



June 28, 2016

Lisa M. Lee, PhD, MA, MS
Executive Director
Public Commentary
Presidential Commission for the Study of Bioethical Issues
1425 New York Ave. NW, Suite C-100
Washington, DC 20005

Sent via email to: info@bioethics.gov

Re: Requests for Comments on National Bioethics Advisory Bodies

Dear Dr. Lee:

On behalf of the American Nurses Association (ANA), we are pleased to respond to the request for comments from the Presidential Commission for the Study of Bioethical Issues concerning the role of past, present, and future national bioethics bodies in the United States and elsewhere. As the only full-service professional organization representing the interests of the nation's 3.6 million registered nurses (RNs), ANA is privileged to speak on behalf of its state and constituent member associations, organizational affiliates, and individual members. RNs serve in multiple direct care, care coordination, and administrative leadership roles, across the full spectrum of health care settings. RNs provide and coordinate patient care, educate patients and the public about various health conditions, and provide advice and emotional support to patients and their family members. ANA members also include the four advanced practice registered nurse roles: nurse practitioners, clinical nurse specialists, certified nurse-midwives and certified registered nurse anesthetists.¹

The Role of Past and Present National Bioethics Advisory Bodies

The Federal Register notice states that topics of particular interest to the Commission include a reflection on past, present and future national bioethics advisory bodies; the influence of national bioethics bodies on public policy; the advantages and disadvantages of narrowly or broadly focused advisory bodies; and the future of national bioethics advisory groups in the United States. When the first national bioethics advisory board was established in 1974 (initially called the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research), the public was unsure of its purpose and direction in a national advisory capacity. During this time, bioethical principles were emerging in the United States and the Commission was designed to provide guidance to the President, but also to provide education to the citizens of the United States. Fast forward almost 45 years and the value of the Commission is undeniably recognized by evaluating national crises such as human rights at the end of life; the definition of death during the *Cruzan*², *Quinlan*³, and *Schiavo*⁴ court cases; restrictions on stem cell research; and of course, the ethical impacts of the Genome Project, cloning and "Dolly". Today, the Commission openly collaborates with the public to assist in formulating ethical recommendations. The Commission's reports and opinions are heavily

¹ The Consensus Model for APRN Regulation defines four APRN roles: certified nurse practitioner, clinical nurse specialist, certified nurse-midwife and certified registered nurse anesthetist. In addition to defining the four roles, the Consensus Model describes the APRN regulatory model, identifies the titles to be used, defines specialty, describes the emergence of new roles and population foci, and presents strategies for implementation.

² *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261, 110 S.Ct. 2841 (1990).

³ *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

⁴ *In re Schiavo*, No. 90-2908GD-003 (Cir. Ct. Pinellas County, Fla. February 25, 2005).

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influenced throughout the health care and bioethics communities. The effect of the Commission's work is demonstrated through its educational resources, national research, reports, and efforts to raise awareness of evolving issues in medicine, science and technology. The Commission's findings are cited in clinical practice guidelines, professional advisory opinions and have permeated media outlets during times of national bioethics crises. The President relies on the Commission to evaluate bioethical issues and respond to any emerging bioethical issues for which the public seeks guidance. In addition, many professional bioethics advisory ethics bodies, such as ANA's Center for Ethics and Human Rights, rely on the Commission for resource guidance.

National Bioethics Advisory Bodies Influence Our Everyday Practice

These same professional organizations are heavily relied upon by those within their respective professions. The bioethics and ethics advisory boards within these organizations should not go unmentioned. ANA's Center for Ethics and Human Rights shapes ethical policy specifically for the 3.6 million registered nurses, and over 300,000 nursing students. The American Medical Association (AMA) represents over 815,000 licensed physicians in the United States and the AMA Council on Ethical and Judicial Affairs develops policy and opinions on ethical issues specifically relating to physicians and medical students. The American Psychological Association (APA) represents over 117,500 psychologists and the APA Ethics Committee shapes policy and principles governing the conduct of its members. The impact of these national advisory bodies is profound and reaches a significant number of health care professionals. For example in 2014, ANA advocated for a U.S. Navy nurse who exemplified moral courage when refusing to continue managing tube feedings of a detainee who was on a "hunger strike" in the Guantanamo Bay Detention Camp. This nurse faced disciplinary action from the military and possible loss of military credentials. ANA fiercely advocated for the recognition of the professional ethical code of conduct for which the nurse was accountable and for the nurse's right of refusal. As a result of these actions, the U.S. Navy nurse was able to resume full military duties without disciplinary action. This is just one example of the power of a national organization's impact on an ethical dilemma.

A Call for a Diverse Commission

During the Commission's public meeting on May 3, 2016, guest speaker Dr. Michael Gazzaniga made an impressionable comment, "I'm a big believer in a diverse group" when reflecting on the work of the Commission. An advisory body should be diverse and encompass different disciplines and areas of practice. The current Commission is comprised of ten members, which include four physicians, two attorneys, but only one nurse. As noted, there are 3.6 million registered nurses in the United States, making it the largest health care profession in the nation. As such, ANA encourages the future bioethics advisory commission to incorporate more nurses, as well as other disciplines, to reflect the diversity of the health care team. Nurses are faced with ethical dilemmas every day and adequate representation on the Commission is essential for implementation of relevant resources and policy into practice. The *Code of Ethics for Nurses with Interpretive Statements* calls on nurses to "be vigilant and take action to influence leaders, legislators, governmental agencies, non-governmental organizations, and international bodies in all related health affairs to address the social determinants of health" (Code of Ethics for Nurses Interpretive Statement 9.3).⁵ During the Commission's public meeting on May 3, 2016, Commission member Dr. Christine Grady, RN, raised a valid issue that much of the work of the Commission has done was in response to new "public-scaring" technology and issues which caused public concern. Dr. Grady reminded the Commission of the myriad of ethical issues that go unaddressed, such as health disparities and access to health care. She recognized this gap and proposed feedback on how the Commission can handle these types of broad but constant enduring issues that do not get addressed. "Advances in technology, genetics, and environmental science require robust responses from nurses working together with other health professionals for creative solutions and innovative approaches that are ethical, respectful of human rights and equitable in reducing health disparities" (Code of

⁵ American Nurses Association. (2015). "Code of Ethics for Nurses with Interpretive Statements." Silver Spring, MD: Nursebooks.org

Ethics for Nurses Interpretive Statement 8.3).⁶ Nurses are on the frontline and often spending 12-24 hours with individual patients. Poverty, homelessness, abuse and violence, lack of health care access are all issues that registered nurses face on a daily basis. ANA supports the future national bioethics advisory commission's work which we hope will address these critical social determinants of health.

The Future of the Commission and National Bioethics Advisory Bodies

The bioethics community is continuing to expand nationally and internationally. The World Health Organization reports that 112 national bioethics advisory committees exist in the world.⁷ The international bioethics community deals with a myriad of legal, yet controversial scientific ethical dilemmas, many of which are prohibited by law or policy in the United States. Historically in the United States, stem cell research was once banned, medical marijuana was once illegal in all states and medical research without consent was acceptable. The existence of national bioethics advisory bodies is imperative for the United States' to remain ethical when addressing social determinants of health and evaluating quickly emerging advances in science, medicine and technology. There will undoubtedly be bioethical issues in our future that we are unable to predict. Recognizing that these issues are fluid and often rapidly evolving, the President, public, and health care community, require adequate research and guidance on how to handle ethical issues, protect our patients, and transparently inform the public.

We appreciate the opportunity to share our views on this matter. If you have questions, please contact Liz Stokes, Senior Policy Advisor, Center for Ethics and Human Rights, at liz.stokes@ana.org or 301-628-5384.

Sincerely,



Debbie D. Hatmaker, PhD, RN, FAAN
Executive Director

cc: Pamela Cipriano, PhD, RN, NEA-BC, FAAN, ANA President
Marla Weston, PhD, RN, FAAN, ANA Chief Executive Officer

⁶ American Nurses Association. (2015). "Code of Ethics for Nurses with Interpretive Statements." Silver Spring, MD: Nursebooks.org

⁷ World Health Organization (2015). *List of national ethics committees*. Retrieved from http://apps.who.int/ethics/nationalcommittees/NEC_full_web.pdf