

Institute of Aboriginal
Peoples' Health

Institute of Aging

Institute of Cancer
Research

Institute of Circulatory
and Respiratory Health

Institute of Gender and
Health

Institute of Genetics

Institute of Health Services
and Policy Research

Institute of Human
Development, Child and
Youth Health

Institute of Infection
and Immunity

Institute of Musculoskeletal
Health and Arthritis

Institute of Neurosciences,
Mental Health and Addiction

Institute of Nutrition,
Metabolism and Diabetes

Institute of Population and
Public Health

Institut de la santé
des Autochtones

Institut du vieillissement

Institut du cancer

Institut de la santé
circulatoire et respiratoire

Institut de la santé des
femmes et des hommes

Institut de génétique

Institut des services et
des politiques de la santé

Institut du développement
et de la santé des enfants
et des adolescents

Institut des maladies
infectieuses et immunitaires

Institut de l'appareil
locomoteur et de l'arthrite

Institut des neurosciences,
de la santé mentale et
des toxicomanies

Institut de la nutrition,
du métabolisme et du diabète

Institut de la santé publique
et des populations

February 15, 2018

BY EMAIL

Dear Ms. Neilson,

Thank you for your email of January 29, 2018, regarding the release by the US NIH of a proposal for Common Data Elements (CDEs) for ME/CFS. The proposal has the potential to further standardize research in the area of ME/CFS in clinical trials and large epidemiological studies and help guide data collection.

We wish to thank you for taking the time to submit your comments during the NINDS Public Review Period and provide valuable input based on your expertise and lived experience as representatives of the Canadian ME/CFS community.

We are happy to have the opportunity to continue working with you, and other organizations to advance research in this area. As you know, we continue to collaborate with our American counterparts to find opportunities and determine possible next steps to help advance research and to assess how the CDEs will impact Canadian research.

We will follow with much interest the recommendations stemming from the Public Review Period for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) CDEs when they are published this month.

Sincerely,



Michel Perron
Executive Vice-President
External Affairs and Business Development
Canadian Institutes of Health Research