

IAB ETHICS DESIGNATES (IABEDs)

Teleconference December 18, 2013

Minutes

Participants

IABEDs: Françoise Baylis, Angus Dawson, Ronald Heslegrave, Pascale Lehoux, Eric Racine, Ross Upshur, Suzanne Tough

Regrets: Amit Garg, Chris Kaposy, Vassilios Papadopoulos, Vardit Ravitsky, Steve Robinovitch.

CIHR staff: Jane Aubin, Kelly VanKoughnet, Peggy Borbey, Geneviève Dubois-Flynn.

Welcome Remarks

Jane Aubin, CIHR Chief Scientific Officer, welcomed IABEDs to the meeting. She assured them that Governing Council and Science Council are committed to meeting the CIHR's legislative mandate in Ethics and that they have taken very seriously the recommendations of the Ethics Task Force.

Approval of Agenda

The agenda was approved with the addition of an item to discuss a face-to-face meeting of IABEDs and the Standing Committee on Ethics.

Debrief on Task Force on Ethics Reform at CIHR Report

Jane Aubin summarized the successive discussions that took place at Governing Council, Science Council and the Standing Committee on Ethics. She indicated that the Chair of the Ethics Task Force participated in the June 2013 Governing Council meeting and that Governing Council members discussed high-level issues raised by the Task Force at that meeting. Governing Council also discussed the Task Force recommendations at their meeting in November 2013. No final decisions have yet been taken. Governing Council members will continue their deliberations on the Ethics Task Force report at their meeting in February 2014.

IABEDs raised several questions to which Jane Aubin offered responses:

- Q1: Why are the problems with ethics at CIHR (as identified in the Ethics Task Force report) described as "perceptions"? Does this mean that CIHR does not consider these problems a "reality"?

A1: Different people have different perspectives as regards ethics at CIHR. The perspective at CIHR is that there are problems with visibility and effectiveness that need to be addressed. The Ethics Task Force report reflects both a perception of the community and the reality of a less robust ethics function within CIHR. This reality must be addressed by strengthening the function of ethics at CIHR and increasing the visibility of ethics at CIHR – for example, CIHR's investments in Ethics by Institutes.

Following this discussion, it was acknowledged by the IABED who asked the original question, that staff in CIHR's Ethics Office had done important work with limited direction and leadership.

- Q2: Will CIHR accept the Ethics Task Force's first and foremost recommendation to create a position of VP Ethics?

A2: The merits of this option versus a model of integrated, distributed leadership are being considered by Governing Council. The creation of a position of VP Ethics may silo ethics rather than integrate it. Governing Council has made no final decisions.

Following this discussion, it was noted that a shared leadership model is not consistent with taking the recommendations of the Ethics Task Force seriously (all but five of the 20 Task Force recommendations refer to the VP Ethics).

- Q3: What is Governing Council's response to the Ethics Task Force other recommendations?

A3: Governing Council has not yet formulated its public response to the Ethics Task Force. Governing Council asked for additional information that it will use in making its final decision. This will include an international environmental scan on mandate and structure of ethics in health funding organizations. Additional discussion is expected at the Governing Council February, 2014 meeting.

- Q4: Why did Governing Council not consult with (ask for additional information from) persons with ethics expertise and relevant experiential knowledge within CIHR, including IABEDs?

A4: As IABEDs were one of the communities consulted by the Ethics Task Force, Governing Council considered the report to include the views of IABEDs and the broader community. It is now Governing Council's responsibility to formulate a response based on its own perspectives. Governing Council can choose whom it consults with and has not chosen to consult IABEDs.

- Q5: Why were IABEDs not provided with a copy of the Task Force report? One IABED requested the report in the fall of 2013 and was told that only a summary would be available. Later, near the end of November 2013, the IABED was provided with a copy, but the report was not provided to other IABEDs. Later, at the request of the IABED, CIHR invited other IABEDs to write and request a copy. The report was eventually distributed to other IABEDs, by another IABED.

A5: The Ethics Task Force report provided its report to Governing Council in May, 2013. Since that time, Governing Council has been in deliberations regarding the best approach going forward.

- Q6: Why wasn't an update on the Ethics Task Force report provided to IABEDs?

A6: Scientific Directors have the opportunity to update the Institute Advisory Board at their meetings. This can lead to heterogeneity of information flow from CIHR to Institute Advisory Boards (IABs) and IABEDs. The flexibility in the current operational model

responds to needs and interests of various Institutes; however it is clear that there is core information that everyone should receive (IABs as a whole, and IABEDs as a group). It was acknowledged that more systematic communication could have been organized and will be going forward.

Following this response, it was noted that general information was provided by some Scientific Directors to IABs, but that they did not appear to be at liberty to circulate a copy of the Ethics Task Force report or to share any substantive information.

- Q7: Who is ultimately accountable for ethics in the proposed integrated, distributed leadership model?

A7: Ethics is a shared accountability at CIHR with Science Council at the core. There are different possible models for shared leadership. For example, a hybrid model for a working ethics committee of CIHR could include both external and internal members (in particular ethicists and Scientific Directors). The shared/distributed leadership could also include a robust understanding of the role of the Secretariat on Responsible Conduct of Research.

Following this response, it was suggested that the evaluation of ethics must remain an accountability of Governing Council. Jane Aubin agreed.

- Q8: Who will be the ethics champion if ethics is folded into an administrative function (with responsibility for ethics possibly shared among persons lacking ethics expertise)?

A8: The proposed integrated leadership model does not make it clear where ethics leadership will reside. Addressing this issue is part of the ongoing discussion. One possibility would be that the Chief Scientific Officer be the Ethics champion internally and the Chair or Vice-Chair of the ethics advisory committee be the champion externally.

Organize a face-to-face meeting of IABEDs and Standing Committee on Ethics

A request was made for a face-to-face meeting involving IABEDs and members of the Standing Committee on Ethics. Governing Council has not made a decision on the future of the Standing Committee on Ethics and nature of an ethics advisory board for CIHR. At their recent meeting, Standing Committee on Ethics discussed the reappointment of members until Governing Council meets in February 2014.

Draft CIHR Ethics Action Plan

At their meeting in June 2013, Governing Council charged Science Council to have more extensive discussions on a forward action plan for ethics. This in turn led to the development of a draft action plan. Input was recently provided from the Standing Committee on Ethics. The plan will be finalized by the new ethics advisory board that Governing Council will support and will make known at its February 2014 meeting.

IABEDs were invited to provide additional comments on the draft CIHR Ethics Action Plan (other than those shared during the teleconference), based on the documents that were sent to them (draft Ethics Action Plan and powerpoint presentation). The goal of the Action Plan is to strengthen impact through integration of ethics in CIHR's core business.

IABEDs raised additional substantive issues that were addressed by Jane Aubin:

- Q9: The Action Plan begins with a discussion of 3 pillars of ethics – ethical conduct of research; ethics of research; and research on ethics. It seems the focus is on research. Shouldn't the other issues such as the conduct of research, and ethical issues related to partnerships be addressed?

A9: It was agreed that the other pillars need to be better reflected in the Ethics Action Plan, including the role of the Tri-Council Secretariat on Responsible Conduct of Research and other CIHR activities such as current discussions on partnerships. In the draft Ethics Action Plan, there is a focus on ethics research but there should also be a focus on the application of research principles and a focus on the issues of secondary use of data sets and biological samples.

In her concluding remarks, Jane Aubin thanked all the participants for having made themselves available for the meeting and committed to ongoing communications with the group.