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**Tangwa, Godfrey B; Munung, Nchangwi Syntia**
**Sprinting research and spot jogging regulation: the state of bioethics in Cameroon.**

**Abstract:** Cameroon is a Central African country lying at latitude 6°N and longitude 12°E. The country has a surface area of circa 475,442 square kilometers, and is bordered by several other African countries: Nigeria, Chad, the Central African Republic, the Republic of Congo, Equatorial Guinea, and Gabon. With a population of nearly 20 million inhabitants, Cameroon is a very diverse country, geographically, culturally, and linguistically.

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**Document 3**

**ten Have, Henk; Dikenou, Christophe; Feinholz, Dafna**
**Assisting countries in establishing national bioethics committees: UNESCO's Assisting Bioethics Committees project.**

**Abstract:** The Universal Declaration on Bioethics and Human Rights adopted by UNESCO in 2005 advocates for the establishment of independent, multidisciplinary, and pluralist ethics committees at national, regional, local, or institutional levels. The purpose of these committees is (a) to evaluate the relevant ethical, legal, scientific, and social issues related to research involving human beings; (b) to provide advice on ethical problems in clinical settings; (c) to assess scientific and technological development, formulate recommendations, and contribute to the preparation of guidelines; and (d) to foster debate, education, and public awareness of and engagement in bioethics (Article 19). Already in the very first draft of the Declaration the need to promote and establish national bioethics committees was mentioned. Although the text was gradually elaborated, the same basic idea has been preserved throughout the process of drafting, negotiating, and adopting the text.

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The National Bioethics Conference: looking back and looking ahead
Indian Journal of Medical Ethics 2010 October-December; 7(4): 226-228
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In the belly of the whale: some thoughts on preserving the integrity of the new bioethics commission.
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Panel to take broad view of bioethics.
Nature 2010 Apr 15; 464(7291): 971

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Panel to take broad view of bioethics. President Obama appoints commission to advise on stem cells, clinical trials and more. [news]
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New centre to document bioethics in the Arab world [news]

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National Bioethics Council: a Brazilian proposal.
Journal of Medical Ethics 2010 February; 36(2): 99-102
Abstract: The number of national bioethics commissions has burgeoned since the establishment of the first one in
1983. They provide an arena in which stakeholders with widely differing moral views can discuss, interact and negotiate about controversial matters. The establishment of the Brazilian committee is used as an example of how such bodies can be introduced. If such councils are to be implemented effectively and regarded as legitimate, the society as a whole should be included in the construction of the proposal and represented on the council, the council should have the benefit of specialist advice when that is needed, and the council should be linked to the elected government in an official advisory capacity. The article describes long process of planning and consultation to establish Brazil's National Bioethics Council and of eventually defining its task as advising the president on matters relating to bioethics.

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Maloney, Dennis M.  
**New presidential commission includes human subjects focus**  

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**National Bioethics Council: a Brazilian proposal.**  
Journal of Medical Ethics 2010 February; 36(2): 99-102  
**Abstract:** The number of national bioethics commissions has burgeoned since the establishment of the first one in 1983. They provide an arena in which stakeholders with widely differing moral views can discuss, interact and negotiate about controversial matters. The establishment of the Brazilian committee is used as an example of how such bodies can be introduced. If such councils are to be implemented effectively and regarded as legitimate, the society as a whole should be included in the construction of the proposal and represented on the council, the council should have the benefit of specialist advice when that is needed, and the council should be linked to the elected government in an official advisory capacity. The article describes long process of planning and consultation to establish Brazil's National Bioethics Council and of eventually defining its task as advising the president on matters relating to bioethics.

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**Can national bioethics commissions be progressive? Should they?**  
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Obama, Barack

**President Obama Establishes New Presidential Commission for the Study of Bioethical Issues, Names Commission Leadership**


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**Bioethics: left, right, and wrong**
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**End of discussion: why Obama should have kept the bioethics council**
Commonweal 2009 August 14; 136(14): 7-8

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A closer look at the Nuffield Council on Bioethics
Clinical Ethics 2008 December; 3(4): 199-204

Abstract: The Nuffield Council on Bioethics examines ethical issues raised by new developments in biology and medicine. Established by the Nuffield Foundation in 1991, the Council is an independent body, funded jointly by the Foundation, the Medical Research Council and the Wellcome Trust. Independence and quality are the underlining principles of the Council, and the way the Council works has been designed to ensure that its reports are thorough, authoritative and provide a novel, policy-oriented approach to difficult ethical dilemmas. Recent reports have considered the issues raised by public health and critical care decisions in fetal and neonatal medicine. The Council is currently considering the ethical dilemmas surrounding dementia.

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Townend, David; Duguet; Anne-Marie
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National bioethics commissions and partisan politics.
Bioethics 2008 July; 22(6): ii-iii

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Salako, Solomon E.
The Council of Europe Convention on Human Rights and Biomedicine: a new look at international biomedical law and ethics
Abstract: The Council of Europe Convention on Human Rights and Biomedicine is European in conception but has a wider territorial application since non-Member States which have participated in its elaboration may sign it. This article evaluates the Convention as the first legally binding international biomedical law and ethics document to uphold human dignity as a fundamental concept and to provide a legal framework for societies with different sociocultural and philosophical backgrounds. It is argued that such a legal framework must be underpinned by a monist-naturalist conception of justice privileging human dignity as one of its guiding principles.

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The stupidity of dignity: conservative bioethics' latest most dangerous ploy
The New Republic 2008 May 28; 238(9): 28-31
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Challenging Dutch holocaust education: towards a curriculum based on moral choices and empathetic capacity
Ethics and Education 2008 March; 3(1): 57-74
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Skene, Loane
Abstract: Committees appointed by governments to inquire into specific policy issues often have no further role when the Committee's report is delivered to government, but that is not always so. This paper describes the activities of members of the Australian Committee on human cloning and embryo research (the Lockhart Committee) to inform Parliament and the community about the Committee's recommendations after its report was tabled in Parliament. It explains their participation in the political process as their recommendations were debated and amending legislation was passed by Parliament. It illustrates a method of communication about scientific and policy issues that explores people's concerns and what they 'need to know' to make a judgment; and then responds to questions they raise, with the aim of facilitating discussion, not arguing for one view. The paper considers whether this type of engagement and communication is appropriate and could be used in other policy discussions.
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A chat with George W. Bush's conscience: embryonic stem cells crashed against Leon Kass' old-school moralism
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Ethics Advisory Group of the International Union Against Tuberculosis and Lung Disease: policy and operational guidelines
International Journal of Tuberculosis and Lung Disease 2007 December; 11(12): 1272-1281

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Thomas, Cordelia

Public dialogue and xenotransplantation

Abstract: Toi te Taiio: the Bioethics Council was established in 2002 to enhance New Zealand's understanding of the cultural, ethical and spiritual aspects of biotechnology and ensure that the use of biotechnology has regard for the values held by New Zealanders. In 2005, the Bioethics Council focused on xenotransplantation. A series of dialogue events were held, the public had the opportunity to participate in an online discussion forum and were able to make written submissions. There is worldwide interest in the potential of this biotechnology to cure or alleviate a number of serious health conditions. However, there are concerns about the risks, especially the potential for cross species infection. Such risks have not yet been reliably quantified, but any decision about safety and effectiveness is also about cultural, ethical and spiritual factors. This paper considers some of the outcomes from the dialogue process and the reflections of the Bioethics Council on these. It contrasts the process with that of classic consultation and concludes that, although the process may be more costly and time consuming than the traditional consultative approach, it enables the role of science to be appreciated in its full context, including appreciation of the uncertainties of natural systems and the relevance of cultural, ethical and spiritual human values. It will be suggested that the public are able to interweave ethical concerns with scientific knowledge to engage in meaningful dialogue, resulting in useful recommendations.

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Gianelli, Diane M.; Davis, F. Daniel

News from the President's Council on Bioethics
Kennedy Institute of Ethics Journal 2007 December; 17(4): 397-398

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Schmidt, Harald; Schulz-Baldes, Annette

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**Bioethics in liberal regimes: a review of the President’s Council**
Ethics and Medicine: An International Journal of Bioethics 2007 Fall; 23(3): 169-188
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Puljak, Livia
**Croatia founded a national body for ethics in science**
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Johnson, Summer
**A rebuttal to Dzur and Levin: Johnson on the legitimacy and authority of bioethics commissions**
Kennedy Institute of Ethics Journal 2007 June; 17(2): 143-152
Abstract: Bioethics commissions have been critiqued on the basis that they are not sufficiently public or are too reliant upon expertise to have legitimacy or authority in regard to public policy debates. Adequately assessing the legitimacy and authority of commissions requires thinking clearly about the "publics" these commissions serve, the primary tasks of public bioethics, and how those tasks might be performed with a certain kind of ethical expertise and limited authority that makes them legitimate players in public policy debates concerning bioethics.
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Dzur, Albert W.; Levin, Daniel
**The primacy of the public: in support of bioethics commissions as deliberative forums**
Kennedy Institute of Ethics Journal 2007 June; 17(2): 133-142
Abstract: In a 2004 article, we argued that bioethics commissions should be assessed in terms of their usefulness as public forums. A 2006 article by Summer Johnson argued that our perspective was not supported by the existing literature on presidential commissions, which had not previously identified commissions as public forums and that we did not properly account for the political functions of commissions as instruments of presidential power. Johnson also argued that there was nothing sufficiently unique about bioethics commissions to make the public forum perspective particularly applicable. We respond by arguing that analysis of commissions’ work as public forums fits well within the literature on commissions, especially on their agenda-setting functions, and that the political functions of commissions are often compatible with their functioning as public forums. We also demonstrate how the origins and concerns of bioethics make public forum analysis particularly applicable to bioethics commissions.
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Les Cahiers du Comité Consultatif National d’Éthique pour les Sciences de la Vie et de la Santé 2007 April-June;
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Incorvati, Giovanni


Abstract: So far the activities of the Comitato Nazionale per la Bioetica (CNB) have been subject to desultory and fragmentary analyses, stuck to the paradigm (in the way Kuhn means it) which claims the division between the issues of "frontier bioethics" and those of "everyday bioethics" (and between the respective types of communication). According to the above mentioned paradigm, bioethics should just deal with the problems coming from the application of technological progress to extreme cases (which imply a type of communication internal to the scientific communities), and only subordinately with other issues, even if of a more general interest and widespread public involvement. Nonetheless, in the last years another paradigm has come out and it is emphasizing the importance of the interaction between the two models of bioethics and of a type of external communication not just limited to the scientific communities in the strict sense of the word, but based on "open opinions ". The present notes are supposed to be an introduction to a historical comprehension of the CNB activity and of its impact, in the light of the rising of the new paradigm and of the Italian adherence to the Oviedo Convention of the Council of Europe.

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* Document 113
Incorvati, Giovanni; Petrini, Carlo


Abstract: The article consists of a bibliography of the literature concerning the Italian National Bioethics Committee (CNB) from its establishment in 1990 to 2007. It includes only documents published in languages different from Italian. The bibliography is divided into three parts. The first part includes complete or partial translations of the CNB documents. The second part includes publications concerning the opinions expressed by the CNB, ordered by topic. In the third part publications on the CNB as an institution are listed.

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Dagron, Stéphanie

[National ethics committees and representative democracy: is the new German ethics committee more "democratic"?] = Comités nationaux d'éthique et démocratie représentative: le nouveau comité allemand d'éthique est-il plus "démocratique"?

Abstract: The bill passed in April 2007 by the German parliament aims to confer democratic legitimacy on the German Ethics Committee (deutscher Ethikrat) which has replaced the former National Ethics Committee (nationaler Ethikrat) set up in 2001. This law results from a wide debate which began in 2005 within the political parties about the role in democracy of the bodies charged with advising the people's representatives in the areas of biotechnology and modern medicine. In this article, the author explains why it was necessary to confer a certain democratic legitimacy on the new Ethics Committee and analyses the relation that exists between the democratic principle, the work of this type of committee and the national institutional structure retained to stimulate the debate and advise the political decision-makers, and even to prepare legislation concerning bioethics.

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Le comité d'éthique algérien face à la concurrence bureaucratique et religieuse. = The Algerian Ethics Committee in the face of bureaucratic and religious competition

Abstract: Affected by a fashion imported from Europe and following the example of some Arab countries, Algeria has instituted by decree its first Ethics Committee for Health Sciences. Between the fatwahs of the Islamic High Committee and the directives of the Ministry of Health, the Algerian Ethics Committee, in its composition, its way of functioning and its opposition to change, brings together all the contradictions of a society in gestation.

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Bioethics and democracy: competing roles of national bioethics organisations
Bioethics 2006 November; 20(6): 326-338
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Callahan, Daniel
Rejecting the gambler's principle [review of Rights and Liberties in the Biotech Age: Why We Need a Genetic Bill of Rights, edited by Sheldon Kimberly and Peter Shorett]
Nature Biotechnology 2005 October; 23(10): 1220
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Goven, Joanna
Processes of inclusion, cultures of calculation, structures of power: scientific citizenship and the Royal Commission on Genetic Modification
Science, Technology, and Human Values 2006 September; 31(5): 565-598
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Dissanayake, V.H.W; Lanerolle, R.D.; Mendis, N.
Research ethics and ethical review committees in Sri Lanka: a 25 year journey
Ceylon Medical Journal 2006 September; 51(3): 110-113
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FDA to clarify rules on advisory committee members [news]
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Kennedy Institute of Ethics Journal 2006 June; 16(2): 173-188

**Abstract:** National bioethics commissions have been critiqued for a variety of structural, procedural, and political aspects of their work. A more recent critique published by Dzur and Levin uses political philosophy to constructively critique the work of national bioethics commissions as public deliberative forums. However, this public forum critique of bioethics commissions ignores empirical research in political science and normative claims that suggest that advisory commissions can and should have diverse of functions beyond that of being public forums. The present paper argues that the public forum critique too narrowly considers the roles that bioethics commissions can play in public bioethics and ignores the moral obligation of commissions to fulfill their mandates. Evaluations of commissions must consider that these institutions can serve in capacities other than those of a public deliberative forum and use additional measures to evaluate the multiple roles and successes of bioethics commissions in public policy.

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Respecting difference and moving beyond regulation: tasks for U.S. bioethics commissions in the twenty-first century
Kennedy Institute of Ethics Journal 2005 September; 15(3): 289-303
Abstract: This article focuses on two possible missions for a national bioethics commission. The first is handling differences of worldview, political orientation, and discipline. Recent work in political philosophy emphasizes regard for the dignity of difference manifested in "conversation" that seeks understanding rather than agreement. The President's Council on Bioethics gets a mixed review in this area. The second is experimenting with prophetic bioethics. "Prophetic bioethics" is a term coined by Daniel Callahan to describe an alternative to compromise-seeking "regulatory bioethics." It involves a critique of modern medicine. In the contemporary context, the areas of biotechnology and access to health care cry out for prophetic attention. The Council has addressed biotechnology; unfortunately, that experience suggests that the kind of prophecy that it practices poses risks to conversation. With regard to access issues, the article proposes an effort that unites themes of human dignity, solidarity, and limits in support of reform, while highlighting, rather than papering over, differences.

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Promises and perils of public deliberation: contrasting two national bioethics commissions on embryonic stem cell research
Kennedy Institute of Ethics Journal 2005 September; 15(3): 269-288
Abstract: National bioethics commissions have struggled to develop ethically warranted methods for conducting their
deliberations. The National Bioethics Advisory Commission in its report on stem cell research adopted an approach to public deliberation indebted to Rawls in that it sought common ground consistent with shared values and beliefs at the foundation of a well-ordered democracy. In contrast, although the research cloning and stem cell reports of the President's Council on Bioethics reveal that it broached two different methods of public deliberation—balancing goods and following an overarching moral principle—it adopted neither. Thereupon its primer mover, Leon Kass, influenced particularly by the approach of Leo Strauss, sought to develop a method of public deliberation guided by tradition and practical wisdom. When this failed, the Council fell back on a method that took account of shared fundamental values of a free democracy—a method remarkable akin to that employed by the National Bioethics Advisory Commission. Respect for diverse reasonable conceptions of the good in a democratic polity requires national bioethics commissions to seek and incorporate that which is valuable in opposing positions.

Nelson, James Lindemann

The baroness's committee and the president's council: ambition and alienation in public bioethics
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Abstract: The President's Council on Bioethics has tried to make a distinctive contribution to the methodology of such public bodies in developing what it has styled a "richer bioethics." The Council's procedure contrasts with more modest methods of public bioethical deliberation employed by the United Kingdom's Warnock Committee. The practices of both bodies are held up against the backdrop of concerns about moral and political alienation, prompted by the limitations of moral reasoning and by moral dissent from state policy under even the most democratic of governments. Although the President's Council's rhetoric is often scrupulously conciliatory, recurring features of its argumentative practice are regrettably divisive. They order these things better in Britain.

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The role of national ethics commissions in Finland
Bioethics 2003 August; 17(4): 357-368

Abstract: There are six national ethics commissions in Finland. The National Advisory Board on Research Ethics was first established in 1991, followed by the National Advisory Board on Biotechnology and the Board on Gene Technology in 1995. The National Advisory Board on Health Care Ethics was established in 1998, followed by its Sub-Committee on Medical Research Ethics in 1999. The Co-operation Group for Laboratory Animal Sciences was established in 2001. Only the Board on Gene Technology works as a national authority and gives binding opinions and recommendations about the use of genetically modified organisms. The Sub-Committee on Medical Research Ethics acts a national research ethics committee and gives opinions about research projects. Other advisory boards do not make legally binding decisions, but their expertise gives a lot of power to their opinions and statements. The commissions work in close collaboration with each other, having regular meetings. They arrange seminars and conferences, and share information with each other. The commissions also share duties and information in international collaboration. How the voice and opinions of these commissions is heard in society lies in the wide, multi-professional expertise of their members. Large commissions and wide expertise may make it difficult to find consensus in their opinions and statements, although wide expertise may, more than discussion in a small expert group, help to further process difficult ethical issues. Collaboration between different bodies is important in order to share duties, and also to add more emphasis to the statements and opinions where different bodies share interests. In our country, the interest that national commissions share is research ethics, where the advisory boards and their members have discharged collaborative activities for years.

Mongoven, Ann M.

Duties to stakeholders amidst pressures from shareholders: lessons from an advisory panel on transplant policy
Bioethics 2003 August; 17(4): 319-340

Abstract: The distinction between stakeholders and shareholders frequently employed in business ethics can illuminate challenges faced by a bioethics advisory panel. I use the distinction to reflect back on the work of an advisory panel on which I served, a panel on US transplant policy. The panel hearings were akin to a shareholders' meeting, with many stakeholders absent. In addition to 'hearing out' the shareholders who were present, the panel had duties to absent stakeholders to insure their interests were included in public discussion. While panel efforts to include stakeholder perspectives rightfully framed its report, such duties should have framed its operating procedures more robustly. The stakeholder/shareholder distinction also offers a critical prism on the actual evolution of organ allocation policy, which the panel failed to influence. Current policy embodies a compromise among shareholders that obscures major stakeholder interests. This results in under-attention to likely medical benefit of transplant, compared to other allocation criteria. Recognition of duties to stakeholders amidst pressures of shareholders complicates the notion of 'consensus' for an advisory panel. Consensus framed on terms defined only by shareholders, not stakeholders, may be an inadequate measure of public interest.
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Do committees ru(i)n the bio-political culture? On the democratic legitimacy of bioethics committees

Bioethics 2003 August; 17(4): 301-318

**Abstract:** Bioethical and bio-political questions are increasingly tackled by committees, councils, and other advisory boards that work on different and often interrelated levels. Research ethics committees work on an institutional or clinical level; local advisory boards deal with biomedical topics on the level of particular political regions; national and international political advisory boards try to answer questions about morally problematic political decisions in medical research and practice. In accordance with the increasing number and importance of committees, the quality of their work and their functional status are being subjected to more and more scrutiny. Besides overall criticism regarding the quality of their work, particular committees giving political advice are often suspected of being incompatible with democratic values, such as respect for affected parties, representation of diverse values and transparency in the decision-making processes. Based on the example of the German National Ethics Council, whose inauguration caused a still ongoing debate on the aims and scopes of committees in general, this paper discusses: (1) the requirements of modern democratic societies in dealing with complex scientific-technical problems; (2) the composition and organisation of committees working as political advisory boards; and (3) the appointment procedures and roles of laymen and experts, and here in particular of ethicists, who may legitimately be taken on by a committee. I will argue that bioethics committees do not necessarily endanger democratic values, but can considerably improve their realisation in democratic decision-making procedures-if, and only if, they do not act as substitutes for parliamentarian processes, but help prepare parliamentarian processes to be organised as rationally as possible.

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Should consensus be 'the commission method' in the US? The perspective of the Federal Advisory Committee Act, regulations, and case law

Bioethics 2003 August; 17(4): 341-356

**Abstract:** This paper examines the drive for consensus from the perspective of the good government framework for federal advisory commissions in the United States. Specifically, the paper examines the Federal Advisory Committee Act (FACA)—the statute, its regulations, and case law. It shows that the FACA was intended to be an antidote to abuses in consensus-making processes, including the failure to fully include competing views on commissions. The index of suspicion in the FACA scheme rises when a group work product—including a consensus report—is to be the basis of recommendations to federal officials. Once FACA's requirements regarding committee composition are satisfied, the index of suspicion drops and FACA is indifferent to consensus-making; but the conditions for informed, meaningful participation apply to members who dissent from, as well as those who participate in, consensus. In negotiated rulemaking, the push for consensus and closure creates unacceptable tension with the good government goals of openness and accountability. Proponents of consensus-only bioethics commissions can learn from FACA-related legislative, agency, and judicial insights that consensus-seeking is not always desired by government officials; is rarely cost free; and that diversity and dissent enhance openness, accountability, and fairness. The burden of proof is therefore on proponents of a consensus-only standard for bioethics commissions to demonstrate that a drive for consensus furthers sound decision-making by government officials more than it sets back openness and accountability to a diverse public.

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