-of-MECFS-in-the-United-States-and-its-relation-to-research-funding.php

The Canadian Community Health Survey provides good initial data for a Canadian burden of illness study. It shows a higher prevalence rate for ME/CFS than was used in the US study, suggesting that the US study on ME/CFS could underestimate the Canadian situation. It also suggests that the burden of illness for FM and MCS would each be in the same general range as the burden of illness for ME/CFS.

ME/CFS is poised for a research breakthrough and will bring FM and MCS with it (factor 3). This is an area of research which needs more attention (factor 4). Infrastructure and training are badly needed (factor 5). The hold-up is at factor 2, where the funding system confuses scientific merit with scientific maturity, thereby favouring well-established and well-regarded conditions. That issue will be resolved and ME/CFS, FM, and MCS research will soon emerge on the research scene. They will also emerge for other reasons including the growing interest in chronic pain, concern for female dominant illnesses, and concern around social issues like food security and employment.

Altogether, this means that ME/CFS, FM and FM need to be identified under the purpose of research classification because they are important and because their research needs to be monitored.

Describing the fields of research

The types of research being carried out affects the fields of research needed, so the field of research classification should not be finalized without looking at future directions of research. Having current researchers to test the current field of research proposal will not necessarily identify shifts that will happen in the future.

Funding/spending across all sectors

Our best guess is that $7B was spent in Canada on health research in Canada this fiscal year. This estimate is based on an old figure which suggests that health spending is about 20% of total R&D spending.

Other than the CIHR spending ($1B), it is not at all clear to us who is providing the funding and how that funding is being used. This is a major gap in information which needs to be filled.

Key points:

- In developing a classification system, one is identifying issues that one considers important enough to monitor.
- Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical Sensitivities are not yet included in the proposed CRDC. Experts in this area bring a special perspective to health research and should be specifically consulted when addressing this gap.
- The CRDC will be used for monitoring in the future, so future directions of research need to be anticipated. This will particularly affect the purpose of research classification, but it has implications for the type of research classification as well.
- The public's ability to extract information from the CIHR, NSERC and SSHRC funded research databases is very valuable. These databases should continue to be available to the public.
- It should not be the responsibility of the public to compile core information on health research spending. This is public information that should be publicly provided. We particularly call on CIHR to provide statistics on funding by disease, something that is already done by NIH.
- Research data does not exist in a vacuum. It will be matched with data such as prevalence of disease or burden of illness. The supporting data needs to be considered as part of CRDC discussions.
- The four federal funding agencies account for only about 10% of R&D funding in Canada. Information is needed about the other 90%.