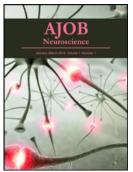


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Tabitha Moses & Judy Illes

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Target Article

## Ethics, Ethicists, and Professional Organizations in the Neurological Sciences

# **Tabitha Moses,** Wayne State University and University of British Columbia**Judy Illes,** University of British Columbia

With the evolving nature of neuroscience discovery and the increasing number of professional organizations that focus on the neurological sciences, we argue that a coordinated effort to organize ethicists with specialized expertise is needed for them. To support this case, we look to the representation of ethicists across professional organizations, and to the current status of ethics representation in professional organizations that focus on the nervous system specifically. We find substantial heterogeneity in described roles and professional background, and variable information about member selection. We conclude with recommendations for harmonization, transparency, and training plans for organizations seeking to fill these important positions in the future.

Keywords: bioethics, education, human subjects, neuroethics, neuroscience, professional ethics

#### A LOOK BACK: ETHICS IN PROFESSIONAL ORGANIZATIONS

Ethics committees have served varied and important roles across most major professions over time, and many organizations have also developed their own codes of ethics to provide members with guidance about their specific professional conduct (Backof and Martin 1991). One of the first was the American Medical Association (AMA), founded in 1847, which created its Code of Ethics in the same year as its formation (Davis 2003). The AMA was a pioneer in this regard; it was not until almost a half century later that other professional organizations began to develop their own ethical codes. For example, the American Bar Association formed in 1878, produced the first national code of legal ethics in the United States in 1901 (Altman 2008), and the American Nurses Association, established in 1896 as The Nurses Associated Alumnae (and renamed as the American Nurses Association in 1911), created its first code of ethics in 1926 (Viens 1989; American Nurses Association 2015). Today, as ethical questions are routinely asked in all professions, new organizations tend to develop codes of ethics proactively to ensure the perceived legitimacy of the organization as it comes into existence (Long and Driscoll 2007).

Most codes can be classified into one of three categories: the Brief Model, the Relationship Model, and the Principles Model (Olson 1998). The Brief Model of a code of ethics consists of a relatively abstract group of statements that provide general terms as to how the members of the organization ought to behave. The Relationship Model consists of a code of ethics that is more concrete and specific in its description of the various kinds of relationships that pertain to an organization, including how members ought to interact within and outside the organization. The Principles Model is grounded in prioritization; it is most frequently seen as a code of ethics with focused applicability and a high level of specificity. The category of any given code of ethics tends to correlate with the field it regulates (Olson 1998). Despite variation, the goals are parallel: standards of conduct and guidelines on how to meet them. In looking at the development of neuroscience organizations, it is possible to see this mindset in action.

The American Psychological Association (APA), for example, was founded in 1892 by 31 men with a shared interest in what was known as "the new psychology" (American Psychological Association 2016a). At the time of its formation, there were only 19 psychology laboratories (11 of which were no more than 2 years old), two psychology journals, and two major psychological texts available in the United States (Fernberger 1932). As such, the group gathered to unite and standardize the field to

Address correspondence to Judy Illes, National Core for Neuroethics, University of British Columbia, 2211 Wesbrook Mall, Koerner S124, Vancouver, BC, V6T 2B5, Canada. E-mail: jilles@mail.ubc.ca

promote psychology as a science. Today, the mission of the APA is "to advance the creation, communication and application of psychological knowledge to benefit society and improve people's lives" and "to excel as a valuable, effective and influential organization advancing psychology as a science" (American Psychological Association 2016b). Between 1945 and 2006, it spun out 54 divisions and one overarching ethics committee that is available to serve all members. While the majority of the APA divisions look toward the main APA governance for ethics guidance, there are three divisions that have their own ethics committees (see Results section for more details).

The American Neurological Association (ANA) is to neuroscience what the APA is to psychology. In 1874 a group of 35 physicians took part in a meeting to form a new society "devoted to the cultivation of Neurological Science, in its normal and pathological relations" (American Neurological Association 2014b). Through its annual meetings, members would share research and knowledge, and spark discussions for future directions of the field (Goetz, Chmura, and Lanska 2003). Today, the refreshed mission is to create a society "devoted to advancing the goals of academic neurology; to training and educating neurologists and other physicians in the neurological sciences; and to expanding both our understanding of diseases of the nervous system and our ability to treat them" (American Neurological Association 2014a), a mission and associated goal set that are similar to-although slightly more expansive than-the original purpose of the organization. The ANA formed its Ethics Committee around 1950, more than 70 years after its creation (Louis 2013). The creation of the ethics committee was in collaboration with the newly formed American Academy of Neurology. Later it also included the Child Neurology Society. The original committee became the Ethics, Law, and Humanities committee, shared by the three organizations with members from each.

Representing the more basic neurological sciences, the Society for Neuroscience (SfN) was established much later, in 1969, after the Committee on Brain Sciences agreed that "formal organization of brain scientists in this country was desirable and feasible." The Committee on Brain Sciences was formed in the United States in 1964 by the National Academy of Science-National Research Council in response to a call from the International Brain Research Organization (IBRO) that each of its member countries organize a committee in order to support the work of the IBRO in that country (Marshall et al. 1996). The aims of the new society were to emphasize "innovative means of communication with students and integrating research specialties" and to direct attention to "the importance of neurosciences for the future intellectual and emotional well-being of this country [United States]" (Society for Neuroscience 2016a). These aims were so important to its founders that the society created the Committee on Social Responsibility (later known as the Social Issues Committee) as one of its first standing committees in 1972. This committee was largely charged with selecting a speaker for sessions to focus on the social issues of neuroscience,

although in the 1980s it also played an important role in alerting the Society for Neuroscience council to public debates of relevance to the organization (Illes and Bird 2006; Society for Neuroscience 2016b). In 2005, the Social Issues committee was decommissioned, and its functions were centralized to the general programming of the society. A new ethics committee that took over some of the roles involving awareness of debates within the neuroscience community was established for the society in 2012. It also assumed responsibility for ethics violations in research conduct, publication, and other ethics-related concerns (Mason 2013; Society for Neuroscience 2016).

The Canadian counterpart of the Society for Neuroscience, the Canadian Association for Neuroscience (CAN), was formed in the 1970s. The impetus for the creation of CAN, as with many professional organizations, stemmed from a confluence of particularly significant advances within both politics and science. In the 1960s, the need for scientists to become more involved in politics was resonating, so the Association of Canadian Scientific, Technological and Engineering societies was created in 1970 in order to provide a voice for scientists within policy discussions. At the same time, the members of SfN itself were coming to realize the significant potential power the society held, and those members who were not in the United States realized the importance of creating such an organization in their own countries. It was for these reasons that the creation of the Canadian Association for Neuroscience (CAN) was organized shortly thereafter (Abrahams 1998). The mission of CAN is more wide-ranging than just political interest. It includes the promotion of communication between neuroscientists, promotion of neuroscience research, advancement of neuroscience education, and neuroscience research dissemination (Canadian Association for Neuroscience 2015).

The question of whether there is a need for ethics within neuroscience is not new. More than 15 years ago, Farah illustrated issues that provided a basis for the emerging field of neuroethics and demonstrated the importance of engaging in appropriate discourse surrounding those issues (Farah 2002). Around the same time, Illes and colleagues were demonstrating a need for ethical considerations in neuroimaging research and the role for neuroethicists in providing ethical frameworks for neuroimaging research as it unfolds (Illes et al. 2002; Illes et al. 2004). Later, Fukushi and colleagues brought forth a discussion on the importance of ethical considerations in neuroscience across cultures (Fukushi, Sakura, and Koizumi 2007). Today, many scholars have contributed to the wide ranging discourse in neuroethics such as in specific discussions of uses for deep brain stimulation (Kadosh et al. 2012), neuroimaging and consciousness (Fins 2015), neurodevelopmental disorders (Rosenbaum et al. 2016), neurodegenerative disease (Peters, Beattie, and Illes 2013), law and neuroscience (Nadelhoffer et al. 2012), neuroscience communication (Racine 2015), ethical considerations in neuroscience in general (Illes 2006; Illes & Sahakian 2011; Giordano 2012a), and much more.

Against this backdrop, and in response to calls for a marriage of neuroethicists and neuroscientists at the level of professional development (Giordano 2012b; Kehagia et al. 2012; Lombera et al. 2010), here we ask questions about the ethics committees of the professional organizations in the neurological sciences that have them, and about how they express their obligation to address and monitor ethical challenges in the neurosciences.

#### METHODS

We performed multiple searches of online publicly accessible information about professional organizations with a neurological sciences mission using the Google search engine. Our goal was to develop an understanding of current trends, strengths, and gaps of their ethics advisory structure and governance. We conducted the initial capture of organizations in November 2015, using search strings and key words such as "professional neuroscience organizations," "professional psychology organizations," "psychiatric professional organizations," "neurological professional organizations," and "professional brain organizations." We also searched Wikipedia and confirmed the legitimacy of organizations by cross-checking individual websites. We excluded websites that were not in English and organizations for which the main focus was on nonhuman research or care, such as veterinary societies. We then searched for the following major sources of content: (1) when and (2) where the organization was founded, (3) how many members were currently registered, (4) whether the organization had its own code of ethics, and (5) whether the organization had a dedicated ethics committee. We utilized tabs for About, History, Governance, and Membership to retrieve this information. For sites that had a dedicated search bar, the entire site was then searched for "ethics," "code of ethics," "ethics committee," and "bylaws."

For organizations wherein an ethics committee was identified, we then searched for an additional seven content areas: (1) information about the committee mission, (2) responsibilities of members, (3) how committee chairs and (4) members are identified, (5) whether members receive special training to join the committee, (6) when the ethics committee was founded, and (7) the constitution of the committee membership.

For information that could not be located via searches on the organization's website, we used specific Google queries to find the content we sought. The final step in the search was to find information about the specific members of the ethics committees. For each, we used all available online means to identify the degrees and certifications, current position, current institution, departmental affiliations, contributions to ethics discourse (e.g., publications, presentations), and professional organization memberships in the past 5 years. To acquire these details we used Google search strings such as "[Individual name] neuro," "[Individual name] psych," "[Individual name] ethics," and "[Individual name] CV." Information regarding the member's contributions to ethics discourse was found through the organization's websites, faculty pages, curricula vitae (CVs), LinkedIn, and other forms of online media. We applied a positive code for ethics background if the individual had previous publications or research in ethics, an ethics fellowship or training, taught courses in ethics, served on previous ethics committees, or had some other ethics-based background (e.g., previous work in creating ethics standards for a field). We coded "no ethics background" if the searches yielded no reference to work in any relevant field or responsibility, and there was no reference to ethics on the person's CV or other professional profile that we could locate.

#### RESULTS

The initial search yielded 191 organizations. After curating the search returns, 165 organizations were eligible for inclusion in the analysis. We included the 54 divisions of the American Psychological Association (APA) as independent units of data since each has its own governance and committees. To ascertain the overall percent of information available as a proxy measure of completeness or public transparency, we calculated the total units of available information for 5 different questions about the 165 organizations. Of the 825 unique queries (5×165), we were able to retrieve 722 answers (88%).

#### **Ethics Committees and Mandates**

Of the 165 professional neurological sciences organizations, 30 have a dedicated ethics committee (Table 1). Those with ethics committees are largely clinically focused. We had a 53% (112/210) success rate in retrieving answers to the 7 different questions asked for each of these 30 committees.

Twenty-six of 30 committees (87%) had publicly identifiable mandates. The majority had more than one mandate (Table 2).

#### **Professional Constitution of Ethics Committees**

We were able to identify 126 different ethics committee members across the 30 professional organizations. We identified and characterized the ethics background and training of all 126 committee members and found that 65 committee members of the total 126 (52%) possess or have demonstrated some professional ethics affiliation or scholarship.

We were able to identify selection processes and criteria for 21 of 30 (70%) ethics committees.

#### A LOOK FORWARD: DISCUSSION OF THE FINDINGS

We sought to characterize the constitution and representation of ethics in professional organizations that focus on

Table 1. Retrieval information about ethics committees <sup>*</sup> .	ics committees <sup>*</sup> .						
	Date Ethics Committee Founded	Committee Mission	Member Responsibility	Member Identification/ Selection	Ethics Training for Members	Current Chair(s)	Current Members
American Academy of Child and	+	+	+	+	+	+	1
Adolescent Psychiatry							
American Academy of Neurology	+	+	÷	+	I	+	I
American Academy of Psychiatry and the I aw	+	+	I	I	I	+	I
American Association of Community	+	+	I	I	I	I	+
Psychiatrists							
American Association of Neuroscience	I	+	I	+	+	I	I
Nurses							
American College of	I	I	+	+	I	+	I
Neuropsychopharmacology							
American Neuropsychiatric	I	+	I	+	I	+	+
Association							
American Psychiatric Association	+	+	+	+	I	I	I
American Psychological Association	+	+	+	+	I	+	+
American Society of Addiction	I	I	I	+	I	+	+
Medicine							
APA 30: Society of Psychological	I	+	Ι	+	Ι	+	Ι
Hypnosis		-	-			-	-
AFA 39: F Sy Choanalysis	I	ł	ł	I	I	ł	ł
APA 46: Society for Media Psychology and Technology	I	+	+	+	I	I	I
Accordation of Black Develoption			_	_		_	
ASSOCIATION OF DIACK L'SYCHOLOGISTS	I	I	ł	ł	I	ł	I
Australian Psychological Society	I	+	÷	÷	I	I	I
British Psychological Society	Ι	+	+	Ι	Ι	+	Ι
Canadian Psychological Association	Ι	+	+	+	I	+	+
Child Neurology Society	I	+	I	I	I	+	+
Congress of Neurological Surgeons	I	+	I	+	I	+	+

European Association of	I	+	I	I			Ι
Neurosurgical Societies							
<b>European Psychiatric Association</b>	I	+	+	I			+
International Association of Applied	I	I	I	I			Ι
Psychology							
International Behavioral Neuroscience	I	+	Ι	+			Ι
Society							
<b>Psychiatric Rehabilitation Association</b>	I	I	+	I			I
<b>Research Society on Alcoholism</b>	+	+	+	÷			+
Schizophrenia International Research	I	I	I	Ι			Ι
Society							
Society for Neuroscience	+	+	+	+			+
American College of Psychiatrists	Ι	+	+	÷			Ι
Japanese Neuroscience Society	I	I	Ι	+			+
World Psychiatric Association	+	+	+	+	I	+	+
*"+": Information found; "-," Information not found.							

Identifiable Mandates	N Committees
Codes and Guidance	
Development of code of ethics and ethics guidance statements	16
Monitoring of evolving ethical needs of profession	13
Policy and procedure development	12
Availability to membership for consultation	9
Promotion of ethical standards for practice within the field (not just the organization)	8
Recommendations about sanctions or procedures for professional ethics violations	8
Monitoring	
Investigation of ethics and code of conduct violations	14
Tracking of misconduct throughout the profession (not just within organization)	3
Ethics Education and Training	9
Other	
Administration of ethics awards	2
Encouragement of the development of ethics committees in other organizations	2
Monitoring of diversity and equality	1

 Table 2. Ethics committee mandates (26/30 committees).

 Some committees articulated more than one mandate.

the nervous system, and the characteristics of members of the cognizant committees. We used publicly accessible information only in this endeavor, giving us a sense of both the comprehensiveness of information available to any who seek it, and gaps in communication or transparency. Overall we found that fewer than 20% of the organizations report formal ethics committees, and among these there is substantial variability in the ways in which ethics committees are formed, their roles, and training of their members.

The need for ethicists within neuroscience has been discussed previously (Illes and Bird 2006). Giordano (2012a) has argued that with the advancement of neurotechnology it is necessary for neuroethicists to be involved in developments in neuroscience so as to be aware of the changes neuroscience is making in human society. Lombera and colleagues (2010) demonstrated the desire for ethics training among neuroscience graduate students, and Kehagia and colleagues (2012) demonstrated the operational need for ethics training for researchers involved in neuroimaging. In related fields such as stem cell research, ethicists have played an expert and vital role in the formulation of research protocols and in their review, including serving on special stem cell research oversight boards (National Bioethics Advisory Commission 1999; Hyun Table 3. Ethics background of committee members.

Contributions to Ethics Discourse	Total
Previous publications and/or research in ethics	34
Ethics fellowship or training	1
Faculty and/or teaching in ethics	2
Previous roles on ethics committees	3
Ethics-based employment (non-teaching)	3
Other ethics-based background	4
Publications and/or research in ethics AND ethics fellowship or training	3
Previous publications and/or research in ethics AND faculty and/or teaching in ethics	4
Previous publications and/or research in ethics AND previous roles on ethics committees	2
Previous publications and/or research in ethics AND ethics-based employment (non-teaching)	3
Faculty and/or teaching in ethics AND previous roles on ethics committees	2
Previous publications and/or research in ethics AND Faculty and/or teaching in ethics AND Previous roles on ethics committees; Previous publications and/or research in ethics AND other ethics-based background	4
No ethics background <sup>*</sup>	61

\*Search on name with the word "ethics" yielded no results and/or professional profile and/or CV did not show any reference to ethics-based discourse or training.

2010). In this regard, as one would not hire a hospital ethics consultant with no background in medical ethics, we argue that the same standard should apply to ethics members of brain-based professional organizations. Given our findings, and toward better depth and harmonization of expertise on these ethics committees, our recommendations are threefold and encompass committee mandates, selection, and training.

#### **Committee Mandates**

The roles of the ethics committees are inconsistent across organizations. We found 13 different mandates for 29 ethics committees. We even found, diametrically opposed to 14 others, one organization whose mandate declares that the ethics committee is in no way to play a role in deliberating on a member's ethical misconduct, in opposition to this otherwise broadly common responsibility.

Major committees in general may vary slightly between organizations, but their overarching mandates are the same: membership committees approve new members; program committees focus on the format of the annual meetings; and finance committees oversee budgets and operations of the organization. This, however, is certainly not the case for the ethics committee, and it is unclear why ethics would be sidelined this way.

Selection of Members	Number of Committees
President/Executive Committee appoints Chair and all Members	7
President Appoints Chair, Chair Appoints Members	5
Self-nominate (with certain requirements) (no information about how members are chosen)	4
President appoints Chair only (no information about how members are chosen)	4
Criteria for joining is by expression of interest	1

Table 4. Five articulated processes for ethics committee member selection (21/30 committees).

Regardless of the source of the exception for ethics committees, we propose a harmonized set of ethics committee mandates that is to:

- Create a code of ethics, customized to the mission of the organization, engaging with and providing guidance about ethical concerns specific to their area of neuroscience.
- Conduct a review of members who break professional rules and determine whether the member has engaged in ethical misconduct.
- Keep apprised of emerging ethical issues in the field and be prepared to comment on and address them by providing position statements on behalf of the organization to help members better understand the potential for ethical concerns and how to deal with those issues appropriately.
- Create training and educational opportunities for members.

This minimum set of responsibilities may not be allencompassing, but they provide the foundational basis on which to customize others. The purpose of these mandates is to ensure that the ethics committee acts as an ethical foundation for the organization, enabling all members to understand the concerns within their field with guidance for both proactive and responsive action in daily practice.

#### Member Selection

The information regarding how members are chosen for the ethics committees was difficult to find, if not sometimes impossible. For the majority of organizations for which we could find this information, the selection of ethics committee members followed the same process as the selection of members for any other committee in the organization. However, this information was often incomplete and it was not possible to fully derive how all the members were chosen. For instance, in certain cases, the way in which the chair of a committee was chosen was specified, but not the process for the remaining members.

We also discovered that many members of the ethics committees did not meet criteria as ethicists, at least not according to the definitions we set. This is not to say that all members need to have a formal training in ethics in order to join the committee—institutional review boards (IRBs)/research ethics boards (REBs), for example, are required to have a mix of people with different backgrounds, but alongside wellarticulated goals of the committee and committee membership, transparency about how and why members are chosen is essential. Harmonization is needed here again, and, moreover, we recommend improved accessibility to the information and clarity for those who wish to find it.

#### Training

We argue that all members of ethics committees should bring to their role some degree of training or background in ethics or a related field, or a specifically articulated interest in ethical, legal, or social issues in the neurological sciences. Currently, members of ethics committees do not appear to have any required training per se. In some ways this is comparable to the structure of a hospital ethics committee, for which individuals are chosen not for their ethics background, but for their dedication to patients' wellbeing. This is a laudable approach for hospitals, but it is not ideal for neuroscience organizations that are tasked, by and large, to serve as the organization's ethics compass. In fact, members of the ethics committees of hospitals are advised to use the Code of Medical Ethics to guide their recommendations; in contrast, ethics committees of professional organizations have to write codes and keep them updated. Through these differences alone it is apparent that the members of professional neuroscience ethics committees require specific training. Perhaps the roles of members of these ethics committees mimic more closely those of the ethics consultant in a hospital. The ethics consultant is "an expert in ethics who provides ethics consultations and may also serve as an educator" (Pearlman 2013).

To this end, we recommend that professional organizations that focus on ethics in the neurological sciences or representatives of ethics committees of organizations with a broader writ come together to develop a common baseline training curriculum. It need not be long or cumbersome, but in our view it must contain the following key elements:

- Introduction into critical ethics theory and thinking, with a focus on medical ethics.
- Relevant prevailing policy and regulatory practices.
- History of ethics in neuroscience.
- Overview of major contemporary ethics issues of the profession and viewpoints.

This information may be well suited to a standardized handbook designed for ethics committee members, akin to the handbook provided to members of hospital ethics committees (Flanigan 2006).

#### CONCLUSION

Given the increasing ethical complexities of neuroscience, we would argue that all professional organizations that focus on the neurological sciences have a resident ethics committee or an identified pathway to an authoritative consulting body with neuroethics expertise. We believe that strategic harmonization among the standing ethics committees for mission and reach would enhance their visibility, authority, and credibility, without compromising the unique identity and valuable service each provides. Better standardization and transparency about how ethics committee members are chosen, how they are trained, and the nature of their roles within the organization will be critical to further meet these goals.

These recommendations are neither reactive nor proactive; they are simply the way forward at a time when neuroethics approaches its 15th anniversary. Ethics in neuroscience must not become just another teachable moment, but rather serve as a cornerstone for the work and products of the next generation.

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