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Key Task Force recommendation rejected

CIHR management's plans for ethics come under fire from ethics researchers

By Mark Henderson, Editor

A prominent research ethicist is asking Parliament to call the president of the Canadian Institutes of Health Research (CIHR) to appear before a committee to explain why the agency rejected a key recommendation by a Task Force on Ethics Reform and is failing to meet its legislated obligation to maintain a strong and substantive ethics program.

Dr Françoise Baylis, a professor and Canada Research Chair in bioethics and philosophy at Dalhousie Univ, issued the "Mayday" following CIHR management's response to the Task Force report, which rejected the call for a VP ethics - a position that figured prominently in the Task Force's 20 recommendations.

CIHR has proposed what it describes as a more integrated model where responsibility for ethics will fall to the chief scientific officer/VP research, knowledge translation - currently held by Dr Jane Aubin. She would be assisted by Dr Paul Garfinkel, a professor of psychiatry at the Univ of Toronto and a recently appointed member to CIHR's Governing Council. Garfinkel is also the new chair of CIHR's Standing Committee on Ethics.

CIHR's decision also prompted the Task Force chair, Dr Bartha Knoppers, to issue a letter to president Dr Alain Beaudet and Aubin. In the March 10th letter, Knoppers - director of the Centre of Genomics and Policy at McGill Univ and Canada Research Chair in Law and Medicine - expressed "disappointment" in CIHR management's response, which she said will perpetuate a situation in which "ethics has been pushed to the periphery".

CIHR governing council rejected the VP ethics position as "neither operationally feasible nor ideal". Instead, it will incorporate its ethics mandate in a "new integrated and shared structure of leadership and accountability" that is now being developed. In addition, the CIHR Governing Council Standing Committee on Ethics will be "refreshed" under a new chair (Garfinkel).

"We liked the report's recommendations but the response from CIHR was deeply disappointing," says Baylis, who previously was a member of the CIHR Governing Council, co-chair of the CIHR Standing Committee on Ethics and is currently the CIHR Institute Advisory Board Ethics Designate for the Institute of Gender and Health. "The VP ethics recommendation is the big issue ... Leadership makes all the difference. CIHR could have proposed a viable alternative (to the recommendation) but didn't."

"The mandate of the CSO/VP and of Science Council includes knowledge creation, knowledge translation and ethics, placing both in a strategic position to integrate all three consistently. Funding for ethics knowledge generation and translation projects can be funded in current open funding programs and will be eligible in the new foundation and project schemes."

— **CIHR management response to Task Force**

Under CIHR's proposed structure for ethics, the CSO will become the organization's ethics champion with support from the refreshed standing committee on ethics.

"We agreed with the need for stronger leadership but not through an independent expert executive ... We did not consider it ideal," says Peggy Borbey, the interim director of CIHR's recently created science, knowledge translation and ethics position. "

The Task Force report was supported by most members of the research ethics community as a strong affirmation for change. The Task Force was struck following a number of internal changes at the council and an international review of CIHR's ethics performance. CIHR also undertook an international scan of other organizations to better understand how other agencies handled the ethics file.

Rejection of the recommendation and lack of clarifying information has raised widespread concern within the research ethics community that the challenges facing CIHR are not being taken seriously.

"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."

— **letter from Dr Bartha Knoppers to CIHR senior management**

"CIHR has been slow to respond to queries over the last few weeks and that has led to rumours, including one that the Standing Committee on Ethics was being dissolved. There's a lack of transparency in the decision-making process," says Dr Lisa Schwartz, the standing committee's vice-chair and chair in health care ethics at McMaster Univ. "I think CIHR rushed to do the right thing but it hasn't been properly clarified ... It's not clear why they are making the choices they are making in response."

Like Baylis, Schwartz says she's disappointed in CIHR's decision to delegate ethics to a person who is currently holds two senior roles within the council.

"Jane Aubin is a terrific person and will be a great ethics champion. This is reasonable and to be applauded but it's not sufficient," says Schwartz. "Aubin has no specialized training in ethics and she's also extremely busy ... It's not fair for a portfolio as significant as this one to founder at the corner of a desk."

"The ethics function at CIHR is more than an ethical imperative or best practice in research. Instead, CIHR has a clear legal obligation to have a strong and substantive ethics programme as an essential part of its broader mandate to improve the health of all Canadians."

— **Task Force on Ethics Reform**

Schwartz says she's eager to hear more about the "refreshed" standing committee after its "gradual diminishment" over the past several years. Once quite active and populated by 13 members, the committee now has little to do and only meets once a year (down from four).

"A first (and this is only the first) step is to create a position of ... VP Ethics, or a position of equivalent stature, and then hiring a strong individual to fill that role. 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." — **Task Force on Ethics Reform**

Departing members were not replaced and attempts to find an appropriate individual to head up the committee failed, leaving members demoralized, says Schwartz.

"It diminished the strength and cohesiveness of the message of ethics within the organization and our ability to raise issues coherently. Everything broke down," says Schwartz. "We were lucky in that there were no flaws or problematic outcomes ... My concern is that, in the future, if leadership is not comfortable hearing opposition, we may run into problems."

Borbey notes that CIHR management's response to the Task Force report includes several other changes that will improve the ways in which the council integrates and utilizes ethics. She says the new structure will ensure that CIHR promotes, assists and undertakes research that "reaches the highest international standards of ethics".

Proposed changes

Changes includes drafting a new communications plan to explain the new approach to ethics and an action plan that will oversee the refreshed standing committee on ethics.

"The refreshed standing committee is not completed as it was just decided in February. The governing council nominating committee will take action but we need a transition strategy," says Borbey, adding that the new committee will be expanded in terms of the types of members it includes. "The committee currently doesn't interact with management at CIHR as there's no structure for this. Once we start working with them (research ethics community) they will see we are taking up the mantle."

Compromise uncertain

As for the community's current protest over the rejection of a VP ethics, Borbey says "we're going to have to disagree ... We'll continue to reach out and reassure people that the direction we're going is up".

Whether the changes and communications outreach will satisfy critics remains to be seen. Baylis says the Task Force was comprised of eminent people who provided advice grounded in a legislated mandate, hence the recommendation for a VP ethics.

"That's the big issue. If it was accepted, I would not be doing what I'm doing. Leadership makes all the difference. They could have recommended a viable alternative but they didn't," says Baylis, who maintains a blog at www.impactethics.ca. "I was the last member of Governing Council to co-chair the Standing Committee on Ethics who was a researcher in ethics ... I don't question CIHR's authority to respond to the report but there's a huge gap between that authority and the substance of what is being recommended. I want to hold them accountable."

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