

The Role of Healthcare Ethics Committee Networks in Shaping Healthcare Policy and Practices

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As national and state health care policy-making becomes more contentious and complex, arguably there is a need for a forum to debate and explore public concerns and values on the issues, serve as a voice for local citizens, attempt to achieve consensus among various stakeholders, and provide feedback and direction to health care institutions and policy makers. The issues at stake may range from end of life care and allocation of scarce health care resources, e.g., flu vaccine, to expansion of health care insurance coverage. One potential vehicle to carry out these functions is regional healthcare ethics committee networks. In this article we explore whether these networks might serve in this role, and provide two contrasting examples of Network involvement in the facilitation of public input into the development of health care policies and adoption of new state-wide practices.

Regional healthcare ethics networks began forming in the U.S. in the mid-to late-1980's, beginning with the Midwest Bioethics Center (now the Center for Practical Ethics) in Missouri, and the Medical Ethics Resource Network of Michigan. There are no data on the number of currently functioning regional ethics networks in the U.S. They appeared to increase from 1985 to the mid-nineties, but some networks have disbanded since then. Many

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regional networks struggle with lack of funding and over-reliance on volunteer support, while others are adequately funded and have broad influence on ethics issues.

Such networks serve as umbrella organizations that provide ethics resources to healthcare institutions in their geographic area. Services typically include educating healthcare professionals (ethics committee members in particular) at member institutions about clinical ethics, and increasing communication and networking among such professionals. Other goals include educating the community about healthcare ethics, providing resources and a venue for resolving complex ethical conflicts (both within and across regional healthcare facilities), and responding to pressing ethical issues. For example, the Center for Practical Bioethics has been very active in end-of-life (EOL) care advocacy, having implemented “Pathways to Improve End-of-Life Care,” a community-wide program that involved numerous volunteers and organizations over a three-year time span.¹ Some networks provide resources for their member healthcare facilities to educate their own communities about ethics. For example, in the comprehensive Consortium Ethics Program (CEP), sponsored by the University of Pittsburgh Center for Medical Ethics and the Hospital Council of Western Pennsylvania, CEP faculty members have provided guidance and educational programs for ethics-related community outreach initiatives (Pinkus et al., 1995).

The role that regional ethics networks might play in shaping local, state, or national healthcare policy has yet to be defined. Could such a role be informed by the work of national or state bioethics advisory committees? Dzur and Levin (2004) describe two main functions of such committees in a democracy: expertise (i.e., experts provide facts, interpretations, and recommendations, which are then communicated to the public) and agenda-setting (i.e., a diverse membership voices public concerns and guides public debate). They advocate for the latter—that a national bioethics commission should serve as a public forum in which members strive to represent the national diversity of moral decision-making and to inform and encourage public reflection.

Academics have debated the degree to which national bioethics commissions have achieved this goal. The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (the National Commission) was established by Congress in 1974 to identify the principles of ethics and policy actions needed to protect human subjects involved in research. This was in response to research scandals that were brought to public light, and thus appears to have reflected public concern. That role is in contrast to the focus of the short-lived Ethics Advisory Board

(EAB) on human embryo research. The EAB was established in 1978 to advise the Secretary for Health and the Department of Health, Education, and Welfare on controversial ethical, legal, and social issues posed by biomedical research protocols. Other national ethics commissions have included the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1978), the Biomedical Ethics Advisory Committee (1985), the National Bioethics Advisory Commission (NBAC, 1996), and the President's Council on Bioethics (2001). Proponents of these commissions point to the impact their reports have had in shaping policy, scholarship, and public education. Opponents criticize them for being overly politicized and not in tune with public concerns. Wolpe and McGee, for example, criticized NBAC for its minimal public involvement, and for conducting itself "under a rubric" that they termed "expert bioethics, in which issues are framed and conceptualized at a high level of academic sophistication and political authority by groups of highly skilled professionals who are deputized to identify and resolve moral conflict" (Wolpe and McGee, 2001).

State bioethics advisory committees have faced similar shortcomings. While many state panels focused on a single issue (e.g., health care access), New Jersey, New York, and Colorado created bioethics advisory groups to consider a broad range of issues. New Jersey's Commission on Legal and Ethical Problems in the Delivery of Health Care, created by the state legislature in 1985, was formed to:

[P]rovide a comprehensive and scholarly examination of the impact of advancing technology on health care decisions [in order to] enable government, professionals in the fields of medicine, allied health care, law, and science, and the citizens of New Jersey and other States to better understand the issues presented, their responsibilities, and the options available to them (U.S. Congress Office of Technology Assessment, 1993).

For each of the topics it studied, the New Jersey Bioethics Commission published reports to explain their recommendations and to promote discussion among policymakers, lawyers, health care professionals (HCPs), and members of the community. However, since these panels are appointed and staffed by legislators, they, like the national commissions, are vulnerable to politicization.

Another example of a state level commission is New York's State Task Force on Life and the Law, which formed in 1985 in response to problems with do-not-resuscitate orders in state hospitals. Designed to provide counsel on a broad range of topics, the Task Force makes policy recommendations to the State executive and legislative branches. It has produced eleven reports,

and all of its recommendations have been enacted in some form.² Some have criticized the Task Force for not having meetings open to the public, as its advisory status exempts it from open meeting laws that apply to other State bodies. However, one former staff member thought the ability to conduct closed meetings actually contributed to the Task Force's success—i.e., that private deliberations protected members from political pressures that would have been more influential in public meetings (U.S. Congress Office of Technology Assessment, 1993).

Because of their closed process and lack of outreach, a major criticism of government bioethics advisory committees has been inadequate public input. Could there be a role, then, for regional ethics networks as facilitators of input to public debate and policymaking when ethical issues transcend individual healthcare institutions? Some regional ethics networks have addressed ethical issues affecting public policy. The Bioethics Network of Ohio recommended changes in the advance directive law to the state legislature (Minogue, 1993). The Midwest Bioethics Center has been extensively involved in EOL care policy. Brody, Weber, and Fleck (Brody et al., 1992), writing at the time of the Clinton healthcare reform efforts, saw a role for regional ethics networks in facilitating discussions about healthcare rationing, i.e., “broad, sustained community conversations aimed at articulating a very detailed understanding of what a just and caring community should do by way of establishing health priorities in the face of real resource limits.” Some have challenged such efforts (Grunfeld, 1993), claiming that aggregates of institutional ethics committees do not accurately reflect the values of the public at large, and are biased toward the needs and values of individual hospitals and healthcare professionals. However, some ethics networks, such as the Medical Ethics Resource Network (MERN) of Michigan, have successfully involved the public in ethics dialogues. MERN's “Just Caring” project involved creating public forums of healthcare professionals and citizens who came together to discuss a variety of issues related to healthcare access and justice. The hope was to create “some significant degree of moral agreement regarding, for example, rationing protocols that would become part of the workings of each community hospital” (Wolpe and McGee, 2001).

Another example of an ethics network that has served to impact health policy is the Maryland Healthcare Ethics Committee Network (MHECN, formerly the Maryland Institutional Ethics Committee Resource Network). MHECN was established in 1991 with support from the Law and Health Care Program at the University of Maryland School of Law. Establishing an ethics network in a school of law is not without some controversy. Since the inception of healthcare ethics committees, questions have been raised about

the role lawyers should play on ethics committees. While lawyers with bioethics knowledge could add value to ethics committee deliberations, opponents have argued that lawyers are too focused on risk management concerns, particularly if they serve as institutional counsel. In addition, healthcare professionals and other committee members tend to defer to “the authority of the law,” short-circuiting necessary dialogue about relevant ethical issues (Watson, 1993).

MHECN’s close affiliation with the law school, however, yielded several advantages. Cross-fertilization among MHECN’s executive board, its education committee, its members, and Maryland policy makers served to educate this diverse group of professionals about healthcare ethics issues that could be addressed through policy initiatives. For example, MHECN was formed about four years after the 1987 Patient Care Advisory Committee (PCAC) Act was passed in Maryland. Spearheaded by Senator Paula Hollinger, the PCAC Act established Maryland as the first state to mandate formation of ethics committees or “patient care advisory committees” for all hospitals. This mandate was extended to all nursing homes in 1990. In 1991 Law Professor Diane Hoffmann formed MHECN to buttress the legal requirement mandating healthcare ethics committees and provide the committees with education, training, networking, and resources to ensure their quality performance. In 1993, in response to a case similar to that of Theresa Schiavo (*Mack v. Mack*, 1993), Hoffmann and colleagues were instrumental in the drafting and passage of the Maryland Healthcare Decisions Act, which establishes a range of mechanisms for decision-making when a patient lacks decisional capacity. MHECN’s working relationship with the School of Law and the Maryland State Attorney General’s office of healthcare policy has provided numerous opportunities to educate members about the role of law and ethics in health care decision-making and how to interpret healthcare legislation at the bedside. This has prompted important discussions among MHECN members about the interface between ethics, law, and healthcare policy.

The Network has also served as a facilitator of discussions between state healthcare decision-makers and ethics committee members. This was the case when a MHECN physician member asked the Board for assistance addressing an issue related to transfers of severely chronically ill elderly from nursing homes (NHs) to local hospital emergency departments (EDs). These NH residents often lacked decisional capacity and arrived at the ED with no advance directives. ED physicians expressed frustration about having to implement aggressive EOL treatments when it was unclear whether these patients wanted such aggressive treatment, and whether this was in their best interest. This led MHECN to bring together its board

members, representatives of the state's Office of Health Care Quality (responsible for licensing long term care facilities and hospitals in the state), the head of the Maryland Chapter of the American College of Emergency Medicine, and a representative of the state's nursing home trade organization to discuss the reason for this practice and how to reduce such transfers. As a result of the meeting, MHECN sponsored a conference that focused on the issue of transfers of NH residents to the hospital, and related EOL decision-making.

Working on a parallel track, Jack Schwartz, Director of Health Policy Development at the Maryland State Attorney General's office, who also is a member of MHECN's Board, put forth House Bill 556, which was passed by the Maryland General assembly in 2004. It amends the Health Care Decisions Act to authorize a new document, the Patient's Plan of Care (PPOC) Form, which focuses on the patient's ultimate goal of care and current (rather than future) preferences for life-sustaining treatments.³ The PPOC form went into effect October 1, 2005. This is a policy solution that ideally will help redress the problem of uncertainty regarding EOL wishes among patients entering an ED, particularly elderly patients lacking decisional capacity. MHECN members provided feedback to Schwartz on early versions of the PPOC form and the accompanying explanatory guides. In addition, MHECN recently sponsored a conference to address implementation of the PPOC form, and plans to conduct research to measure the outcomes of the PPOC form that can be shared with legislators in the future. Through these various activities, MHECN has not only educated its members about relevant healthcare policy, but also has served as an intermediary between practicing health care providers with hands-on experience and policy-informers and legislators. In this latter role, the Network has been a bridge between clinicians working in the community and state agency officials and legislators responsible for developing and implementing healthcare laws and regulations.

This example demonstrates a different dynamic than that of the national and state bioethics advisory committees discussed above. Instead of the legislature bringing issues to appointed committee members for their expert opinions and recommendations, healthcare providers at the frontlines of clinical care were able to bring issues to the regional ethics network for discussion and problem-solving in a setting that included state health care decision-makers and network members active in state policymaking.

While the Maryland Network provides an example of how a regional network can play a role in bringing the voice of practicing healthcare providers to policy debates, the Regional Ethics Network for Eastern Washington (RENEW) presents an example of a network that has taken a

further step in bringing community voices to bear on changing healthcare practices at a statewide level. RENEW was formed by a group of HCPs and ethicists. RENEW's first project, driven by public involvement, was a response to concerns about EOL care. Specifically, HCP providers came to RENEW with concerns that patients' EOL wishes were not being honored, especially after being transferred between healthcare settings. Moreover, RENEW's project was developed in a context of public concern about a new and problematic Department of Social and Health Services (DSHS) policy that restricted surrogate decision-making for nursing home residents.

The RENEW leaders began developing a POLST (Physician Orders for Life-Sustaining Treatment) form for use in Washington State. Originally developed in 1991 by an ethics task force at the Oregon Health Sciences University, POLST translates EOL treatment decisions into a portable physician's order form that can be honored in all health care settings, including the home. POLST goes beyond do-not-resuscitate orders to include directions regarding comfort measures, use of antibiotics, and artificial fluids and nutrition. Unlike Maryland's PPOC, which originated as a policy initiative that was then circulated in draft form to MHECN members, other health care providers and citizens to critique, the Washington POLST form was developed outside of the legislative process.

RENEW leaders first brought in key stakeholders, such as the Department of Health (DOH), which oversees all EMS services and acute care facilities, and the Department of Social and Health Services (DSHS), which has authority over all long term care settings. RENEW proponents sought guidance to create a POLST form that could be honored in all health care settings. While DOH immediately supported the POLST initiative, DSHS opposed the use of POLST forms for nursing home residents who lacked decision-making capacity and who had not executed an advance directive specifically mentioning code status. A 1998 DSHS policy required that these residents have "full code" status and that surrogate decision-makers could agree to a do not resuscitate order in only four very limited circumstances, e.g., persistent vegetative state. Surrogates could not make decisions for EOL care on the basis of a condition anticipated in the future. The effect of this policy was that surrogates could not address code status for their loved ones who were nursing home residents nor, consequently, could they complete a POLST form that converts those advance wishes into physicians' orders. Several months of negotiations failed to resolve the DOH/DSHS impasse, but grassroots unrest finally did. RENEW organized a public forum that received excellent media coverage. RENEW invited a panel of speakers for that forum, which included a key DSHS decision-maker. In that "standing room only" audience, family members of nursing home residents,

guardians, and many elderly citizens outside of nursing facilities expressed their outrage at the DSHS mandate. Ordinary citizens were eloquent in their demands that nothing should interfere with their ability to direct their EOL care for themselves or their loved ones. Discussions with DSHS resumed after the public forum, the DSHS policy was rescinded, and DSHS objections to POLST were resolved.

RENEW members agree that one of the best outcomes of the POLST project was the unprecedented cooperation between DSHS policy makers and those affected by their policies. Particularly, a RENEW member and nursing home administrator, Sally Denton, was instrumental in working with DSHS representatives to develop a sample policy for use of POLST in nursing homes. At the conclusion of RENEW's work, the DSHS director distributed a letter to every extended care facility in the state. This "official letter" gave approval for use of POLST to direct EOL care, as long as each facility had a policy in place for use of the form. Facility administrators were directed to the sample policy created during the dialogue between DSHS and RENEW. RENEW members, DSHS officials, and nursing home administrators all agree that this model of cooperation sets a new and more positive precedent in their work to improve EOL care for the state's nursing home residents.

In the fall of 2000, with these key stakeholders and their grassroots network, RENEW launched the POLST pilot program in two eastern Washington counties. They set up a training session for nursing home administrators and asked for the support and help of their network contacts to pilot POLST in several facilities. Key DSHS officials attended the training session to answer questions about their old surrogate decision-making policy, and provide assurance to nursing home administrators. In early 2001, an evaluation study was conducted. The study determined that the informed consent process was being honored during completion of the POLST form, and that POLST orders were congruent with residents' or surrogate decision-makers' wishes. These findings provided the data needed for the DOH's endorsement and DSHS approval. In 2002, RENEW guided the county-by-county "roll-out" of the form. Since then, RENEW has used the same grassroots approach to revise the POLST form and educate the public and other HCPs about its use.

RENEW leaders found that starting from a grassroots approach worked better than using a legislative or "top down" approach. RENEW's network of colleagues includes healthcare ethics committee members, professional association members, hospital administrators, local and state governmental officials, the media, academic researchers, and more. These communities provided invaluable input and support both in the development and

implementation of POLST statewide. Through this networking, the Washington State Medical Association became a prime sponsor of the form and provides information about POLST on their website.⁴ This points to the importance of local champions. While the Washington State POLST is endorsed and recognized by all the major health-related associations in the state, it has not been legislatively mandated as the only “no code” form to be used. Its implementation and use depends upon local HCPs who champion POLST in their communities. The list of these champions continues to grow, and RENEW continues to identify and support them through a resource list and speakers bureau.

RENEW and MHECN demonstrate that regional ethics networks may be in a position to lead the way in reaching out to citizens across professional, educational, and socioeconomic backgrounds to educate them about ethical issues in healthcare, and to obtain their insights and opinions. When that is accomplished, they will be in an even stronger position to inform local healthcare policy. Dzur and Levin suggested conducting public opinion surveys and town-hall meetings as a way of making national bioethics commissions more responsive to public concerns. The Medical Ethics Resource Network of Michigan’s project in which community forums were held throughout the state is an example of one solution to achieving a more inclusive voice. Despite the resource challenges confronting many regional ethics networks, finding ways to increase public involvement in health care policy making would likely solidify the position of these networks as authentic regional public forums for bioethics. As the examples from Washington and Maryland demonstrate, knowledge of local context and networking is critical.

NOTES

- ¹ See www.practicalbioethics.org/mbc-aging.htm. (Last accessed October 12, 2005.)
- ² Available at www.health.state.ny.us/nysdoh/taskfce/taskbio.htm. (Last accessed November 1, 2005.)
- ³ Available at www.oag.state.md.us/Healthpol/PPOC.htm. (Last accessed November 1, 2005.)
- ⁴ Available at www.wsma.org/patients/polst.html. (Last accessed November 1, 2005.)

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