

March 10, 2014

Dr. Alain Beaudet, President
And Dr. Jane Aubin, Chief Scientific Officer/Vice-President of Research at CIHR
Canadian Institutes of Health Research (CIHR)
160 Elgin Street, 9th Floor
Address Locator 4809A
Ottawa, ON K1A 0W9

Re: Task Force

Dear Drs. Beaudet and Aubin,

The Task Force is heartened to hear that the President of the CIHR and the CIHR management agree with our report on the need for strong ethical leadership at CIHR and that Governing Council takes very seriously its legislated mandate in ethics.

Our key recommendation on ethical leadership called for a person to animate CIHR in this direction. We described that person as follows:

In order to properly reflect the prominence of ethics within the CIHR mandate, this person must have earned a standing within the research ethics community that is at least analogous to that of the Institutes' Scientific Directors. He or she must have the knowledge, skills and experience to elevate the status of ethics to a position within the organization that more fairly reflects the prominence of ethics in the CIHR mandate, and to develop and execute innovative, world-class programming in research ethics and related research policy. The person in this position should be recognized nationally and internationally as a leading scholar and researcher in ethics familiar with interdisciplinary approaches to research in and application of ethics. (p. 10)

In no way does the proposed management plan do this. Indeed, we would ask whether CIHR as a knowledge-based organization would appoint a non-expert for leadership of any of its Institutes.

The letter from the President mentions a scan of international health research organizations and states that "... there is no single common model of governance of the ethics function. ... [T]he scan indicates that executive leaders are not typically experts in ethics, but rather that they are informed by strong, knowledgeable advisory bodies." We would point out that CIHR is different than most other international health research organizations in having a strong and explicit legal mandate to show ethical leadership in

health research. Yet, by way of comparison, the USA has an independent Presidential Commission on Bioethics and the NIH has one of the world's most productive bioethics centers. The latter is focused on research ethics as an intramural program and provides ethics consultation across the NIH. France, another leading comparator, has an independent National Consultative Ethics Committee. Despite the stronger mandate for ethics at CIHR, there are no analogous leadership or governance mechanisms in Canada.

The CIHR Management Response rejects our key recommendation of an independent VP as "neither operationally feasible nor ideal" on the grounds that the position "is not integrated within CIHR leadership and decision-making". In our Report, we propose a definite and clear change to CIHR's current managerial structure. Our Report laid out in clear terms how this leadership in ethics can be well integrated into a new and revitalized management structure.

In the absence of a Chair with nationally and internationally recognized expertise in ethics, we do not believe that the newly proposed Ethics Advisory Board (EAB) will have the credibility to provide the leadership we recommended in our report. Furthermore, by not having a leader with a high level of expertise and credibility directly involved in the deliberations of the Scientific Directors, Governing Council is sending the message that ethics is peripheral at both the governance and operational levels of CIHR. To speak plainly, we do not see the plan proposed as a significant advance beyond the current situation at CIHR - one in which ethics has been pushed to periphery. Our Task Force report has struck a chord within the Canadian bioethics community. We have received a great deal of support for our conclusions and recommendations.

While we thank you for responding to our report, we wish to express our disappointment in the response.

Yours truly,



Bartha Maria Knoppers
Chair, CIHR Task Force on Ethics

Members:

Daryl Pullman
Tim Caulfield
Jim Lavery
Michael MacDonald

Cc: IAB EDs

Aboriginal People's Health—Suzanne Tough (suzanne.tough@albertahealthservices.ca)

Aging—Ross Upshur (ross.upshur@sunnybrook.ca)

Cancer Research—Ronald Heslegrave (hesgrave@uhnres.utoronto.ca)

Circulatory and Respiratory Health—Vacant

Gender and Health—Francoise Baylis (francoise.baylis@Dal.ca)

Genetics—Vardit Ravitsky (vardit.ravitsky@umontreal.ca)

Health Services and Policy—Pascale Lehoux (pascale.lehoux@umontreal.ca)

Human Development, Child and Youth—Vassilios Papadopoulos (vassilios.papadopoulos@mcgill.ca)

Infection and Immunity—Chris Kaposy (christopher.kaposy@med.mun.ca)

MSK Health and Arthritis—Stephen Rabinovitch (stever@sfu.ca)

Neurosciences, Mental Health and Addiction—Eric Racine (eric.racine@ircm.qc.ca)

Nutrition, Metabolism and Diabetes—Amit Garg (amit.garg@lhsc.on.ca)

Population and Public Health—Angus Dawson (a.j.dawson@bham.ac.uk)

SCE Chair—Lisa Schwartz (schwar@mcmaster.ca)