

**Development, Administration, and Analysis of a Questionnaire for
Indiana Hospital Ethics Committees**

An Honors Thesis (HONRS 499)

by

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Dr. Jon Hendrix

A handwritten signature in black ink, appearing to read "Dr. Jon R. Hendrix". The signature is written in a cursive style with a large, looping initial "D".

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Abstract:

A mailing was sent to 127 Indiana hospitals asking for information on the existence of HECs and the chairperson's mailing address. A four-page questionnaire with questions relating to the committee's composition, stated purpose, and functions was mailed to the 47 committees identified in the first mailing. The responses of the 37 committee chairpersons were tabulated and discussed along with the previously existing literature dealing with HECs.

Introduction:

Hospital ethics committees (HECs) have risen from obscurity to become one of the prime forums for the discussion and, sometimes, resolution of moral and ethical concerns in medicine. Dealing with the ethical complexities and uncertainties of modern medicine has become a daunting task for many patients, their family members, and health care professionals. Today, conflicts between: (1) a patient's wishes and a hospital's policy, (2) economics and beneficence, (3) logic and faith statements, and (4) opposing views on the rights of the incapacitated and the unborn can and do arise in modern medicine.

The traditional approach to medical decision-making, with the family physician giving directive advice to the patient and/or family, has been called into question. Paternalism by physicians, the low diversity of views heard, and ethically questionable decisions made by patients and their families have all been criticisms of the traditional style of addressing ethical questions. Multidisciplinary HECs were created to address some of these issues and to ensure adequate analysis of biomedical ethical problems. It is no accident that the formation of HECs has paralleled the

spread and implementation of advanced medical technology. Modern technology has made death, once an apparent absolute, a subject for continuing redefinition (President's Commission 1981). Many of these technologies are so expensive and in such short supply that distributive and economic concerns become important.

At a time when one's actions can quickly become public, subject to litigation, and possible public outrage; many people may be comforted if they have more thoroughly explored their options and if they have heard "experts" support their decision (even if others have disagreed). During times of great personal tragedy and stress, people are often in need of reasoned support and guidance.

The "information explosion" has impacted medicine more than most other fields. Understanding the medical procedures that people undergo are arguably of more direct personal concern than are advances in spaceflight or social theory. Without expert advice, it is unrealistic and dangerous to expect most people to be informed enough to make adequate decisions. One of the positive attributes of the HEC is the clarification of information which may raise ethical concerns. HECs can provide quality information gathering and issue clarification that can be accommodating to people of varying faiths and beliefs. Perhaps the HEC is a mechanism better equipped to deal with some concerns than is law or hospital policy.

One of the roles of the HEC is to provide a forum where all sides of an issue will be heard so that the decision made is more likely to be considered reasoned and equitable by all. Finally, in keeping medical decision-making out of the courts, HECs may reduce legal costs (Bowen 1986).

Literature Review:

The explanations for the emergence of HECs fall into one of four broad categories: (1) advances in technology, (2) an increase in patient desire for information and autonomy, (3) the belief that HECs are better equipped to handle many concerns than is the judicial system, and (4) government rulings calling for the establishment of ethics committees. The increase in technology is perhaps partially responsible for the other three causes. Weighing the pain, indignity, and expense of life-sustaining medical treatments against the desire to preserve life requires attention on a case-by-case basis that a set of laws or policies cannot provide. A growing opinion exists that decision-making by the patient, family and attending physician alone is often inadequate to address properly the ethical concerns of modern medical practice (Levine 1984).

Concern with civil rights and consumer protection has not stopped at the hospital doors. The emergence of HECs correlates with a trend toward questioning traditional authority. Health care consumers are no longer content to allow physicians to decide which course of action is best for themselves or their family (Fleetwood *et al.* 1989).

Within the medical community at least, there is a strong desire to keep decision-making out of the courts. The proper role of the judiciary is viewed as the protection of legal rights and the establishment of guidelines and safeguards but not decision-making in an individual case (Jaffe 1989). The HEC is seen as a compromise between a single physician dominated decision-making process and the judiciary. The HEC may be able to respond quickly to a given situation, its members are informed and experienced in the field of medical ethics, and proper discussion and dialogue should be ensured (Fleetwood 1989).

Finally, many court and government agency decisions have supported the formation of HECs. Perhaps the most important is the 1976, New Jersey Supreme Court ruling on the Karen Ann Quinlan case. In *Quinlan* the court suggested that an "ethics committee" should review withdrawing-of-treatment decisions. The committee, as defined in *Quinlan*, however, was more of a prognosis committee than a committee to truly discuss the moral and ethical concerns of the case (Hosford 1986).

In 1978, Congress approved the formation of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. One of the commissions nine reports, issued in 1983, dealt with decisions on withholding or withdrawing treatment (Hosford 1986). It suggested that a more structured attention was deserved by these concerns and stated that HECs could be effective in helping to make these decisions (Fleetwood *et al.* 1989).

Throughout the early 1980's, the Department of Health and Human Services (DHHS) issued three regulations in response to cases where medical treatments for newborns were refused. These regulations included suggestions concerning the formation of "infant care committees." The third statement, Baby Doe Regulation III, was issued in 1984. It also included suggestions for the membership of such committees (Hosford 1986).

Other, nongovernment groups have endorsed HECs. The Joint Commission on Accreditation of Healthcare Organizations' (JHACO) 1992 Accreditation Manual for Hospitals, in a new chapter on patient's rights, includes a requirement that all hospitals reviewed for accreditation must have ethics committees or other forums for addressing ethical issues. Hospitals are not required to be accredited by JHACO, but accreditation is a

prerequisite for receiving some types of federal funding (Joint Commission on Accreditation of Hospitals 1992). The American Academy of Pediatrics and the American College of Hospital Administrators have also formally recommended the formation of HECs (Levine 1984).

Several precursors to HECs have existed in the United States. Committees have been formed in the 1920's to review sterilization decisions and in the 1950's and 1960's to review abortion decisions (Levine 1984). Institutional review boards (IRBs) became numerous in the 1970's, following a 1966 Surgeon General of the United States Public Health Service requirement that grant applications which involve human subjects must be approved by a committee in the institution in which the proposal originates (Beecher 1970). IRBs review research or experimental treatment protocols which involve human subjects.

Applegate *et al.* (1992) found that 60 out of 149 (40.3%) of Indiana hospitals possess HECs. The mean number of members is 15.9 and the composition is 30.2% physicians, 19.5% nurses, 6.9% social workers, 10.1% clergy, 6.3% lawyers, 3.8% ethicists, 6.3% community representatives, 8.8% administrators, and 8.2% other (Applegate *et al.* 1992).

Varying opinions exist on the proper composition of HECs. Physicians are well represented on HECs because of their ability to understand and explain the technical aspects of the issues with which a committee deals. The five most common specialties among physicians on HECs are general practice, neurologist, pediatrician, surgeon, and anaesthesiologist (Jaffe 1989). One study reported that 57% of HEC members were physicians and has raised the concern that HECs might not be effectively avoiding physician-dominated decision-making (Levine 1984).

Nurses are also numerous among ethics committee members. Nurses are chosen because of their extensive experience with patients and because they traditionally fill a "patient's advocate" role on the committee (Jaffe 1989).

Clergy and lay members are chosen to keep the committee in touch with the prevailing moral norms of the community. Clergy are also recognized for their skills in moral analysis. Some committees include strong lay person representation in order to prevent the committee from becoming a "rubber stamp" for whatever physicians want to do (Lloyd 1988). On the other hand, concerns have been raised about confidentiality in committees that include lay members (Aroskar 1984). Social workers are valuable for their insights on the personal effects various interventions might have (Jaffe 1989).

Administrators and lawyers are common members of HECs. There is, however, disagreement concerning the desirability of their inclusion. Both are criticized as they may cause the committee to be more concerned with prevention of liability than provision of quality care. These concerns may be offset by the help that administrators can give in policy formation and implementation (Jaffe 1989).

Lawyers too bring valuable perspectives and information to an HEC, but fears remain that they will shift the focus of the discussion away from ethics and that they might dominate the committee whenever legal concerns arise (Mitchell and Swartz 1990). Two suggestions for ameliorating these concerns are selecting an attorney that is not affiliated with the hospital (Jaffe 1989) and having, when needed, a lawyer available for consultation who is not a member of the committee (Levine 1984). Lawyers may contribute to an HEC by delineating the legal obligations of

the committee and the hospital, applying his or her interpretive skills in understanding and drafting policy, and preventing legal mistakes and thereby preserving the credibility of the committee (Mitchell and Swartz 1990).

Professional ethicists and philosophers are also common members of ethics committees. The utility of their skills in ethical analysis and their ability to understand different methods of approaching a dilemma make them valuable additions to a HEC. They may also serve to focus the attention of other committee members on the ethical aspects of a case rather than the technical and legal considerations. Nationwide 77% (Schierton 1993) and in Indiana 49% (Applegate *et al.* 1992) of HEC chairpersons are physicians. Schierton (1993) suggests that, at least in terms of the number of actions taken by a committee, HECs chaired by professional ethicists were more successful than those chaired by physicians.

The four commonly stated functions of HECs are education, policy formation, case consultation, and retrospective review. How well and how often committees perform these functions has been the subject of much concern. Applegate *et al.* (1992) reported that only 6 of 33 (18%) of Indiana HECs were involved in more than three ethics related educational activities per year. This stands in contrast with the facts that almost all HEC's include education as a stated function in their purpose statement and that many people feel that education is the most important and least controversial function of a HEC (Jaffe 1989).

In Indiana, 59% of HECs have been involved in policy formation (Applegate *et al.* 1992). The HEC may provide an excellent multidisciplinary forum for the discussion of potential policy and the

policy developed may be implemented more easily by a body already adept at education.

Case reviews are perhaps the most celebrated and least utilized function of HECs. In 1990 in Indiana, 10 out of 34 (29%) HECs reviewed no cases, 12 (35%) reviewed 1 to 3 cases, and 12 (35%) reviewed 4 or more cases (Applegate *et al.* 1992). Few people would suggest that HECs should make decisions on individual cases. Goals of HEC members in a case consultation should include: (1) ensuring that all relevant information has been gathered, (2) determining which issues are ethical concerns and establishing which interests are in conflict, (3) facilitating communication between all parties involved, and (4) providing support to health care professionals and families (Levine 1984).

Retrospective review is also a stated function of many committees. Retrospective review may be useful in determining if an appropriate decision has been made, deciding how a case could be better handled in the future, and determining what policy or educational offering needs to be considered (Levine 1984). Concerns include a fear that retrospective review will increase physician liability should the HEC decide that inappropriate actions were taken (Jaffe 1989).

As many HECs have been in existence for a number of years, many people have begun to ask questions concerning the ethics committee's effectiveness that go beyond the number of times per year that a certain function is performed. Often self-evaluation measures exist, but many times they do not. Many committees find themselves spending their time on efforts other than those that were the stated rationale for their formation. Qualitative evaluation, in a form other than anecdote, remains largely unexplored (VanAllen *et al.* 1989).

Methods:

The addresses of chief executive officers of 127 Indiana hospitals were obtained from the American Hospital Association Directory of Health Care Professionals (1991). Institutions that were solely mental hospitals or drug and alcohol rehabilitation centers were excluded. The CEOs were sent a brief letter explaining the goals of the survey and were asked to complete and return a postcard with information on the existence of a committee and the chairperson's address.

Following a study of the available literature on HECs, an extensive list of questions was prepared. The questions focused on points raised in the literature that did not have adequate support. The goal was to fill in some of these gaps in order to provide a more solid framework with which to support or question the authors' speculations. Function, effectiveness, and information on member composition were stressed.

Numerous revisions were made with the help of Dr. Jon Hendrix in order to sharpen the focus of the questionnaire and omit questions that did not pertain to the stated goals. The final draft of the questionnaire was limited to four-pages and most questions were yes/no, scale, check-all-that-apply, or fill-in-the-blank in order to promote a high response (Berdie *et al.* 1986). The goals of the survey were: (1) to gather information about the composition, prevalence, and time of formation of HECs, (2) to determine what the stated goals of HECs are, (3) to assess the attitudes of chairpersons toward the effectiveness of their committees, and (4) to determine what activities HECs commonly perform.

The second mailing, which contained the questionnaire, was mailed to chairpersons of existing HECs or currently forming HECs that had already

selected a chair person. One follow up mailing, including a second copy of the questionnaire, was sent to those committees not returning the survey.

Some data were analyzed with an independent-groups t-test, chi-square tests, and a Q statistic chi-square test for multiple samples.

While surveys were being returned a copy of an unpublished report by Applegate *et al.* (1992) was discovered. Many of the questions addressed by this survey were addressed in their survey of Indiana hospital and extended care facility ethics committees. In personal communication with the authors it was learned that their report was being prepared for publication.

Results:

The first mailing, sent to 127 hospitals received 90 responses (71%). Of those responding, 39 (43%) stated that they do not have HECs, 42 (47%) stated that they do have active HECs, and 9 (10%) stated that they were in the process of forming an HEC. The questionnaire was sent to 47 hospitals and 37 responded (79%).

Larger hospitals were more likely to have a HEC and respond to the survey than were hospitals with smaller bed size (Table 1). A marginally significant relationship between hospital bed-size category and positive response was observed when the data were analyzed with a Q statistic chi-square test ($Q=10.02$, $d.f.=5$, $P<0.10$). Hospitals in urban areas (cities with greater than 50,000 population) appear to be more likely to have HECs (Table 2).

Table 1Response Rate Data by Hospital Bed Size

<u>Bed size</u>	<u>Hospitals sent first mailing</u>	<u>HECs responding</u>	<u>Percent</u>
0-99	47	10	21%
100-199	29	10	34%
200-299	15	6	40%
300-399	17	6	35%
400-499	6	4	67%
500+	12	6	50%

Table 2Percent Response by Hospital Location

	<u>Urban</u>	<u>Rural</u>
Hospitals receiving first mailing	24%	76%
<u>HECs responding</u>	<u>33%</u>	<u>67%</u>

The year of formation (Table 3) ranged from 1981 to 1993. The distribution of years of formation was strongly bimodal with peaks at 1985-1986 and at 1991. When asked what the most important government ruling or statement was in the decision to form the committee, the most frequent response, chosen 8 times, was the 1984 Department of Health and Human Services (DHHS) endorsement of HECs. The DHHS recommendation corresponds with the first of the peaks in committee formation. Other responses included *Quinlan* (3), The President's Commission (3), JCAHO (5), and other (1). No direct relationship between these statements and the timing of the formation of committees is apparent.

Table 3Number of New HECs per Year

<u>Year</u>	<u>Number of committees</u>		<u>Estimated total in Indiana</u>
	<u>New</u>	<u>Cumulative</u>	
1981	1	1	1
1982	0	1	1
1983	1	2	3
1984	4	6	8 (DHHS Regulation III)
1985	5	11	16
1986	5	16	23
1987	4	20	28
1988	2	22	31
1989	1	23	32
1990	3	26	37
1991	7	33	47
1992	3	36	51 (JCAHO statement)
1993	1	37	52

The mean number of committee members was 14.6 and the range was 6 to 36. Seven committees had twenty or more members. The composition of the committees was as follows: 33% physicians, 21% nurses, 9% hospital administrators, 5% lawyers, 3% ethicists, 10% clergy, 7% social workers, 5% lay community members, and 7% other. Only 4 of 37 committees (11%) were composed of 50% or more physicians. Of the committees surveyed, 54% of the members were male and 46% were female. Seventeen out of 30 (57%) of chairpersons felt that their HEC approximated the racial and ethnic distribution of the community.

The length of term of HEC members is variable for 13 committees, 1 year for 5, 2 years for 6, 3 years for 3, and 4 or more years for 7 committees.

A task committee to assess the potential need for an HEC preceded the formation of 20 of the committees (54%). Initial and replacement committee members are selected by the task committee, hospital administrators, medical chiefs of staff, or by the committee itself.

Thirty of the committees have purpose statements (81%). All of these statements include case review and education as functions of the committee. Five out of these 30 (17%) include policy formation and 18 (60%) include retrospective review as functions.

Ten questions concerning the effectiveness of HECs were asked. The responses were on a scale of one to five and are summarized in table 4.

(1) The distribution of speaking time between members is:

(1=Dominated by a few, 5=Very even)

(2) How effective do you perceive the committee to be in facilitating sound ethical decision-making? (1=Ineffective, 5=Very effective)

(3) How effective do you perceive the committee to be in protecting the rights of those who cannot speak for themselves? (1=Ineffective, 5=Very effective)

(4) How effective do you perceive the committee to be in preventing cases from being settled by the judicial system? (1=Ineffective, 5=Very effective)

(5) How effective do you perceive the committee in providing support, guidance, and solace for family members faced with difficult decisions? (1=Ineffective, 5=Very effective)

(6) How effective do you perceive the committee to be in increasing consciousness of ethical issues in the hospital community? (1=Ineffective, 5=Very effective)

(7) How effective do you perceive the committee to be in easing/preventing friction between patients, family, and various health care providers? (1=Ineffective, 5=Very effective)

(8) How effective do you perceive the committee to be in providing an effective compromise between physician-dominated decision making and the courts? (1=Ineffective, 5=Very effective)

(9) How do you believe most physicians who have dealings with the committee rate its effectiveness? (1=Ineffective, 5=Very effective)

(10) Do you feel that there are adequate due process safeguards present to ensure representation of the patient? (1=No safeguards, 5=Adequate safeguards)

Table 4

Scale Question Results

<u>Question</u>	<u>Mean</u>	<u>N</u>	<u>Range</u>	<u>Number of 1 and 2 responses</u>
1	3.88	34	2-5	4
2	4.22	32	2-5	2
3	4.41	32	3-5	0
4	3.58	31	1-5	3
5	3.84	32	2-5	3
6	4.06	32	3-5	0
7	3.75	32	2-5	1
8	3.41	27	1-5	5
9	3.77	31	2-5	2
10	3.97	31	3-5	0

Education was the most frequently performed function. Policy formation, case review, and retrospective review were about equal (Table 5).

Table 5

Number of Committees Performing Each Function by Frequency Interval

<u>Function</u>	<u>Times per year function performed</u>					<u>Mean assuming center of range</u>
	<u>0</u>	<u>1-3</u>	<u>4-10</u>	<u>11-20</u>	<u>21-50</u>	
Case review	5	9	14	3	0	5.2
Retrospective	7	8	8	4	0	5.0
Policy formation	0	11	8	1	0	5.5
Education	0	15	9	4	4	9.3

Cases were referred by several sources. All committees reviewed some cases. Cases have been referred by the following:

Table 6

Source of Case referral With Percent of HEC's Reporting Use

<u>Person or Method</u>	<u>Percent (N=33)</u>
Patient	6%
Nurse	100%
Attending physician	97%
Other physician	15%
HEC member	24%
A referral form exists	21%
<u>A HEC phone number exists</u>	<u>55%</u>

HEC meetings were open to professionals involved with the case but generally were closed to the general public. Records are kept by 29 of 34 (85%) committees. Access to these records is somewhat more restricted.

Table 7**Meeting and Record Access**

	<u>Meetings open to (N=32)</u>	<u>Record access (N=26)</u>
The physicians involved	97%	73%
The family of the patient	78%	35%
The nurses involved	94%	43%
Other physicians	44%	19%
<u>The general public</u>	<u>6%</u>	<u>0%</u>

HECs informed patients and other health care workers at the institution of their existence with literature (52%), patient handbooks (42%), newsletters (19%), and by speaking at meetings and other functions (84%).

A need for standardization of HEC operating policy was perceived by 24% of those responding. Forty-four percent feel that HECs are cost effective members of the hospital community. Thirty-five stated that they felt that HEC members should be immune from liability in their functions as HEC members, none stated that HEC members should not be immune from liability in this function, and two omitted the question.

Investigative follow-up was never practiced by 2 committees, sometimes by 7, usually by 13, and always by 8. Self evaluation procedures were practiced by only five committees (14%). On a scale of 1 to 5 the mean effectiveness of self-evaluation procedures was 3.7.

Discussion:

The 47% of hospitals with existing HECs is somewhat higher than the 40.3% reported in Applegate *et al.* (1992). The difference is likely due to

the difference in response rate between the two surveys (71% as opposed to 97.4%).

No commentary on the significant relationship in committee existence versus hospital bed size was found in the literature. The trend toward higher frequency of HEC existence in urban hospitals may be a function of the tendency for large hospitals to also be urban.

The observed 1984-1987 peak in HEC formation correlates with the most often chosen reason for forming an HEC, the DHHS Baby Doe Regulation III. The emotion aroused by the Baby Doe cases, particularly the 1982 Bloomington, Indiana case is an understandable impetus for committee formation. The 1991 spike in committee formation is more difficult to explain in terms of rulings or recommendation.

Hosford (1986) states that a "bioethics committee can perform successfully at any size from about 5 to 25 members." He mentions difficulty in finding qualified and enthusiastic potential members, convenience in scheduling meetings, and the ability of a small committee to quickly learn to work together in a meaningful way as benefits of small committee size. The diversity of viewpoints and skills and the ease of finding some one available to perform a given task are stated advantages of large committee size.

The numerical response for question 2, the assessment of effectiveness in facilitating sound ethical decision-making, was examined for small (14 or fewer members) and large (15 or more members) committees. The results were analyzed with an independent groups t-test and the large committees showed a significantly higher satisfaction with the quality of decision-making ($t=2.18$, $d.f.=33$, $\alpha<0.05$).

For frequency range of functions performed, frequency differences between large and small committees were analyzed by chi-square tests. Committees not including the given function in their purpose statements were excluded. Large committees performed more case reviews than small committees, but this relationship was only marginally significant ($\chi=6.52$, d.f.=3, $P<0.10$). Large committees also performed more retrospective reviews ($\chi=1.02$, d.f.=2, $P<0.90$), more policy formations ($\chi=1.13$, d.f.=2, $P<0.20$), and more educational activities ($\chi=5.61$, d.f.=3, $P<0.20$), but none of these frequency differences proved to be significant. Perhaps larger committees with more members are more conscious of cases that might be reviewed or they make the committee more well known so the more cases are referred to the committee.

Data on HEC composition in other states were not available in the literature. The survey's results were in close agreement with Applegate *et al.* (1992). Indiana's ethics committees, taken on a whole, seem to approximate the desired composition stated in the literature. Hosford (1986) suggests that committees should be one-third physicians. This is exactly the overall composition for Indiana HECs. In the earlier literature on HECs fears existed that physicians would numerically dominate HECs (Levine 1984). For 89% of Indiana's HECs, these concerns are unfounded.

The profession of HEC chairpersons was explored by Applegate *et al.* (1992). Three-fourths of Indiana HEC chairpersons were found to be physicians. Schierton (1993) suggests that committees numerically dominated by physicians or chaired by physicians are less successful than those that are not. Success was judged on the basis of the number of educational, policy formation, and consultative functions performed. While Indiana is diverse in member composition, perhaps, as Schierton suggests,

bioethics training is a better criteria for chairperson selection than departmental rank or physician status.

The length of term varies widely between committees. Hosford (1986) states that committees with one or two year terms for members, of which there are at least 11 in Indiana, are at a disadvantage as members may leave just as they become well educated in the issues with which the committee deals. Renewing membership may be one way to avoid this problem, but the survey did not address how frequently members are reappointed. Committees may desire short terms so that members who are not helpful to the committees purpose may be replaced.

For the ten scale questions the range is perhaps more telling than the mean. The means varied by only 1.00 point between questions. In each case a similar assessment by a non-HEC member doctor or other hospital employee would have been interesting, but this was beyond the scope of the survey. Question 8 received both the most unfavorable responses and the most committees that chose to omit the question. Possible explanations are that HEC decision-making in a given case is physician-dominated decision-making or perhaps these chairpersons do not estimate the potential for judicial involvement in medical decision-making to be very great.

Educational activities, the most frequently performed function, have been described as "the least controversial" activity of HECs (Jaffe 1989). The high number of educational activities indicates that committees are actively involving themselves in relevant issues rather than waiting for problems to be discovered.

The fact that only two committees report that cases have been referred by patients may indicate a lack of knowledge about the committee

by the patient. It could also be an indicator of apprehension on the part of patients to request help from the committee.

Jaffe (1989) states that "a major reason for confidential proceedings is lack of immunity. If, however, [HECs] are immune from civil and criminal liability, the need for confidentiality decreases." Most meetings are closed to individuals not directly involved with the case. The unanimous opinion that HEC members should be granted immunity from liability concerning their functions with the committee may suggest that liability concerns are an important factor in the function of HECs, possibly affecting the openness of meetings. For the two committees whose meetings are open to the general public openness appears to be paramount.

Jaffe (1989) also states that "the first way to achieve some [HEC] legitimation ... is with standardization." In Indiana, 76% of committee chairpersons apparently disagree, stating that they see no need for outside regulation of committee procedures. Existing committees seem confident of their competence.

Aroskar (1984) stresses the importance of self-evaluation. While 93% of Indiana's HECs at least sometimes seek follow-up information after a case review, only 14% participate in other self-evaluation procedures. Aroskar (1984) recommends that costs "should be assessed in relation to benefits to the institution and most important, benefits of adequately performed decision-making in patient care and in policy making that takes explicit account of ethical aspects." In light of this statement, it is possible that the 44% satisfaction with the cost effectiveness of HECs may be, in part, a result of inadequate self evaluation. A more thorough approach to assessing realized benefits might increase feelings of cost-effectiveness.

Summary:

Hospital ethics committees are the subject of a great volume of literature but until recently little of this literature has been backed by data. As the HEC has matured, so has the analysis of its prevalence, function, and effectiveness turned from anecdote and speculation to information gathering and analysis. In Indiana, HECs are present in about half of all hospitals, are increasing in number, and are playing active roles in determining how the hospital responds to ethically difficult cases, what is done to educate staff on ethical issues, and what policy modifications are needed to deal with ethical concerns.

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[CEO]
[Hospital]
[Street Address]

September 14, 1992

The concerns raised by the use of modern medical technology, tissue and organ donation, advance directives, and issues related to medical treatment have created the need to form institutional ethics committees (IEC's). The stated functions of these advisory bodies vary as do the decision-making methods employed, but case consultation, policy review, and education are common tasks assigned to IEC's. However little empirical data has been collected for IEC's in Indiana.

It is our intent to determine how many hospitals in Indiana possess IEC's, the reasons for their formation, the relative amount of time and effort spent on various functions, and their perception of the relative effectiveness of these roles. The results of this study will be returned to participating ethics committees and a paper will be prepared and submitted for publication. In order to send a questionnaire to your hospital's ethics committee or review board, we require the information on the enclosed self addressed postcard.

Thank you for your time,

Dr. Jon Hendrix, Professor of Biology

Robert Emerson, Undergraduate honors fellow
and premedical student

Response Postcard (Front and Back)

1. **Is your institution served by an IEC?**
 - a) **yes**
 - b) **no**
 - c) **one is currently being formed**

2. **What is the chairperson's name and mailing address?**

3. **Does this committee jointly serve any other hospital?**
 - a) **yes.**

What is the name of the other hospital(s)? _____
 - b) **no**

4. **Which of the following best describes your hospital:**
 - a) **complete care**
 - b) **mental hospital**
 - c) **rehabilitation center**
 - d) **other, please specify** _____

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Cover Letter to HEC Chairperson

A3

3 December 1992

[chair]
[hospital]
[address]
[city], IN [zip]

Dear [chair],

Earlier this fall your hospital's CEO responded to my initial mailing by stating that an ethics committee existed at your hospital and by supplying me with your address so that you might participate in my survey on the structure and function of hospital ethics committees in Indiana. This mailing was sent to 125 Indiana hospitals identified in the 1991 *American Hospital Association Directory of Health Care Professionals*. Of the 88 responding, 47 (or 53%) have hospital ethics committees (HEC's) in place. I hope that you will take a few minutes to complete this survey and return it in the enclosed envelope.

I am a biology major at Ball State University and have been accepted to enter Indiana University Medical School in the fall of 1993. As a student and undergraduate honors fellow working with Dr. Jon Hendrix, Ball State's bioethics professor, I have become interested in the subject of medical ethics. Over the past decade, articles on HEC's have been regular occurrences in medical and ethics journals. However, in my literature search I have found no references to surveys of Indiana HEC's. In addition, relatively few authors attempt to assess the functions and effectiveness of HEC's in a systematic manner.

My goal is to provide a quantitative assessment of attitudes of committee chairpersons toward the effectiveness of their committees. I also hope to obtain data on the stated goals and the constituency of these committees. The information gained by this survey will be used to prepare an article that will be submitted for publication.

The survey forms are numbered for purposes of correlating responses to hospital size and region. They will also be used for preparing a list of committees that responded so that I might mail a copy of the resulting publication to each committee chairperson who returns this survey. Once the data are entered, the hospital and chairperson names will be erased from my data base and no responses will appear in my article that may be traceable to a person or institution. I believe that the insights and comparative information gained will be well worth your time

Thanking you in advance,

Robert E. Emerson

Indiana Hospital Ethics Committee Survey

- 1) What year was the committee formed? _____
- 2) How many committee members are there? _____
- 3) How many members are:
- | | |
|-------------------------------|-----------------------------|
| Physicians _____ | Clergy _____ |
| Nurses _____ | Social Workers _____ |
| Hospital Administrators _____ | Lay Community Members _____ |
| Lawyers _____ | Other, please specify _____ |
| Ethicists _____ | |
- Male _____ Female _____
- 4) Does the membership of the committee approximate the racial and ethnic distribution of the community?
- Yes
- No
- 5) Who selected the original members of the committee?
- _____
- _____
- _____
- 6) How are names of potential replacement members obtained?
- _____
- _____
- 7) What is the length of a term served by a member? (Check one.)
- | | |
|---|--|
| <input type="checkbox"/> Less than one year | <input type="checkbox"/> Three years |
| <input type="checkbox"/> One year | <input type="checkbox"/> Four or more years |
| <input type="checkbox"/> Two years | <input type="checkbox"/> Not all members have terms of the same length |
- 8) Was a task committee formed to assess the possible need for an IEC prior to the establishment of the ethics committee?
- Yes No
- 9) Does the committee have a mission or purpose statement?
- Yes (If yes, a copy would be appreciated if possible.)
- No (If no, omit question 10.)
- 10) Which of the following functions are included in the mission statement? (Check all that apply.)
- | |
|---|
| <input type="checkbox"/> Case consultation |
| <input type="checkbox"/> Education |
| <input type="checkbox"/> Policy formation |
| <input type="checkbox"/> Retrospective review |

11) Which of the following was most important in the decision to form an ethics committee?

(Check one.)

- The 1976 New Jersey Supreme Court Quinlan ruling
 The 1978 President's Commission recommendation
 The 1984 Department of Health and Human Services endorsement of IEC's
 The 1992 Joint Commission on Accreditation of Healthcare Organizations
 Other, please specify _____

Directions: For questions 12 through 21 please indicate your perception of the committee's effectiveness by circling a number from one to five.

12) The distribution of speaking time between members is:

Dominated by a few 1 2 3 4 5 Very Even

13) How effective do you perceive the committee to be in facilitating sound, ethical decision making?

Ineffective 1 2 3 4 5 Very Effective

14) How effective do you perceive the committee to be in protecting the rights of those who cannot speak for themselves?

Ineffective 1 2 3 4 5 Very Effective

15) How effective do you perceive the committee to be in preventing cases from being settled by the judicial system?

Ineffective 1 2 3 4 5 Very Effective

16) How effective do you perceive the committee to be in providing support, guidance, and solace for family members faced with difficult decisions?

Ineffective 1 2 3 4 5 Very Effective

17) How effective do you perceive the committee to be in increasing consciousness of ethical issues in the hospital community?

Ineffective 1 2 3 4 5 Very Effective

18) How effective do you perceive the committee to be in easing/preventing friction between patients, family, and various health care providers?

Ineffective 1 2 3 4 5 Very Effective

19) How effective do you perceive the committee to be in providing an effective compromise between physician dominated decision-making and the courts?

Ineffective 1 2 3 4 5 Very Effective

20) How do you believe most physicians who have dealings with the committee rate its effectiveness?

Ineffective 1 2 3 4 5 Very Effective

21) Do you feel that there are adequate due process safeguards present to ensure representation of the patient?

No Safeguards 1 2 3 4 5 Adequate Safeguards

22) Are there cases where committee review is mandatory?

- Yes No (If no, omit question 23.)

23) If so, are the decisions of the committee binding?

- Yes
- No

24) Do you feel that the decisions of the committee, in some or all cases, should be legally binding?

- Yes
- No

25) Do you feel that IEC's should be granted immunity from liability?

- Yes
- No

26) Approximately how many times per year is the committee involved in:
(Check one box per function.)

0 1-3 4-10 11-20 21-50 50+

Case Review
 Retrospective review
 Policy Formation
 Educational outreach activities

27) What methods are employed to alert the committee to cases that are reviewed? (Check all that apply.)

- No cases are reviewed
- Case review may be requested by patients/family members
- Case review may be requested by nurses
- Case review may be requested by the attending physician
- Case review may be requested by other physicians
- Case review may be requested by ethics committee members
- Referral forms exist
- A committee telephone number exists

28) Do you feel that there is a need for standardization of basic operational IEC policies on a state or federal level?

- Yes
- No

29) When reviewing cases, to whom are ethics committee sessions open?
(Check all that apply.)

- The physicians involved
- The family of the patient
- Nurses, other health care providers involved
- Other physicians
- The general public

30) Are records of the committee proceedings kept?

- Yes
- No (If no, then omit question 31.)

31) Who has access to these records? (Check all that apply.)

- The physicians involved
- The family of the patient
- Nurses, other health care providers involved
- Other physicians
- The general public

