Document generated on 11/14/2026 6:30 a.m.

Canadian Journal of Bioethics
Revue canadienne de bioéthique

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Volume 7, Number 4, 2024

URI: https://id.erudit.org/iderudit/1114961ar
DOI: https://doi.org/10.7202/1114961ar

See table of contents

Publisher(s)

Programmes de bioéthique, École de santé publique de l'Université de Montréal

ISSN

2561-4665 (digital)

Explore this journal

Cite this article

Lapteva, A., Bubela, T., Chandler, J., Knoppers, B., Upshur, R., Ravitsky, V. & Illes, J. (2024). From Patchwork to Framework: Expert Interview Insights on Establishing a Bioethics Council for Canada. *Canadian Journal of Bioethics / Revue canadienne de bioéthique*, *7*(4), 84–89. https://doi.org/10.7202/1114961ar

Article abstract

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

From Patchwork to Framework: Expert Interview Insights on Establishing a Bioethics Council for Canada

Alice Lapteva[a], Tania Bubela[b], Jennifer Chandler[c], Bartha Knoppers[d], Ross Upshur[e,f], Vardit Ravitsky[g,h], Judy Illes[i]

Résumé
Le Canada s'est historiquement appuyé sur un système de comités *ad hoc* pour l'orientation éthique de la santé publique et de la politique scientifique, contrairement à l'approche plus centralisée de plus de 140 pays dans le monde. En s'appuyant sur des entretiens avec des responsables de tout le pays, nous proposons ici une perspective sur l'impératif et une stratégie pour un Conseil de bioéthique coordonné pour le Canada, structuré pour assurer une réflexion proactive, fournir des réponses rapides et engager le public sur des questions urgentes de bioéthique concernant la santé et le bien-être des Canadiens.

Mots-clés
bioéthique, politique de santé, conseil national de bioéthique

Abstract
Canada has historically relied on a system of ad hoc committees for ethical guidance on public health and science policy, unlike the more centralized approach of more than 140 countries worldwide. Here, drawing on interviews with leaders across the country, we offer a perspective on the imperative and a strategy for a coordinated, Bioethics Council for Canada structured to ensure proactive thinking, provide rapid responses, and engage the public on urgent bioethics matters concerning the health and well-being of Canadians.

Keywords
bioethics, health policy, national bioethics council

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INTRODUCTION

More than 140 countries around the world rely on a national bioethics body for advice on critical issues of concern to their citizens. Although models vary by country, such advisory bodies have been mandated to systematically address ethical dimensions of science, technology, and health. Unlike these other countries, Canada's approach to obtaining bioethics advice has historically relied on a patchwork of ad hoc committees. For example, the Tri-Council Working Group on Ethics, the National Council on Bioethics in Human Research, the Canadian Institutes of Health Research Standing Committee on Ethics (now Ethics Advisory Committee), and different committees of the Public Health Agency of Canada, Health Canada, and of Parliament have been convened to address bioethics issues at different times in contemporary history. The House of Commons and Senate of Canada committees, as well as professional organizations such as the Council of Canadian Academies and the Royal Society of Canada, have participated in discussions of ethical issues that have spanned COVID-19 response and pandemic preparedness, genomics, and emerging technologies.

While Canada's approach has yielded important guidance, the patchwork of specialized committees, each working with differing mandates and for different receptors, is disjointed in its pursuit of overlapping and diverging goals. Writing 34 years ago for the Law Reform Commission of Canada, Baudouin et al. argued for a national advisory body that would bring "*coordination and consistency in the country's scientific and ethical activities*." (1, p.49) This recommendation was unsuccessful at the time. With the abolishment of the Law Reform Commission in 1993 and a change in government, the proposal for such a body was sidelined. Yet, the call for a centralized framework resonates louder than ever today. Unprecedented current-day and anticipated imperatives have created a need for a national bioethics entity whose advice would anticipate Canadian solutions to global challenges. These include Indigenous rights, social media as a platform for public discussion, misinformation joined with politicization and polarization of issues, the impacts of the climate crisis on human health, and artificial intelligence. Strengthening the ethics infrastructure on a national level, allows each country to reflect upon its society's needs and concerns in providing reasonable and responsible guidance given its specific cultural and moral diversity. As such, legally mandated, independent, and diverse national bioethics committees represent important providers of recommendations and guidance to governments and the public regarding policy (2).

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ISSN 2561-4665

Previously, through an international consultation beginning in 2020, we provided the first proof of principle for centralizing bioethics-informed guidance for Canada (3,4). Seven participants selected for their current and prior leadership positions on bioethics bodies provided significant insights into the establishment, best practices, and impacts of national bioethics bodies worldwide (4). In discussing examples of success, the consultations highlighted the importance of interdisciplinary representation, organizational autonomy, and the need for a clear mandate. For example, Japan's Expert Panel on Bioethics has effectively advised government on policymaking in addressing issues such as human genome editing, demonstrating the benefits of capturing public perspectives in ethical decision-making. Similarly, the German Ethics Council set an exemplary model for a council's political independence and diverse membership through its social and religious representative approach. Overall, participants emphasized that Canada could benefit from such a body to handle complex issues such as pandemics, environmental degradation, and the ethical implications of new technologies, ensuring robust and anticipatory bioethics-informed governance of current and future issues.

In February 2022, we also conducted a national consultation with Canadian experts selected for the roles they have played in Canadian bioethics (4). They further expressed support for a national bioethics body for Canada as long as it presented a clear mandate and purpose, and was independent from political influence.

In addition, the movement toward a unified bioethics body is well aligned with the recent 2023 Report of the Advisory Panel on the Federal Research Support System that highlights significant fragmentation, lack of coordination, and inadequate funding as critical challenges in the country's approach to research support (5,6). By addressing fragmentation, promoting a national strategic vision, and enhancing agility and diverse representation, the proposed Bioethics Council for Canada would align with the goal of supporting a coordinated and agile research and innovation ecosystem that is competitive on the global stage.

Further benefits to centralizing guidance on a national level also resonate with insights generated by the *Navigating Collaborative Futures* report from the Council of Canadian Academies, which provided a comprehensive strategic framework for evaluating and prioritizing international partnerships in science, technology, innovation, and knowledge (6). The report underscores the importance of Canada's international collaboration, national priority alignment, and robust governance. A national Bioethics Council for Canada would stand to serve as an important facilitator for Canada as a structured and strategic hub for international collaborations that address complex global challenges such as climate change, pandemics, and cybersecurity (6,7).

METHODS

To examine the relevance and responsibilities of a national Bioethics Council for Canada, semi-structured interviews were conducted on themes related to critical ethical thinking, guidance, and action at provincial and national levels (Table 1).

Table 1: Interview themes

- Current resources for government to seek input and receive advice on ethical issues in science, technology and health.
- Helpfulness of current resources.
- Value and need in Canada for an independent, national bioethics council like those in other countries.
- Desirable features of a Canadian bioethics council.
- Target users and receptors.
- Empirical and strategic next steps (e.g., formal needs assessment, business case).

Interviews lasted 30-60 minutes, and were audio recorded and transcribed for review. A purposive sampling strategy was used to identify participants based on their academic and professional expertise in public health, law, policy, and ethics, as well as their geographic and linguistic diversity. None were the same as for the first round of Canadian consultations in 2022. The participants were approached via email and the interviews were conducted over Zoom by members of the author group between July and December 2023, under the Université de Montréal REB protocol #2023-4484. Interviews were anonymized to protect confidentiality.

We used an iterative process to characterize and classify answers to the questions posed (8,9). Through a constant comparative analysis approach, we formulated codes as tags to identify concepts and themes that emerged within each individual interview transcript. With each transcript review, we identified subcategories to represent the research questions and emerging themes (9). We offer select quotes to support the interpretation of the findings and enrich the discussion.

RESULTS

Of the twelve invited participants, one declined. Overall, participants were supportive of the proposed concept. Ten of 11 participants responded favourably to the need for an additional bioethics body to fill current gaps in the Canadian bioethics landscape. One dissenter referred to current organizational mandates and existing mechanisms as sufficient for providing ethics advice to priority issues in Canada.

Six major themes from interviews emerged from the thematic analysis, generally consistent with the interview questions: 1) current ethics infrastructure, 2) synergism, 3) policy, 4) anticipation, 5) composition, and 6) education and responsibilities to the public.

Current ethics infrastructure

There was consensus that while resources for ethics counsel exist in Canada, efforts are "*scattered all over the place*," non-collaborative "*across the different ethics groups*," and limited in scope with "*only bits and pieces of what would make a good system*." Experts reported that Canada's reliance on committees and ad hoc working groups is inefficient and unresponsive to an increasing desire for proactive bioethics advice (see also Anticipation below). Moreover, the work of bodies operating in parallel and without the benefit of coordination has led to duplicative efforts and gaps in ethical guidance. Clearly, "*there is a need for something*" and "*we could benefit from a council of some kind.*" The way forward, one participant offered, is to "*connect and figure out how do we actually work in a collaborative way to provide counsel in building on each other's work and expertise*."

Synergism

Participants expressed the need for synergism in ethics advice and anticipation of critical emerging issues on a national level. As such, a Bioethics Council for Canada would not supplant other existing advisory bodies; rather, it would foster collaboration across the system and serve as "*a structure for advice and coordination that is drawn on regularly*" that is interdisciplinary and with diverse representation. One participant noted that an "*ethics commission that is advocating positions [is not] the best approach.*" It would instead function as a body that "*provides access to different perspectives,*" with work that delivers well-considered critical reflection of all points of consideration, thereby fulfilling "*a potential coordination function or helping to reduce duplication and helping to better leverage Canada's ethics community*."

Policy

As an organized body ready to support government priorities, a Bioethics Council for Canada would provide timely analyses and evidence-based options for policy. One participant noted that the current process is "*not terribly efficient […] we grab what we can to develop the policies.*" The participant noted the need "*for further conversation about how we make choices in some policy areas*" where "*evidence needs to be weighed against a billion other factors*," because "*science doesn't say what to do […] Science told you there's a problem and gave you some options […] everything else is social, political, normative.*" As an example, several experts highlighted that the COVID-19 pandemic underscored the urgency of implementing strategies for ethical decision-making. The need for timely, accurate, and balanced policy options to avoid future delays in crisis responses, among other things, continues to be critical: "*We really have to have a balanced policy development process, […] an approach that says, okay, bioethics is full of conflicts. So, what are the different perspectives? And how do we manage these different perspectives*?"

Anticipation

Participants expressed a need for a bioethics council that would serve to anticipate future challenges and ensure that Canada remains at the forefront of bioethics-informed governance in science and healthcare. They thought that such a dedicated forward-looking function would be crucial to "*create a space to talk about [bigger issues we need to prepare for] that are not the current first item on the political agenda*" and thus "*safely anticipate the kinds of very complex challenges that are on the horizon.*" In occupying such responsive and anticipatory roles, experts further suggested that a dedicated body could also be valuable as a point of contact for Canada by communicating Canadian stances and values on key nationally- and internationally-relevant issues. One participant suggested, "*Government should be involved in looking forward and into things that might seem a bit speculative, or anticipatory. Maybe an [independent national bioethics committee] could do that… especially [as] a clear point of contact for Canada on these topics*."

Composition

Experts noted that the value of a Bioethics Council for Canada is inextricably linked to the council's independence and representativeness. Bioethics advice must be communicated through an independent voice and be free of political, financial, and religious affiliation and influence. It should also encompass a broad range of disciplines (e.g., public health, law, policy, ethics, medicine) and incorporate diverse voices and perspectives, including those from Indigenous and Francophone communities. Potential challenges related to adequate funding, maintaining independence from political influences, and achieving meaningful representation can be mitigated by implementing a transparent governance structure and engaging diverse stakeholders early in the process to ensure the council's success and credibility. This model positions a Bioethics Council for Canada to "*really capture the dynamism of the Canadian intellectual system*" and to fulfill "*a role in helping people to problematize things and think about what kinds of things need a consultation from different resources and different kinds of support.*" This independence and representation of community voices is crucial for maintaining objectivity and integrity in its outputs: "*If you want to have a critical voice, [you need] a commission that would provide broad perspectives [and] you need to have independence.*"

Education and responsibilities to the public

Experts emphasized that a bioethics body would be well-positioned to strengthen democratic participation by serving as a focal point for public discussion and debate on bioethical issues. If such a body is also committed to transparent policy discussions with public involvement and education, it will foster a more informed and engaged Canadian citizenry. This additional mandate stands not only to enrich the body's work but also to reinforce the democratic fabric of Canadian society by promoting a culture of participatory ethical decision-making. By engaging its citizens in meaningful dialogue, a Bioethics Council for Canada can ensure that diverse voices are considered in formulating policies that affect Canadians. Unlike current ad hoc committees and task forces, a dedicated body has the potential to build a legacy of trust through consistent and transparent decision-making processes. By partnering with the public in decision-making processes, deliberation will help to improve the public's understanding of the moral issues associated with public health, increase capacity-building, and promote a social solidarity that is based on credibility and trust. One expert noted, "*If a commission could be a site for the discussion of those very difficult, complex, thorny welters of issues, and the deliberation of those and constructive conversation of them, […] it would be very good for our society*."

DISCUSSION AND CONCLUSION

The insights obtained from a second round of consultations and interviews with Canadians with expertise and interests in bioethics confirm the compelling case for establishing a national Bioethics Council for Canada. The current fragmented nature of Canada's bioethics advisory system, which relies on ad hoc committees with limited scopes and varying mandates, is not optimized to address emerging challenges in science, technology, and health. Instead, a unified Bioethics Council for Canada would be pivotal in enhancing Canada's ethical deliberation on pressing topics, including concerns about the climate crisis and impact on human health (10), the ethical implications of artificial intelligence (11), and the ongoing need for robust pandemic preparedness (12).

By learning from the successes and challenges faced by international examples as outlined in UNESCO's National Bioethics Committees in Action report (13), and ensuring a transparent, inclusive, and proactive approach, Canada can enhance its ethical deliberation and better meet the needs and represent the values of its citizens. For example, the United Kingdom's Nuffield Council on Bioethics – highly regarded for its thorough, independent, and policy-oriented work – is exemplary in producing reports widely used in policymaking and for providing independent ethical advice while fostering public understanding and dialogue (13). On the other hand, El Salvador's National Bioethics Commission has faced challenges in its establishment and functionality (13). Although officially established in 2009, this Commission struggled with limited resources as well as with a lack of awareness and understanding of bioethics among the public and professionals. By learning from these successes and challenges, a Bioethics Council for Canada should prioritize inclusive representation and multidisciplinary input while establishing concrete frameworks for operationalizing deliberative processes that are responsive to needs of Canadians.

A Bioethics Council for Canada that provides organized, timely, and expert advice, fosters public trust, and enhances democratic participation, would ensure a coordinated effort to respond to current and future issues concerning the health and well-being of Canadians. The establishment of such a council aligns well with the broader goals outlined in key reports, which emphasize the importance of addressing fragmentation, promoting a national strategic vision, and enhancing agility and diverse representation (5,6). By adopting these principles, a Bioethics Council for Canada can enhance Canada's capacity to address ethical challenges in science, technology, and health to ensure coordinated and anticipatory bioethics-informed governance. Furthermore, as noted in one interview, the council could serve as a vital "*point of contact*" for international collaborations by addressing a potential "*gap seen by other international countries looking for advice from Canada.*" In this way, a Canadian council is well-positioned to produce tailored, yet internationally relevant strategies concerning its national priorities (2,7). This role is crucial for addressing complex global challenges such as climate change, pandemics, and cybersecurity, ensuring that Canada remains at the forefront of ethical governance in science and healthcare.

The absence of a cohesive framework that reflects the country's distinct healthcare system and values remains a challenge for bioethics in Canada. In this vein, Racine noted that rather than developing a uniquely Canadian approach, the field of bioethics has largely adopted American models (14). Such an approach, however, cannot adequately capture the ethical priorities and local realities of Canadian society, including equitable access to healthcare, and the recognition of Indigenous and linguistic minority rights. In parallel, one participant noted a lack of existing resources as "*sites of measured reflection on what's right or wrong*" and offered the reflection that Canada must "*figure out a mechanism to actually deliberate over these things before it's too late.*" This participant noted that "*a commission like this could really contribute to us coming to ethical consensus on things.*" Without coordinated initiatives, Canada will continue to face significant barriers in addressing moral issues and considered solutions that resonate with its diverse cultural and political landscape.

To this point, while expert consultations have proved invaluable to identifying the imperative for a Bioethics Council for Canada, future consultations ought to look beyond current bioethics leadership roles. They must include a wide range of relevant stakeholder input, including healthcare professionals and representatives from marginalized communities, to ensure that diverse perspectives and lived experiences are meaningfully integrated into the development of a unified and participatory approach to bioethics in Canada.

In conclusion, establishing a national Bioethics Council for Canada has emerged as a priority in providing efficient, timely, and evidence-based policy options that set national standards and are aligned with international ones (2,4,7). This unified approach is not only cost-saving but also trust-building, fostering a culture of participatory ethical decision-making and reinforcing the democratic fabric of Canadian society. By engaging its citizens in meaningful dialogue and ensuring diverse voices are considered in formulating policies, a Bioethics Council for Canada stands to significantly contribute to the prosperity and well-being of Canadians. The establishment of a Bioethics Council for Canada represents an opportunity not only to effectively address pressing national challenges in science, technology, and health, but also to position Canada as a global leader in ethics governance grounded in the values and priorities of its citizens.

Reçu/Received: 12/6/2024

Publié/Published: 2/12/2024

Notes
Le Conseil Canadien de bioéthique a été constitué le 21 octobre 2024.

Notes
The Bioethics Council for Canada was incorporated on 21 October 2024.

Remerciements
JI est chercheur universitaire distingué en neuroéthique; son travail et la direction de l'IBI sont soutenus par les IRSC, le FRQ, le CRSNG et la North Family Foundation. JAC est titulaire de la Chaire de recherche Bertram Loeb à l'Université d'Ottawa.

Acknowledgements
JI is UBC Distinguished University Scholar in Neuroethics; her research, as well as leadership of the International Brain Initiative (IBI), are supported by CIHR, FRQ, NSERC, the North Family Foundation. JAC holds the Bertram Loeb Research Chair at the University of Ottawa.

Conflits d'intérêts
JAC siège au conseil consultatif d'INBRAIN Neuroelectronics. BMK est titulaire de la Chaire de recherche du Canada en droit et médecine. Aucun autre auteur n'a d'informations à déclarer.

Conflicts of Interest
JAC sits on the advisory Vision Board for INBRAIN Neuroelectronics. BMK held the Canada Research Chair in Law and Medicine while during the course of this study. No other authors have disclosures to declare.

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