

The University of Kansas Hospital and KU Medical Center

CLINICAL ETHICS HANDBOOK

This handbook has been prepared by the Hospital Ethics Committee to provide staff with easy access to information about the Committee and its subcommittee, the Pediatric Ethics Committee. It also provides information regarding guidelines and policies that have been adopted by this institution for responding to ethical issues in the care of patients.

The handbook will be revised and expanded as needed. Suggestions for revisions or additions are welcome.

Requests for ethics case review with the Hospital Ethics Committee can be made by placing an order in the electronic record, paging 913-917-1579, or contacting the hospital page operator/switchboard (913-588-5155) and asking them to page the Ethics Committee team member on call.

There are two sections to this Handbook. Part A includes guidelines and policies adopted by the Hospital Ethics Committee and the Pediatric Ethics Committee. Part B adds guidelines and policies adopted by the University of Kansas Hospital.

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A. Policies and Guidelines Adopted by the Ethics Committees

A.1. ACCESSING THE ETHICS COMMITTEES AND CONSULTATION SERVICE

The Hospital Ethics Committee and its sub-committee, the Pediatric Ethics Committee, may be accessed for ethics consultation 24 hours a day by calling the hospital's page operator at 913-588-5155. The operator always has access to the on-call schedule of consultants and will either page them or provide contact information to the requester. The consultation service for adult patients may be reached directly anytime by using the dedicated pager number 913-917-1579. It is possible also to place an ethics consultation request electronically in Epic O2 (electronic medical record) as a physician's order. The Pediatric committee is consulted for patients who are under 18 years of age, and that contact number is available also by calling 913-588-5155.

In addition to formal consultation, ethics consultants welcome questions or requests for informal discussion of clinical ethics. A current list of ethics committee members and consultants can be obtained by contacting the Department of History and Philosophy of Medicine at 913-588-7040.

A.2. ETHICS COMMITTEES MISSION STATEMENT

The Hospital Ethics Committee of the University of Kansas Hospital and its subcommittee, the Pediatric Ethics Committee, serve the entire hospital and medical center community by encouraging and supporting: ethical reflection, mutually respectful dialogue, critical analysis, and most importantly, standards of conduct which reflect this institution's commitment to patient-centered care.

A.3. POLICIES AND PROCEDURES: HOSPITAL ETHICS COMMITTEE

A.3.1. Function

The Hospital Ethics Committee (hereafter referred to as "the committee") will have three functions or roles:

A.3.1.a. Education

In cooperation with the hospital administration, its various departments and divisions, and its medical/nursing and allied health professional staff, the committee will undertake educational efforts in clinical ethics. Depending on the availability of resources, the committee will develop or assist others in the development of lectures, seminars, workshops, courses, rounds, in-service programs and

the like in clinical ethics. The aims of these educational efforts will be to provide participants with access to the language, concepts, principles and body of knowledge about ethics that they need in order to address the complex ethical dimensions of contemporary hospital practice.

A.3.1.b. Policy Review and Development

The committee will assist the hospital and its professional staff in the development of policies and procedures regarding recurrent ethical issues, questions or problems that arise in the care of patients. In this role the committee may provide analysis of the ethical aspects of existing or proposed policy or assist in the development of new institutional policy in areas of need.

A.3.1.c. Ethics Consultation and Case Review

An important function of the committee will be its role as a forum for analysis of ethical questions which rise in the care of individual patients. In many circumstances these questions concern appropriate care of patients with diminished capacity to participate in decision-making regarding their care. In its consultation role the committee's ethics consultation service will attempt to provide support and counsel to those responsible for treatment decisions including health care providers, patients, surrogates and members of the patient's family.

Clinical ethics consultation and case review is particularly recommended in three specific categories of decision-making:

- decisions involving significant ethical ambiguity and perplexity in which consultation may provide insight into complex ethical issues;
- decisions involving disagreement between care providers or between providers and patients/families regarding the ethical aspects of a patient's care;
- decisions that involve withholding or withdrawal of life-sustaining treatment, especially those which are not adequately addressed in policies and procedures included in this Handbook.

In this consultation role the committee will not act as a decision-making body, but will attempt to assist and to provide support to those who do have this responsibility. Its role in all such cases shall be advisory.

A.3.2. Appointment and Membership

The committee membership will be multidisciplinary. A majority of the membership will be non-physicians. Additional membership will include as available at least the following disciplines: nursing, social work, pastoral care, clinical ethics, law, respiratory care, and dietetics and nutrition. In view of the unique ethical problems involved in situations involving pregnant women, one physician member shall be from the Department of Obstetrics and Gynecology. The Chief Executive Officer of the Hospital (or designee), the Chief of the Medical Staff (or designee), and an attorney employed by the Medical Center shall be ex-officio, non-voting members. The committee will also identify and nominate for appointment at least one community representative who is not an employee of the hospital or medical center.

Members will be approved by the committee and the Chief Operating Officer of the Hospital, as will the Chair or Co-Chairs of the committee. The Vice-Chair, if any, will be chosen by the membership of the committee. It is recommended that the Vice-Chair be identified from among those who have served on the committee at least one year. If the committee is led by co-chairs, a vice-chair is optional.

A.3.2.a. Hospital Ethics Committee Advisory Group

At the discretion of the Chair (or Co-Chairs), and with approval of the Chief Operating Officer, an auxiliary to the committee may be formed as the Hospital Ethics Committee Advisory Group. The membership of this group will be recruited by the Chair, and added by majority vote of the committee. Advisory Group membership will not be fixed, but will range from approximately 6-12. Membership will be comprised mostly of physicians, but may include other disciplines, including possibly community members. Membership may come initially from current committee members whose status

is inactive, per attendance requirements of active membership. Advisory Group members will agree to:

- receive notifications of the HEC on a regular basis
- support its mission
- be available as informal consultants
- take on specific, time-ended roles on an “as needed” basis
- meet with the committee and/or its Chair (or Co-Chairs) on an ad hoc basis

A.3.3. Jurisdiction

In view of the establishment of a Pediatric Ethics Committee as a standing sub-committee (see “Policies and Procedures of the Pediatric Ethics Committee”), the mandate of the committee will be to engage in its functions of education, policy development and case review as these relate to the care of patients who are adults, i.e., 18 years of age or older. The committee’s jurisdiction will also include the unique ethical issues involved in decision-making involving pregnant women when gestation is felt to have progressed to the stage of fetal viability. Policies and procedures and all non-case review activities of the Pediatric Ethics Committee are subject to the review and approval of the Hospital Ethics Committee.

A.3.4. Procedures

A.3.4.a. Educational Functions

A primary educational emphasis for the committee is its own education and mechanisms to ensure the continuing education of its members. The field of clinical ethics is a broad and rapidly evolving one. In order to maintain an appropriate level of expertise, the committee will develop means of providing members information about clinical ethics and access to the rapidly expanding body of literature in this field. Methods may include orientation of new members, specific reading assignments, an annual retreat, seminars, mock case/policy review exercises and the like. In addition, the committee may participate in networking with other area/regional ethics committees, such as the Greater Kansas City Ethics Committee Consortium of the Center for Practical Bioethics, and participate in continuing educational programs for ethics committee members as feasible.

Any educational efforts undertaken by the committee for members of the hospital staff will be coordinated with existing educational efforts as much as possible. Primary emphasis will be on assisting departments and divisions to incorporate material about the committee and the field of clinical ethics into their existing educational programs and activities.

A.3.4.b. Policy Review and Development Functions

At the request of the Chief Operating Officer of the Hospital, the Chief of Medical Staff, or the Executive Committee of the Medical Staff, the committee will undertake review of any existing policy, protocol or procedure; provide analysis of the ethical issues involved; and, provide recommendations regarding appropriate modifications, where needed. With the approval of the Chief Operating Officer of the Hospital, the committee may also undertake such review at the request of any member of the hospital staff.

In addition, when requested, the committee will assist the hospital and/or its staff in the development of new policies in areas that involve significant ethical questions or problems. If the committee feels that there is a need for policy development in order to address a significant ethical issue, it will submit a written recommendation to this effect to the Chief Operating Officer of the Hospital and request permission to develop a policy statement. Any recommendations for modification of existing policies or development of new policy must be submitted in writing to the Chief Operating Officer of the Hospital.

A.3.4.c. Ethics Consultation and Case Review

A.3.4.c(1). Access to Committee and Consultation Service

An ethics consultation team, comprised of committee members and directed by a committee chair or co-chair, will be available on-call to respond to requests for case review at all times. A roster of team leaders and members, with contact information for those on-call, will be available through the Hospital Page Operator. A consultant will attempt to have an initial discussion with the person making the request within twenty-four hours of the request or sooner, whenever possible.

Ethics consultation will occur in response to a reasonable and appropriate request by: (1) any involved member of the medical staff, house staff, hospital staff, or hospital administration; or (2) the patient, patient's guardian, surrogate or a member of the patient's family. Prior to proceeding with the consult, the consultant typically will notify the patient's designated attending physician of the request, discuss the possible basis for the review and request his/her support and involvement.

A.3.4.c(2). Informal and Formal Ethics Consultation and Case Review

Designated committee members serving on the ethics consultation service will be available to provide consultation regarding a case in either an informal or formal manner. The remaining portions of this section A.3.4.c. relate only to requests for formal consultation. In the case of a request for informal consultation, no documentation of the comments of any committee member will be placed in the patient's medical record. Informal requests for ethics consultation will, however, be documented and reported by the involved committee member to the committee's director of ethics consultation service. Typically, all case consultations, formal and informal, will be reviewed by the full committee at the next regularly scheduled meeting of the committee.

A.3.4.c(3). Standard Response to a Request for Ethics Consultation

Following receipt of a request for ethics consultation, one or more of the on-call consultants will respond in a timely fashion, within 24 hours or less. In most cases, the on-call consultants will follow a standard protocol involving:

- return phone calls to requesters so as to discern what sort of additional response, if any, is called for;
- review of the electronic medical record, if there is need to know specific patient information;
- visit to the unit for interviews with requester, patient, surrogates, other caregivers;
- research the ethics issues in journals, online, in this Handbook, via intranet for hospital policies of relevance, and elsewhere, as needed;
- participate in multidisciplinary team meetings called by the attending physician, most often organized by a social worker or nurse case manager;
- consult with Risk Management, Palliative Care, or other ethics committee members, as needed;
- draft and post an ethics chart note in the electronic medical record, typically using a template to construct a concise, thorough, well organized note, as follows:
 - Basic Information (Who, What, When, Where?)
 - Ethics Issues (Why?)
 - Recommendations and Resources
 - Follow Up and Contact Information

A.3.4.c(4). Determination of Need for Urgent Review by Full Team

If it is a difficult and complicated case situation, the director of the committee's ethics consultation service may be consulted as well. A collaborative determination will be made as to whether or not there is a need to present the case before a specially called meeting of the full team. In most situations, there is likely to be no such need, and the consultant can, on his or her own, proceed to review the case and provide a recommendation, as is otherwise described in this section. Formal ethics consultation and case review by the entire team is advisable in cases that involve especially complex ethical issues.

Following a decision by an ethics consultant and consultation service director that it is appropriate to have case review in a specially called meeting, the director will convene a group of at least two to five members of the committee. The group will reflect the multidisciplinary composition of the committee. The consultation service director, along with the on-call consultant(s), will have reviewed the request

to determine the nature of the case, the status of the patient, the ethical question(s), concern(s) or problem(s) prompting the request, and will have reviewed the electronic medical record and any other information needed in order to determine if a team meeting is appropriate.

A.3.4.c(5). Preparation for or Opposition to a Multidisciplinary Team Meeting

If ethics consultants have not already participated in a multidisciplinary meeting organized by the care team, one involving perhaps the patient and/or surrogates, it may be necessary for the ethics service to initiate such a meeting. If so, the consultant(s) will contact the patient's physician to discuss the consult request and the perceived need for a meeting. The physician's participation will be requested, along with other caregivers, and ethics consultants will schedule the multidisciplinary team meeting regarding ethics concerns.

Absent special considerations, the patient and/or the patient's family or surrogate decision makers should also be notified that the case review will be taking place, and they will be invited to participate. Their decision not to participate, or their objection to the ethics consult, would not prevent a formal ethics consult or meeting from taking place.

If the patient's attending physician is not the consult requester and also believes that ethics consultation, with or without a meeting, is not appropriate, this conflict should be referred immediately to the Chief of Medical Staff for resolution. In the event of a persistent conflict, the Chief of the Medical Staff may assist in the orderly transfer of responsibility to another attending physician who is willing to permit the ethics consultation and case review to go forward.

A.3.4.c(6). Conduct of Ethics Consultation Multidisciplinary Case Review Meeting

At a multidisciplinary meeting called by the ethics consultation service, the lead consultant will instruct all present regarding the advisory role of the ethics committee; the intent to serve as a supportive forum for those who have the primary decision-making responsibility; and the need for strict confidentiality of all material presented and discussed.

If the patient's attending physician and other health care providers are present, it will likely be appropriate for them to present information to the team regarding the history of the patient, the present condition of the patient, the prognosis and any other material believed to be relevant to the case consultation. Ethics consultants might then find it useful to ask those involved, including patient/family members if present, to describe what specific ethical questions, problems or issues prompted the request for case review.

Following appropriate discussion of these and issues identified by members of the team, the consultants, along with the director of the hospital ethics consultation service, may convene a "closed" (committee members only) session in order to develop a specific recommendation and/or course of follow up action.

Members of the consultant team may also decide before or after the meeting that urgent formal review of the case by the entire ethics committee is appropriate. In this case, the lead consultant or consultation service director will notify the committee Chair (or Co-Chair) who will convene an emergency meeting of the entire committee as soon as possible.

A.3.4.c(7). Recommendations, Documentation, and Review

The results of the ethics consultation and any recommendations will be communicated to the individual who requested case review; to the attending physician; to other members of the staff; and, to the patient/family as appropriate. Typically, this will occur as a carefully and thoroughly constructed ethics note submitted to the patient's electronic medical record. This note will be printed and filed securely also by the director of the ethics consultation service. The case consultation will be reported to, and reviewed by, the full ethics committee at its next meeting.

A.3.5. Meetings

The committee shall meet monthly in addition to any meetings called for specific case review. An agenda will be developed by the Chair (or Co-Chairs) and distributed electronically prior to the meeting.

Meetings which do not involve discussion of specific case material will be open to any member of the hospital community. Guests and other interested parties will be allowed to attend any meeting, including case review of de-identified cases, at the discretion of the Chair.

For purposes of conducting business, seven members shall constitute a quorum. Actions of the committee shall be taken by the vote of a majority of the members attending the meeting.

Each member will be required to attend at least five of the committee's regularly scheduled meetings each year. Failure to do so can be considered to constitute a resignation and the vacancy shall be filled by appointment of a new member. Committee members unable to fulfill attendance requirements may be eligible for membership on a Hospital Ethics Committee Advisory Group (see section A.3.2.a).

A.3.6. Record Keeping

The committee will maintain minutes of all of its meetings, which will include a summary listing of all case reviews and recommendations of the full committee. A separate and secure file of all ethics consultation chart notes, inclusive of any recommendations made by consultants, will be maintained by the designated director of the ethics consultation service. Minutes will be submitted by the Chair for approval by the committee and forwarded to the Chief Operating Officer of the Hospital. Those records will not include identifying information about specific patients, family members, individuals requesting case review or professional staff participating in the case review process. All records will be maintained in accordance with hospital policy and applicable law governing the confidentiality of records of medical review committees.

A.3.7. Liability

The Hospital will take whatever steps are necessary in order to provide liability protection for committee members who do not have such protection by virtue of their status as members of the professional staff.

A.3.8. Adoption and Approval of Policies and Procedures

Policies and procedures of this committee will be reviewed as deemed appropriate by the membership of the committee. Proposed modifications of approved policies or procedures will be submitted to the committee in writing at least four weeks in advance of a regularly scheduled meeting. Following approval by the committee, they will be forwarded to the Chief Operating Officer of the Hospital for review and approval.

A.4. POLICIES AND PROCEDURES: PEDIATRIC ETHICS COMMITTEE

A.4.1. Introduction

The Pediatric Ethics Committee (PEC) is a standing sub-committee of the Hospital Ethics Committee. The development of such a committee was recommended in federal legislation (Child Abuse Amendments of 1984: P.S. 98-457) which dealt with so-called "Baby Doe" cases, i.e. treatment abatement decisions regarding the care of imperiled and/or handicapped newborns. The Pediatric Ethics Committee provides consultation in cases involving pediatric patients, works to increase awareness of the developing decision making capacity of children as they develop and mature, and provides education related to ethical issues that may be involved with the health care of infants, children and adolescents. The primary focus of the PEC is to assure ethical treatment of pediatric patients. Other than in its ethics consultation and case review function, all actions by the PEC must be submitted for review and approval by its parent committee.

A.4.2. Jurisdiction

The jurisdiction of the Pediatric Ethics Committee includes clinical situations involving infants and children from birth to age eighteen years, unless otherwise emancipated. Occasionally, the PEC will be asked to consult in unique situations which may include a fetus or young adult patient. In some cases, joint consultation by the PEC and Hospital (Adult) Ethics Committee is indicated.

A.4.3. Purpose

A.4.3.a. Educational

PEC will assist the Department of Pediatrics and other departments and divisions which provide services to children in development of appropriate educational programs in clinical ethics. Such programs would have as their goal the fostering of sensitivity and an ability to respond appropriately to the ethical aspects of the care of pediatric patients and families. In addition to ethics topics of a pediatric nature, the PEC offers education to patients, families and health care providers regarding the pediatric patient's developing ability to provide assent to care as the young patient progresses along a continuum toward autonomy in health care decisions.

A.4.3.b. Policy Review and Development

The PEC will assist the medical center and its component institutions in the review and development of institutional policies relating to the care of patients under the jurisdiction of the PEC.

A.4.3.c. Case Review

PEC will serve as a forum for discussion and analysis of complex individual cases, particularly those involving withholding or withdrawal of life-sustaining treatment; and for discussion and resolution of conflicts regarding the ethical aspects of a patient's care among members of the staff providing care to the patient; or conflict between staff and patient or family members. The committee will also undertake retrospective review and analysis of selected cases as further described herein.

A.4.4. Committee Structure

A.4.4.a. Membership

Membership shall be representational of the pediatric care community and shall be multidisciplinary. The PEC will have at least twelve members.

- Physician members will include subspecialists, general pediatricians, and a Pediatric Resident. Nurse members will include one from Nursing Administration; and one each from neonatal and pediatric nursing staffs.
- Membership shall include as available the following disciplines: psychology, social work, education, spiritual care, and clinical ethics.
- The committee will also identify and nominate for appointment at least one community representative who is not an employee of the hospital or medical center.
- Ex-officio members will include the Chair of the Department of Pediatrics; Chief of the Medical Staff or designee; and a representative of the Office of Legal Counsel.

The committee shall recommend individuals for Chair and Vice-chair of the committee (or two Co-Chairs) from amongst its members. Individuals recommended should have served at least two years on the committee.

A.4.4.b. Meetings

The committee will meet monthly in addition to any meetings called for specific case review. Written notice of regularly scheduled meetings and an agenda will be distributed one week prior to the meeting. For all regularly scheduled meetings, a quorum shall be six members. Meetings which do not

include review and discussion of specific cases will be open to anyone expressing an interest in the subject being discussed.

Members must attend at least five of the committee's regularly scheduled meetings each year. Failure to do so will constitute resignation and the vacancy will be filled by appointment of a new member.

A.4.4.c. Minutes/Records

The Chair (or designee) shall keep minutes of all meetings. Minutes of the meetings will be maintained by the Chair of the committee. In order to maintain the privacy of patients, their families, and staff, individuals will be identified by initials only. The Chair will maintain a master list of all reviewed cases should more complete identification of cases be necessary. Copies of minutes will be distributed to all members for review and approval and sent to the Hospital Ethics Committee. Any other request for access to committee minutes or materials shall be considered by the Chair in consultation with the Office of Legal Counsel.

A.4.4.d. Administration

Administrative support for the committee will be provided by the office of the Chair of the Department of Pediatrics. In addition to its minutes, the committee will prepare an annual report of its activities which will be submitted to the Department of Pediatrics and to the Hospital Ethics Committee.

A.4.5. Procedures for Case Review

Committee members will be available to provide advice regarding a case in both an informal and formal manner. In the case of a request for informal case review, no documentation of the comments of any committee member will be placed in the patient's medical record. Informal requests for case review will, however, be reported by the involved committee member to the full committee at the next regularly scheduled meeting of the committee. The remaining portions of this section relate only to requests for formal case review.

A.4.5.a. Prospective Case Review

Prospective review—review prior to the undertaking of a particular course of action in the treatment of a patient—will be conducted by the committee when indicated.

Case review may be appropriate in situations in which a proposed course of treatment of a patient involves the withholding or withdrawal of life-sustaining medical or surgical treatment. [See section A.11, "Ethical Guidelines for Decision-Making: Withholding or Withdrawing Life Sustaining Treatment (Pediatric Patients)."] Case review is recommended in cases in which there is disagreement regarding the ethical aspects of a proposed course of treatment involving a pediatric patient, the parent(s)/guardian and/or the professional staff providing care to the patient.

Since one of the essential responsibilities of the Committee is that of assisting patients, families and staff facing difficult ethical decisions regarding health care, it is anticipated that most requests for case review will arise in a voluntary context. Requests for review may be made by the patient, the parent(s)/guardian, or any member of the professional staff providing care to the patient.

A.4.5.b. Ethics Consultation and Review Procedure

The primary role of the committee in ethics consultation and case review is to provide advice and support to those who have primary responsibility as decision makers, i.e. the patient, the parent(s)/guardian and the professional staff providing care. The committee should not be viewed as a decision-making body. Even in situations in which the committee plays a role in identifying ethical problems in proposed courses of treatment, the committee will not recommend specific alternative treatments to be undertaken.

A.4.5.c(1). Consultation and Case Review Team

Upon notification to the Chair or designee of a case requiring review, the chair will appoint an ad hoc Case Review Team. The team will consist of two to five members of the committee, including at least one physician, and will reflect the multidisciplinary composition of the committee.

A.4.5.c(2). Involvement of the Attending Physician

The individual appointed to lead the consultation and case review team will review the request to determine the nature of the case, the status of the patient, the ethical question, concern or problem prompting the request and any other information needed in order to determine if review is appropriate. If, in the judgment of the leader of the case review team, the request is appropriate, he/she will contact the patient's attending physician to discuss the request, to request his/her participation and to schedule the case review meeting. If the patient's attending feels that ethics case review is not appropriate, this conflict will be referred to the Chief of the Medical Staff for resolution. In the event of persistent conflict, the Chief of the Medical Staff may assist in the orderly transfer of responsibility to another attending physician.

A.4.5.c(3). The Case Review Meeting

The consultation case review meeting will be held within twenty-four hours of the request for case. Any member of the hospital staff who is directly involved in providing care to the patient or family may be invited to attend the meeting. In appropriate circumstances, the patient, his/her parent(s)/guardian and other members of the patient's family may also be allowed to be present for at least part of the meeting if they desire.

At the meeting the leader of the team will instruct all non-members present regarding the advisory role of the ethics committee; the intent of the committee to serve as a supportive forum for those who have the primary decision-making responsibility; and the need for strict confidentiality of all material presented and discussed. The patient's attending physician and other health care providers will be asked to present information to the review team regarding the history of the patient, the present condition of the patient, the prognosis and other material relevant to the case review. The leader will ask those involved, including the patient/family members if present, to describe what specific ethical questions, problems or issues prompted the request for case review.

Following appropriate discussion of these and issues identified by committee members, the team leader may convene a "closed" (members only) session in order to develop a specific recommendation if appropriate. Members of the Consultation and Case Review Team may also decide before or after the case review meeting that formal review of the case by the entire ethics committee is appropriate. In this case the leader of the review team will notify the Chair (or designee) who will convene an emergency meeting of the entire committee as soon as possible.

A.4.5.c(4). Recommendations

The results of the case review and any recommendations will be communicated, in separate conversations, to the individual who requested the case review, the attending physician, the patient/patient's family, and to appropriate members of the staff. Following these discussions, and with concurrence of the attending physician, the team leader will record the results of the ethics consultation and case review in the patient's medical record.

A.4.5.c(5). Retrospective Case Review

In order to evaluate its utilization and effectiveness, the committee may undertake periodic retrospective review and analysis of selected cases or categories of cases. Examples would include: cases in which a "Do Not Attempt Resuscitation" ("DNAR") decision had been made; cases in which decisions were made to withhold or withdraw a medical or surgical intervention; cases in which the committee had provided prospective case review; and others as appropriate. The results of this review would be used to identify educational needs, to evaluate existing policies or procedures, to determine areas in which existing policy requires modification, or in which policies need to be developed.

A.4.6. Adoption and Approval of Policies and Procedures

Policies and Procedures of the PEC will be reviewed annually. Suggested modifications of approved policies or procedures will be submitted to the committee in writing at least four weeks in advance of a regularly scheduled meeting. Following approval by the PEC, they will be forwarded to the Hospital Ethics Committee for review and then forwarded to the Chief Operating Officer of the Hospital for approval.

A.5. PATIENT RIGHTS AND ORGANIZATIONAL ETHICS COMMITTEE

The goal of the Organizational Ethics Committee, when constituted, is to help improve patient outcomes by respecting each patient's rights, and conducting business relationships with the patient and the public in an ethical manner.

Patients have a fundamental right to considerate care that safeguards their personal dignity and respects their cultural, psychosocial and spiritual values. These values often influence patients' perceptions of care and illness. Understanding and respecting these values guide the provider in meeting the patient's experience of and response to care. Thus, access, treatment, respect and conduct affect patient rights.

The standards address the following processes and activities:

1. Promoting consideration of patient values and preferences, including the decision to discontinue treatment
2. Recognizing the hospital's responsibilities under the law
3. Informing patients of their responsibilities in the care process
4. Managing the hospital's relationships with patients and the public in an ethical manner

The multidisciplinary membership of this committee includes but is not limited to members from the following departments: Patient Relations, Medicine, Nursing, Social Work, Allied Health Sciences, Interpreter Services, Pastoral Care, Quality Improvement and Risk Management.

A.6. ADVANCE DIRECTIVES

A.6.1. Introduction

This statement seeks to provide guidance to members of the hospital staff and to promote increased support and recognition of the concept of the autonomy or right of self-determination of the patients of the hospital and medical center. One of the major goals of this policy is to encourage patients and their health care providers to make plans regarding treatment in situations in which patients are likely to lose the capacity to participate in decision-making. Discussion and planning are particularly essential when patients are diagnosed as having conditions that may eventually raise questions about limitation or termination of certain forms of treatment.

An advance directive is a document allowing a person to give directions about future health care, or to designate who should make decisions regarding care if he/she should lose the capacity to do so. There are at present two types of documents used for this purpose.

- One type is used to provide health care providers and institutions directives regarding treatments that a person wishes to receive or forego should he/she lose decision-making capacity, such as a Health Care Treatment Directive or a Living Will.
- The other type allows a person to designate a "proxy" or "surrogate" who would be authorized to make treatment decisions on behalf of the individual should he/she be unable to make such decisions. This typically is referred to as a Durable Power of Attorney for Health Care Decisions (or DPOA-HC).

These two types of directives may also be incorporated into a single form. Such a form is available in English and Spanish languages, and can be obtained from Hospital Admitting, through Hospital Administration, the Department of Social Services, or the committee.

A.6.2. Treatment Directives and Living Wills

Any individual with the capacity to make decisions concerning health care can prepare a document providing directions about treatments he/she might wish to receive or to forego in the event of his/her future incapacity to make such decisions. Such a document might indicate general treatment preferences, include a list of specific treatments, contain statements about palliative care, appoint another person to serve as "proxy" or surrogate (see following section: Proxy Directives) and might include a variety of other provisions. Individuals preparing such documents must inform appropriate health care professionals, family members, friends, and health care institutions to which they are admitted of the existence and contents of any such directive. Such a directive should also be reviewed and revised regularly or as required. The individual is also free to revoke the directive at any time.

The State of Kansas in its "Natural Death Act" [65-28,101 65-28,109; 1979] recognized the "right of an adult person to make a written declaration instructing his or her physician to withhold or withdraw life-sustaining procedures in the event of a terminal condition." The law additionally stipulates a number of procedures that must be followed in order that a "declaration" (Living Will) be legally valid. Although a "qualified patient" may include other specific directions, the declaration must be "substantially" in the form provided in the law. It is important to note that at the present time this is the only legally valid form of advance "treatment directive" in the State of Kansas. Its use is limited to adults "who have been diagnosed and certified in writing to be afflicted with a terminal condition by two physicians who have personally examined the patient."

Treatment directives or Living Wills which are prepared by individuals who are not "qualified patients" as defined by the Kansas Natural Death Act, or documents which are not executed according to the provisions of this law, are not legally binding on health care providers or institutions. However, such a document may well provide important insight and helpful guidance to health care providers and family members or surrogate decision-makers in the event that the patient loses the capacity to participate in decision-making. Knowledge of the patient's values, preferences and wishes can be essential in evaluating the ethical aspects of treatment decisions.

It is also important for health care providers to understand that completion of a directive does not in itself change the interests or status of a patient. For example, providers should not make assumptions about treatment preferences based on the mere existence of a Living Will or other health care directive, but rather see the directive as an instrument by which an individual seeks to provide direction regarding certain specific treatment options.

It should also be understood that a competent adult patient need not utilize this mechanism in order to have his/her present directives regarding utilization of life sustaining treatments respected. Competent adults clearly have the legal and ethical right to forego any or all life sustaining procedures.

A.6.3. Proxy Directives and Durable Power of Attorney

Alternative means for providing advance directives are instruments that allow an individual to appoint another person to make his/her health care decisions in the event of the loss of capacity to do so. Any individual can prepare a written statement authorizing another person to act as their proxy or surrogate. Such a designation can be very helpful to health care providers since it identifies for them the appropriate surrogate decision maker. This surrogate can then participate on behalf of the patient in addressing the ethical aspects of decision-making and in making decisions regarding utilization of life-sustaining treatments in persons who are no longer capable of participating in the decision-making process.

In the State of Kansas an individual may complete a "Durable Power of Attorney for Health Care Decisions" (KSA 58-625; 1990) as a mechanism for designation of a surrogate decision maker. This law allows the individual ("principal") to designate another as their "agent" for making health care decisions "upon the disability or incapacity of the principal." "All acts done by an agent . . . have the

same effect as if the principal were competent and not disabled." This law allows an individual to convey to the agent a broad range of authority including, but not limited to the following: to consent, refuse consent or withdraw consent to any care, treatment, service or procedure; to make all necessary arrangements regarding admission to a health care institution; to employ or discharge health care professionals; and to have access to information including all medical and hospital records. The law also requires that the document be in substantially the form of a model document included in the law.

A.6.4. Implementation

An essential aspect of implementation of this policy will be the willingness of health care providers and the institution to make information regarding advance directives available to patients. In particular, physicians working with individuals facing life-threatening, chronic, and/or terminal illness have the responsibility of encouraging patients to make plans about treatment in advance of a crisis and to engage in an on-going dialogue regarding mechanisms by which their values, preferences, and directives might be respected in the event of their loss of capacity to participate in decision-making. It will also be essential that the information about advance directives be incorporated into in-service and other educational programs and into patient education programs and materials.

It will also be necessary for each department and division to develop procedures necessary to allow these advance directive mechanisms to be effective. Admission procedures will need to be developed for ascertaining if the patient has completed an advance directive document, and for consistent and timely scanning of documents into the electronic medical record.

A.7. GUIDELINES FOR "DO NOT ATTEMPT RESUSCITATION" (DNAR) ORDERS

A.7.1. Introduction

In 2010, the Hospital Ethics Committee participated in a process of policy review and revision for Do Not Resuscitate (DNR) orders. The result was not only a shift in terminology but one that supports the option of unilateral resuscitation status orders in situations of medical and ethics consensus that resuscitation attempts would almost certainly be ineffective, nonbeneficial, and harmful to a patient. The policy document goes beyond typical ethics guidelines, but is reproduced here in its entirety, with formatting changes only.

A.7.2. Introduction to DNAR Policy

It is the policy of the University of Kansas Hospital to provide quality care as we respect the rights of our patients to participate in their health care decisions. The utilization of cardio-pulmonary resuscitation (CPR) has become routine in almost all hospitals in the United States. In fact, it is one of the few medical interventions which can be undertaken without a physician's order. Yet, when effectiveness of CPR is measured in terms of the patient's surviving to the point of discharge from the hospital, studies of CPR of hospitalized patients demonstrate only a 5% to 15% success rate. This rate is even lower in select patient populations such as those with metastatic cancer, chronic debilitating illness or multiple organ failure.

Appropriate resuscitation status designation has several elements which must be considered in order for medical providers to safely and efficiently respond to emergency situations in a patient centered fashion. For some individuals, a designation of "Full Attempt at Resuscitation" is appropriate, while for others, a designation of "Limited Attempt at Resuscitation" or "Do Not Attempt Resuscitation" is appropriate and fitting with optimal patient care.

This policy provides guidelines to be followed in the determination of appropriate resuscitation status designation, and it outlines process steps to be implemented according to each patient's code status designation. If a patient has included directives regarding such treatment as part of an "advance directive" such as a Living Will, the provisions of that declaration and related legislation will apply. (See Care of Patients, Patient Rights, Informed Decision Making) Note that nothing in those provisions

should be interpreted to obligate providers to offer treatments reasonably expected to be harmful and/or of no benefit to the patient according to the standard of care for medical practice.

A.7.3. Definitions

Capacitant Adult Patient - Patient of at least 18 years or older of age who is determined to have the capacity to make his/her own treatment decisions, i.e. the capacity to understand relevant information, reflect on it in accordance with his/her values, verbalize an understanding of the consequences of various decisions that can be made, and communicate with caregivers.

Incapacitated Adult Patient - Patient of at least 18 years of age or older who is determined by a physician to lack capacity to make his/her own treatment decisions, i.e. the capacity to understand relevant information, reflect on it in accordance with his/her values, verbalize an understanding of the consequences of various decisions that can be made, and communicate with caregivers.

Incompetent Adult Patient - Patient who has been declared by a judge in a court of law to have an irreversible lack of decision-making capacity and to be legally incompetent.

Pediatric Patient - Patient of less than 18 years of age who is not otherwise legally responsible for their own health care decisions.

Cardiopulmonary Resuscitation (CPR) - Emergency treatment for acute failure of cardiac or respiratory systems (cardiac and/or respiratory "arrest") utilizing BLS and/or ACLS protocols: chest compressions (closed chest cardiac massage), intubation/ventilation, cardiac defibrillation and ACLS protocol medications.

Cardiopulmonary arrest - Physiologic state wherein the patient actually has no palpable pulse and no spontaneous respirations or is likely to progress to such a state (impending cardiopulmonary arrest) in a matter of a few minutes without emergency intervention.

Full attempt at resuscitation (Full) - Resuscitation status designation whereby in the event of actual or impending cardiopulmonary arrest the patient is a "Full Code," with no limitations set on medical interventions provided in the attempt to restore physiologic function in the patient.

Limited Attempt at Resuscitation (LAR) - Resuscitation status designation whereby in the event of actual or impending cardiopulmonary arrest there are specific limits set on the medical interventions provided, including limitation in the use of shocks, chest compressions, intubation and mechanical ventilation, pressor agents, or other ACLS medications. Decisions about the use of antibiotics, dialysis, blood products, transfer to a higher level of care, and decisions about the global focus or "goals of care," such as a plan for "comfort measures only," are separate decisions and separate orders which are not encompassed by the code status designation.

Do Not Attempt Resuscitation (DNAR) - Resuscitation status designation whereby in the event of actual or impending cardiopulmonary arrest there is not to be any attempt to restore physiologic function to the patient. In such cases, the focus of all intervention should be to maximize the physical comfort of the patient in their own natural state and to maximize comfort and support for family members involved with the patient.

NOTE that the DNAR status does not come into effect until the patient is in a state of actual or impending cardiopulmonary arrest. Conditions leading up to this physiologic state should be addressed according to the standard of care. Decisions about the use of antibiotics, dialysis, blood products, transfer to a higher level of care, and decisions about the global focus or "goals of care," such as a plan for "comfort measures only," are separate decisions and separate orders which are not encompassed by the code status designation.

A.7.4. Procedures

A.7.4.a. Guidelines for Decision-making

A.7.4.a(1). Evaluation and Discussion

Discussion of appropriate resuscitation status designation should be a part of every inpatient admission to the hospital. Orders to limit resuscitation should be considered in any clinical situation in which resuscitation would likely be unsuccessful or in which the use of such treatment would be inappropriate in view of the patient's diagnosis and/or prognosis. Orders to limit resuscitation should also be discussed with the patient when the patient has documents such as an advance directive indicating that the patient desires to have such limits in place. The patient's attending physician has the primary responsibility to evaluate the patient and to facilitate discussion with patient and/or family in situations where such an order is judged to be appropriate. Nursing staff, residents and fellows also play an important role in this evaluation process and in supporting discussion with patient and/or family. The attending physician should be made aware of any discussions related to code status designation if these have taken place with a resident, fellow, nurse or other members of the health care team as opposed to the attending themselves.

A.7.4.a(2). Identification of Decision-Maker

If the patient is an adult with decision making capacity, discussion and decision-making regarding resuscitation status need only involve the patient, though it is strongly recommended that the patient's surrogate decision makers be involved in discussions so that they are aware of patient wishes and understand their role as surrogate. The surrogate role is to uphold the wishes of the patient in the event that the patient cannot voice those wishes him or herself, even if the surrogate does not agree with the wishes of the patient. If the patient has been adjudged to be mentally incompetent by a court, the primary decision-maker is the patient's guardian. In such cases, care providers need to be aware of state laws pertaining to guardian limitations surrounding decisions to withhold or remove forms of potentially life sustaining treatment. If the patient is determined to lack the capacity to participate in the decision-making process, the physician should determine if the patient had previously indicated a choice of the appropriate individual to act as decision-maker or seek to identify a member of the patient's family who will act as a surrogate decision-maker.

A.7.4.a(3). Making the Decision

The decision about resuscitation status should be made in accordance with accepted medical practice and with due consideration of the expressed wishes of the patient, the explicit written directives of the patient, i.e. "advance directives," or the known preferences and values of the patient. Lacking any known patient preferences, or in the instance where there are no known surrogate decision makers for the patient, the decision should be based on a careful and reasoned consideration of the patient's best interest, considering patient diagnosis and prognosis. (See Hospital Ethics Handbook section A.10.5.c(3)(c)1-3: Medical Decision-Making for the Incapacitated Adult Who Lacks a Surrogate Decision-Maker.) The patient/surrogate has the right to request that orders to limit resuscitation be in place as a legal and ethical expression of the right to refuse medical treatment. The patient/surrogate does not have the right, however, to demand that a "Full Code" status be in place when such an order is not believed by the consensus of medical providers to be medically appropriate or consistent with the standard of medical care, based on best available scientific evidence of the patient's condition and prognosis. (See process for handling disagreements, below.)

A.7.4.a(4). Pediatric Patient

Decision-making regarding resuscitation status for pediatric patients should be made according to the previously approved guidelines. (See section A.11, "Ethical Guidelines for Decision-making: Foregoing Life Sustaining Treatment in the Care of the Pediatric Patient.")

A.7.4.a(5). Conflict/Disagreement

Since decision-making regarding resuscitation status will frequently involve shared responsibility, there may be situations in which there is disagreement among health care providers or between providers and surrogate decision makers regarding the appropriateness of orders to limit resuscitation in any way. Such disagreements should be discussed and examined thoroughly and efforts should be

made to achieve agreement. Even with the best of efforts, in some cases disagreement cannot be resolved, and the attending physician may wish to write orders to limit specific resuscitative efforts. If there is unanimous agreement among the patient's attending and consulting physicians that the performance of specific resuscitative efforts on the patient would not be consistent with medically appropriate care, then the following process should guide the attending physician's actions:

A.7.4.a(5)(a). The attending physician should consider involvement of the ethics committee, the Palliative Care team, or both, to facilitate communication, identify relevant ethical principles and policies, and attempt to achieve consensus between the providers and the patient/surrogate. The attending physician could also consider getting a second opinion from a practitioner of their own specialty/subspecialty, as an additional, external review of the medical facts and conclusions drawn by the treating providers.

A.7.4.a(5)(b). The attending physician should inform the CMO (or administrator on call after hours) of the attending physician's intent to write unilateral orders to limit resuscitation.

A.7.4.a(5)(c). The attending physician should inform the patient/surrogate that based on the patient's condition, prognosis and unanimous professional opinion of attending and consulting physicians, the performance of chest compressions, shocks, and intubation in the event of full cardiopulmonary arrest is medically inappropriate and will not be offered or performed, and that orders to limit such interventions will be written in the chart. The patient/surrogate should be informed that ALL treatments thought to be medically appropriate will be offered. The patient/surrogate should be informed that if they continue to feel strongly that they wish resuscitative procedures to occur, then they will be responsible to seek an alternative venue and team of medical providers for ongoing care.

The only circumstance under which the attending physician should not enact this plan would be in the presence of a court injunction mandating that treatments occur.

A.7.5. Resuscitation Orders

A.7.5.a. All orders to limit or to not attempt resuscitation must be signed by the physician. It is imperative that caregivers and patients/families realize that full resuscitative measures (calling a "Code Blue" and initiation of CPR) will be performed as a matter of routine on all patients for whom there is not a written LAR or DNAR order.

A.7.5.b. Resuscitation orders written by resident and fellow physicians are valid and should be respected. If an attending physician feels strongly that their residents not write orders for resuscitation status, then it is the responsibility of that attending to make that expectation clear to their team and to appropriately manage resuscitation status discussions and order entry themselves.

A.7.5.c. Telephone orders for resuscitation status should be handled in accordance with hospital policy for telephone orders.

A.7.5.d. Resuscitation orders remain valid and in effect regardless of the presence of co-signature.

A.7.5.e. Once an order for resuscitation status is written it shall remain valid for the remainder of the hospital stay or until a new order to change the resuscitation status is written.

A.7.5.f. Even if an advance directive has been completed, or the patient arrives to the hospital with an Out of Hospital DNR order, if the patient is admitted a written physician order must be on the patient's chart to authorize the designation of the patient for "Do Not Attempt Resuscitation" or "Limited Attempt at Resuscitation" status.

A.7.5.g. If any health care provider is aware of a conflict regarding the patient's resuscitation status and the advance directive, they will immediately notify the attending physician.

A.7.6. Patient Identification and Process

A.7.6.a. Full Attempt at Resuscitation (FULL): The patient's chart will indicate a resuscitation status of "FULL". The patient will not have any identifying band to limit resuscitative efforts. In the event of actual or impending cardiac arrest:

- Call a "Code Blue" and initiate chest compressions

A.7.6.b. Limited Attempt at Resuscitation (LAR): The patient's chart will indicate a resuscitation status of "LAR". The patient will have identification in the form of a purple and white striped wrist band. The specific resuscitation orders should be checked at every nurse shift handoff to maintain clarity. In the event of actual or impending cardiac arrest:

- Call a "code blue" but do **NOT** start chest compressions. The only appropriate resuscitation status for a person who wants compressions is FULL.
- Rapidly determine level of desired interventions by locating the patient specific resuscitation orders in the chart and follow them as appropriate.

NOTE: If the patient is in distress/extremis which has not yet progressed to the point of impending or actual cardio respiratory arrest, call a rapid response and follow procedures outlined therein.

A.7.6.c. Do Not Attempt Resuscitation (DNAR): The patient's chart will indicate a resuscitation status of "DNAR". The patient will have identification in the form of a solid purple wrist band. In the event of actual or impending cardiac arrest:

- There should not be any resuscitative efforts initiated.
- Immediately notify physician and family that the patient has died or is imminently dying.
- Assure patient comfort through the use of positioning, oxygen, medications to relieve distress if any is present.

NOTE: If the patient is in distress/extremis which has not yet progressed to the point of impending or actual cardio respiratory arrest, call a rapid response and follow procedures outlined therein.

A.7.7. Documentation

In addition to the order itself, physicians must make certain that the patient's medical record provides adequate documentation of the evaluation, discussion and decision-making process. A specific entry attendant to the order must be written which includes: a short description of the patient's condition and prognosis, reference to discussions concerning the order with the patient, guardian, and/or family as well as the attending physician if they were not present for the discussion. The note containing this documentation should be tagged in the electronic medical record as a note containing information related to resuscitation status. To do this the care provider picks the note type "resuscitation status" as the note designation. In the event of a telephone order, the nurse should document this conversation in the nursing progress notes.

A.7.8. Review, Renewal and Revocation

Resuscitation orders should be reviewed when there is a major change in patient condition, when the patient is to go for any procedure which will require anesthesia, or if the patient/surrogate expresses a desire to review the order. The resuscitation orders for Full Attempt, Limited Attempt, or Do Not Attempt Resuscitation shall remain valid for the duration of the hospital stay, unless a new order to change the resuscitation status is written. Caregivers and patients/surrogates should be informed that a decision to forego resuscitative treatment can be reviewed at any time.

A.8. RELATED ISSUES AND POLICIES FOR DNAR ORDERS

A.8.1. Level of Care.

Although orders to limit resuscitation may be part of an overall treatment plan which involves reduction of the level or intensity of care the patient is receiving, caregivers, patients and families

must understand that the order to not attempt resuscitation in the event of actual or impending cardiopulmonary arrest has no implications for any other treatment decisions. Patients with orders to limit resuscitation should be treated according to the standard of care for any and all conditions leading up to the state of impending or actual cardiopulmonary arrest, including transfer to intensive levels of care if appropriate to optimize patient care.

A.8.2. Comfort Measures Only,

In addition to a designation of LAR/DNAR, some patients shift from a curative/interventional plan of care to one that has a sole focus on assuring patient comfort through symptom management only. In addition to the code status designation, these patients should have a **separate** order in the chart which indicates that the patient is receiving "comfort measures only." A "comfort measures" order set should be completed and implemented for these patients.

A.8.3. Terminal Illness.

It should be understood that a candidate for orders to limit resuscitation need not be suffering from a terminal illness. Many chronically ill, debilitated or elderly patients may wish to forego these particular forms of life-sustaining treatment.

A.8.4. Communication and Notification.

Consideration must be given to mechanisms by which various departments and divisions will establish appropriate procedures to insure adequate communication and notification of the existence of orders to limit resuscitation when patients are transported, sent off the nursing unit for procedures and/or treatment, transferred to other institutions, and the like.

A.8.5. Pre-Admission and Post-Discharge DNAR Orders

A.8.5.a. There has been development of strategies to improve patient care across the continuum specifically with regard to resuscitation status and related decision making for seriously ill individuals. For several years in the Kansas City area there has been recognition of a standard "DNR" Request Form, developed by the Ethics Committee Consortium of the Center For Practical Bioethics. This directive can be used by the patient as an expression of their wishes at any point along the continuum of care. Since this is a standardized form, providers must use the approved form: "PRE-HOSPITAL DNR REQUEST FORM: An Advanced Request to Limit the Scope of Emergency Medical Care," No. 5587. These forms are available through the Department of Care Coordination.

A.8.5.b. In addition to the Pre-Hospital DNR Request Form, there has been development of Out of Hospital physician orders regarding resuscitation status and other related medical treatment decisions, for example, the Missouri Out of Hospital DNR order and the Transportable Physicians Orders for Patient Preferences (TPOPP).

A.8.5.c. To be actionable, each of these forms must be signed by the patient, guardian or legal representative, and by the patient's physician. Each of these forms will be honored by area emergency medical personnel in response to, for example, an "emergency" or "911 call." Each of these forms should accompany the patient to the hospital and will be honored by receiving care providers at the time of patient presentation. If the patient is admitted to the hospital, the orders must be reviewed with the patient and/or their surrogate and translated into appropriate orders in the electronic medical record.

A.8.6. Surgery, Anesthesia, and Invasive Procedures

When a patient with orders to limit resuscitation is to undergo surgery, receive an anesthetic agent and/or be subject to an invasive procedure that may be associated with risk to cardio-pulmonary function, it is the obligation of the physician performing such procedures to discuss the resuscitation status with the patient or surrogate decision-maker as part of the consent process and alter the official order as indicated.

A.9. HONORING DNAR ORDERS DURING INVASIVE PROCEDURES

A.9.1. BACKGROUND

Since January 1998, health care facilities accredited by The Joint Commission (TJC) are required to have written policies and procedures allowing patients to forgo cardio-pulmonary resuscitation, so called "Do Not Resuscitate" (DNR) policies. However, questions have persisted about honoring such orders when a patient undergoes an operative or invasive procedure. Often in the past, these orders were disregarded under such circumstances. However, this approach, as a matter of assumption, is clearly incompatible with the goals and principles of the Patient Self-Determination Act of 1990. Patients' legal and ethical rights to direct the course of their health care include the right to refuse resuscitative procedures.

Many anesthesiologists, surgeons, and physicians undertaking invasive procedures have felt a responsibility to treat any cardio-pulmonary arrest their treatment may precipitate. It is also the case that many procedures undertaken in operating rooms can be classified as forms of resuscitation, such as: intubation, the use of ventilators, and drugs to control heart rate and blood pressure. An arrest in the operating room or during the course of an invasive procedure may result from the use of anesthetic agents, the procedure itself, the underlying disease, or a combination of factors. The majority of these arrests can be promptly treated with no long lasting or residual effects. Thus it is important for medical providers and patients to have a clear understanding of the circumstances under which a suspension of orders to limit resuscitation may occur and the timeframe of that suspension. Appropriate informed medical decision making and documentation regarding these issues is part of the informed consent process.

It is essential that orders to limit resuscitation be reviewed and discussed prior to an invasive procedure, as part of the informed consent process between the performing physician, anesthesiologist, and patient and/or their surrogate. A critical aspect of this review is consideration of the patient's rationale for the orders to limit resuscitation. For example, if the patient is requesting orders to limit resuscitation on the basis of an unacceptable quality of life, suspension of such an order during the invasive procedure may be inappropriate. In these instances, all physicians involved in the performance of that invasive procedure need to be aware of and agree to not attempt resuscitation in the event of actual cardiac arrest.

Ultimately, it is the right of the patient or the surrogate of an incapacitated patient to agree to suspend or not suspend orders to limit resuscitation, and it is the right of the involved physicians to agree or not agree to perform or be involved in the procedure based on that decision. This is a process of shared decision making, the outcome of which should be understood and accepted by the patient, the surrogate of an incapacitated patient, and all care providers who are to be involved in an invasive procedure, prior to its occurrence.

A.9.2. GUIDELINES

A.9.2.a. These guidelines refer to cardiac and/or respiratory arrest which occurs inadvertently during an invasive procedure. Correcting this condition may require cardiac compression, artificial respiration, counter shock and other resuscitative measures.

A.9.2.b. A cardiac and/or respiratory arrest is a condition separate from that requiring the invasive procedure. Patients/surrogates who consent to anesthesia, surgery, or other invasive procedures may not necessarily consent to treatment of such an arrest. This issue should be elucidated clearly as part of the informed consent process.

A.9.2.c. For purposes of these guidelines an invasive procedure should be understood as one during which cardiac and/or respiratory arrest is a foreseeable risk. Obviously this is a risk for procedures undertaken in the operating room, particularly those involving the use of general anesthesia. However, it is also a risk for many procedures, such as those involving the use of anesthetic techniques like "moderate sedation," whether undertaken in the operating room or not. It may also be assumed that most procedures for which written informed consent is required are "invasive" in this sense. If the individual performing a procedure is unable to determine whether or not cardio-respiratory arrest is a foreseeable risk of the procedure, prior discussion regarding appropriate interpretation of the patient's resuscitation status is recommended.

A.9.2.d. Treatment for an arrest under these circumstances can, like other treatments, be accepted or refused by patients with capacity or by the appropriate surrogates of patients without decisional capacity. Health care providers have a responsibility to honor such acceptances or refusals. If the health care providers believe that a limitation regarding the performance of resuscitative procedures puts them in a position where they are no longer comfortable to perform the procedure, then those providers have the right to refuse to perform the procedure. Those providers must then notify the patient's attending physician so that arrangements can be made for identifying an alternative provider of care.

A.9.2.e. Before a patient with orders to limit resuscitation undergoes an invasive intervention, at least one physician (surgeon or anesthesiologist or physician performing the invasive procedure) must engage in discussion with the patient or surrogate regarding the handling of these orders. Discussion needs to include the following elements:

1. the original rationale for the orders to limit resuscitation as previously documented in the patient's medical record;
 2. information about the likelihood of requiring resuscitative measures;
 3. a brief description of standard resuscitative measures;
 4. the chance of successful resuscitation; and,
 5. possible outcomes with and without resuscitation.
- Documentation that this discussion has occurred should be present in the medical record.

A.9.2.f. If the patient and providers agree that the orders to limit resuscitation should be suspended during an operative or invasive procedure, the terms of the suspension must be discussed and corresponding orders written in the electronic medical record. As a general rule, the period of time for which the orders to limit resuscitation are suspended should include the operative period and the immediate post operative recovery period, defined as sign out from phase 1 post anesthesia recovery or consistent with the guidelines for recovery in the ICU post procedure as written in the "Post Anesthesia Recovery" SOP. Should the patient, the surrogate of an incapacitated patient, and the physicians performing the procedure agree that the suspension should last for more or less time than the standard timeframe above, then this decision should be clearly written as a physician order and should be documented as part of the informed consent process.

A.10. ETHICAL GUIDELINES FOR DECISION-MAKING: WITHHOLDING OR WITHDRAWING LIFE SUSTAINING TREATMENT (ADULTS)

A.10.1. INTRODUCTION

Increasing technological capacity to sustain life has created the need for critical examination of when such treatments are and are not appropriate. The traditional assumption that health care professionals have an obligation to prolong life provides inadequate guidance since this obligation often conflicts with the obligation to relieve suffering and to not "prolong dying." It is also increasingly recognized that patients and families have an essential role to play in health care decision-making. For example, the concept of informed consent includes the right of the patient to refuse treatment, even life sustaining treatments. Yet the decision to forego life-sustaining treatment--particularly a decision to withdraw a treatment that may be sustaining the patient's life--poses significant psychological difficulties for providers, patients and families. These guidelines have been developed to provide support and guidance for those faced with the responsibility of making these hard choices. (For decisions involving pediatric patients, see section A.11, "Ethical Guidelines for Decision-Making: Withholding or Withdrawing Life Sustaining Treatment in the Care of the Pediatric Patient.")

A.10.2. DEFINITIONS

Adult Patient - Any patient who can provide legally valid consent, includes most patients greater than 18 years of age and "emancipated minors."

Comfort Care - A range of interventions intended to provide relief of pain and/or suffering, control symptoms, reduce anxiety and provide comprehensive physical, psychological and spiritual support to patients. Such care is often referred to as "palliative" care--care which serves to relieve or alleviate without attempting to cure.

Competence - Legal status of adults who have not been found and declared incompetent by a court.

Decisional Capacity - Term used to reflect the ability of a patient to make a specific decision, i.e., the ability to understand the relevant information, to reflect on it in a manner consistent with their own life goals and values, and to communicate his/her wishes to providers.

Durable Power of Attorney for Health Care - Legal mechanism by which any adult can delegate the legal authority to make health care decisions. [See section "Advance Directives."]

Foregoing - Refers to a decision to withhold an intervention or to withdraw a treatment already begun. It is assumed that in any situation in which there is significant uncertainty about the appropriateness of foregoing treatment, it will be administered on the basis of a time-limited trial since it can be ethically withdrawn should it prove futile or not in the patient's best interests.

Guardian - Individual appointed by a court to act on behalf of another who has become a ward of the court usually as the result of a finding of legal incompetence.

Life Sustaining Treatment - Interventions which are judged likely to be effective in prolonging the life of a patient or which are being utilized to sustain the life of a patient.

Living Will - Document which can be completed by any adult to provide advance directives regarding treatment in the event that the individual became unable to participate in decision-making.

Surrogate - When a patient lacks decision-making capacity, he/she should participate in the treatment decision as fully as possible; however, another individual, the surrogate decision-maker, must work with the providers to make decisions. The appropriate surrogate may be: 1) delegated by the patient through an advance directive instrument, 2) designated by a court (eg. a guardian), or 3) the adult who is most involved with the patient and most knowledgeable about his/her personal values and preferences. Providers should work closely with the patient's friends and relatives to identify the appropriate surrogate. If agreement cannot be reached regarding the selection of a surrogate, the provider should seek appointment of a guardian.

Terminal Illness - An illness which because of its nature can be expected to cause the patient to die; usually used to refer to an irreversible and unrelenting condition for which there is no known effective treatment or cure.

A.10.3. ETHICAL PRINCIPLES

Health care has traditionally been based on the assumption that life is an important and essential good and that it should be preserved whenever possible. Prevention of premature or avoidable death is seen as part of the goal of health care. However, the principle or duty to prolong/preserve life does not provide an adequate basis for making decisions about when treatments may be withheld or withdrawn.

A.10.3.a. The principle of respect for persons' autonomy

Patients have the right to make decisions about the course of their life for themselves. This is often called the patient's right of self-determination or autonomy. Important aspects of respect for persons' autonomy include: the concept of informed consent, the presumption that patients have the capacity to make decisions, the presumption that patients have a right to delegate decision-making authority, the patient's right to be adequately informed, and the right to authorize or refuse any medical treatment.

A.10.3.b. The principle of "do no harm" (non-maleficence)

One of the most established principles of health care ethics directs providers to avoid or minimize harm to patients. Providers are obligated to carefully weigh the burdens and risks associated with any proposed treatment. When treatment no longer provides reasonable benefits or becomes unacceptably burdensome from the patient's perspective, it should be stopped.

A.10.3.c. The principle of beneficence

The obligation to promote the good of the patient is basic. Attempting to extend life usually promotes the good of the patient. However, the patient's life may, for example, be full of pain and suffering and the patient may prefer to forego the treatment even though it means an earlier death. The obligation to promote the patient's good involves identifying the possible benefits from the patient's perspective. If the patient or surrogate judges that continuing to provide a treatment offers inadequate benefits, it should be stopped.

A.10.3.d. The principle of justice as fairness

Considerations of procedural justice or fairness require that decisions about withholding and withdrawing treatment should involve shared decision-making by patients/surrogates and providers. The magnitude of such decisions requires that they should reflect the ideals of due process for decision-making including appropriate respect for all parties involved in the decision, open and sustained dialogue, careful consideration of all options, appropriate consultation and/or review, mechanisms for addressing differences of opinion, and the like.

A.10.3.e. The principle of equity (distributive justice)

Serious problems regarding the just distribution of health care resources exist in the United States. The lack of guidance and support for withholding and withdrawing of inappropriate life sustaining treatments, for example, may contribute to the unjust distribution of these resources.

A.10.4. PRESUMPTIONS REGARDING DECISIONS TO FOREGO LIFE SUSTAINING TREATMENT

A.10.4.a. A patient's decision to forego such treatment does not constitute a decision to commit suicide. A decision to withhold or withdraw such treatment from a patient does not involve "killing," "causing a person to die," or "active euthanasia."

A.10.4.b. Health care providers who have a conscientious objection to a patient's decision to forego a life-sustaining treatment should, if necessary, inform the patient or surrogate of their position, and must arrange for the orderly transfer of responsibility for care to another provider.

A.10.4.c. Any life-sustaining treatment may be withheld or withdrawn. If doubt exists regarding the possible benefits of a treatment, time-limited trials of treatment should usually be undertaken.

A.10.4.d. Treatments involving provision of life-prolonging artificial nutrition and/or hydration may be withheld or withdrawn under appropriate circumstances.

A.10.4.e. When a decision to forego a particular life-sustaining treatment or treatments is made, both health care providers and the institution have a continuing obligation to provide a comprehensive range of supportive care and treatment including consideration of alternative methods of care such as hospice programs.

A.10.4.f. Providers usually have the obligation to respect the requests of patients/surrogates to be provided or to continue to receive a life-prolonging treatment. However, providers are not obligated to provide treatments that are clearly futile (meaning that they will not produce the physiologic result desired by the patient or surrogate), treatments that are felt to have a greater potential for harm than for benefit, treatments that are considered medically inappropriate by an appropriate professional organization, and treatments that cannot reasonably be provided by virtue of economic or institutional constraints.

A.10.5. GENERAL GUIDELINES FOR DECISION-MAKING

A.10.5.a. Model of Shared Decision-Making

These guidelines presume that the ideal model for making such decisions is one in which the responsibility is shared by providers and patients or surrogates. It is assumed that all members of the health care team and the patient or surrogate must have the opportunity to participate actively in all such decisions. This model also presumes that such decisions will not be implemented unless there is consensus among those responsible regarding the appropriateness of the decision. When there are conflicting judgments regarding the appropriateness of such a decision, mechanisms must be available to address and, hopefully, resolve such conflict.

A.10.5.b. Role of the Health Care Provider(s)

Providers have the responsibility for ensuring that comprehensive and accurate evaluation of the patient's condition has taken place, that the entire range of treatment options has been carefully considered, that appropriate therapeutic trials have been considered and conducted where appropriate, and that the patient or surrogate are informed and involved in the process.

A.10.5.c. Role of the Patient or Surrogate Decision-Maker

A.10.5.c(1). Patient With Decisional Capacity

A decision to forego a potentially life-sustaining intervention in the case of a patient with decisional capacity requires the informed consent of the patient. Adults with decisional capacity, even when not terminally ill, have the right to refuse to authorize any medical intervention, even interventions that are potentially life prolonging.

A.10.5.c(2). Patient Who Has Executed an Advance Directive

Where a patient without decisional capacity has previously executed a directive (e.g., a Living Will) that a life sustaining treatment be withheld or withdrawn and/or has appointed a surrogate to make such decisions (Durable Power of Attorney), such advance directives and decisions should be respected.

A.10.5.c(3). Patient Without Decisional Capacity Who Has Not Executed an Advance Directive

Where possible, providers of such patients should work with the patient's family and appropriate others to identify an appropriate surrogate decision-maker. If the patient has been declared legally incompetent, the surrogate would normally be the court appointed guardian. If not, the appropriate surrogate is that individual who is most available, involved and concerned about the patient, most knowledgeable about the patient's values and preferences, and most willing to apply the patient's values to making the decision.

Appropriate criteria for use in surrogate decision-making are:

A.10.5.c(3)(a). Substituted judgment decisions: If the providers and surrogate agree that foregoing life sustaining treatment is clearly in accord with the patient's values and previously expressed preferences, that plan of care should be pursued.

A.10.5.c(3)(b). Best interest decisions: If the providers and surrogate are not certain that foregoing life sustaining treatment is in accord with the patient's values and preferences, then decisions should be based on what is in that patient's best interest. Another way of expressing "best interest" criteria is to choose so as to promote the patient's interests as they would be conceived by a reasonable person in the patient's circumstances.

A.10.5.c(3)(c). When providers are unable to locate any surrogate decision-maker for the patient, and after reasonable attempts to do so have failed, the following guidelines should be implemented.

A.10.5.c(3)(c).1. If the providers have knowledge of the patient's values and previously expressed preferences with regard to life sustaining treatment, their treatment decisions, to the extent clinically appropriate, should be based on these values and preferences. In such an event, a DNAR order may be written for the patient, and life sustaining treatment may be withheld or withdrawn if the attending

physician and one other physician (from Palliative Care or other relevant service) agree that such is the appropriate course of action for the patient. The opinion of the concurring physician should be documented in the patient's medical record.

A.10.5.c(3)(c).2. If the providers have no knowledge of the patient's values or preferences with regard to life sustaining treatment, then any decision not to resuscitate, to withhold life sustaining treatment, or to withdraw life sustaining treatment, should be based on what is in the patient's best interest. The "best interest" standard requires the providers to choose a course of action they believe would be chosen by a reasonable person in the patient's circumstances. The attending physician and one other faculty physician (an attending from Palliative Care or other relevant service) must agree on what is in the patient's best interest. The opinion of the concurring physician should be documented in the patient's medical record. It may be appropriate also to request an ethics consultation.

A.10.5.c(3)(c).3. If the attending physician cannot secure the concurring opinion of another faculty physician, and/or if there are concerns or dissenting opinions by other members of the care team, then an ethics consultation is required. At least two members of the ethics committee should respond to the consultation request, and then make a recommendation about the appropriate course of action for the patient. Ethics recommendations will be based on input from the attending physician and other members of the patient's provider team, and in accordance with the best interest standard and other relevant ethical principles.

A.10.5.d. Role of the Surrogate

The role of a court appointed guardian or a surrogate appointed by the patient (Durable Power of Attorney) is to substitute for the patient in the decision-making process. If the surrogate has not been empowered by a court or the patient, the role of the surrogate is to work with the providers to determine the appropriate course of action.

A.10.5.e. Role of the Institution and Ethics Committee

One of the primary roles of the Ethics Committee and its Ethics Consultation Service is that of providing a forum in which questions and/or disagreements regarding decisions to forego a life sustaining treatment can be discussed and resolved. Clinical ethics consultation and case review will only be undertaken in response to a formal request by a professional directly involved in the care of the patient, by a guardian or surrogate, or by the patient. Such consultation should be strongly considered in cases in which an appropriate surrogate cannot be identified for a patient without decisional capacity and in cases in which there is persistent disagreement among those responsible for making the decision.

A.10.6. Documenting the Decision

All discussions regarding and decisions to withhold or withdraw a life sustaining treatment should be documented in the medical record. Documentation should include both orders necessary to implement such decisions and appropriate documentation of the rationale for and the process by which the decision was made.

A.10.7. Changing the Decision

All parties to decisions to forego a life sustaining treatment should be aware that such decisions can be changed at any time if desired by the patient (surrogate) or if such a change is felt to be required in view of a reassessment of or change in the condition of the patient.

A.11. ETHICAL GUIDELINES FOR DECISION-MAKING: WITHHOLDING OR WITHDRAWING LIFE SUSTAINING TREATMENT IN THE CARE OF THE PEDIATRIC PATIENT

A.11.1. Introduction

These guidelines have been developed to provide the health care providers of this institution, their child patients and the parents of those patients with support and guidance in making decisions to withhold or withdraw a life sustaining treatment. They also represent the dedication of the institution to ensure that all such decisions reflect a clear commitment to serve the needs and best interests of the pediatric patient; that they are made carefully and in an informed manner; and, that they involve the participation of health care providers, parents and the child (to the extent of his/her capacity) in the decision-making process. Every effort should be made to obtain the informed permission of the parent(s) and to solicit the assent of the child patient (where feasible) prior to any decision to forego a life sustaining treatment.

A.11.2. Definitions

"Pediatric patient" is used to refer to patients who are not empowered to provide authorization (informed consent) to their own medical care. With exceptions (e.g. "emancipated" or "mature" minors) such patients are those who are less than 18 years of age.

"Child" refers to infants, children and adolescents, ages birth to 18, who are "pediatric patients." Occasionally, the fetus may be included in the definition of "child" when ethical issues present.

"Life sustaining treatments" are those interventions which are judged likely to be effective in prolonging the life of the patient.

"Foregoing" refers to any decision to withhold an intervention or to withdraw a treatment already begun. Clearly in situations involving significant uncertainty, treatment of potential benefit should be started since such treatment can be ethically withdrawn should it prove futile or not in the patient's interests.

"Parental permission" includes all the basic elements of the concept of informed consent: the duty to inform parents of the nature of the child's condition; the duty to disclose the risks and benefits of the various alternative treatments; and the obligation to obtain, free of coercion or manipulation, their permission to proceed with the proposed course of action, i.e., in this case, the foregoing of a life sustaining treatment.

"Assent of the child" includes the following elements: the obligation to assist the child in developing an age appropriate awareness of the nature of his/her condition; the obligation to disclose to the child the proposal to forego a treatment and what he/she is likely to experience in foregoing the treatment; and the responsibility of soliciting the child's expression of willingness to forego the treatment. Assent in this context would rarely be solicited in children less than seven years. The dissent of an older child or adolescent to a proposal to forego must be given appropriate respect and consideration including formal procedures to resolve conflict and/or referral to the Pediatric Ethics Committee.

A.11.3. Presumptions

A.11.3.a. Decisions to forego a life sustaining treatment would be considered only after comprehensive evaluation of the patient and all appropriate therapeutic trials.

A.11.3.b. Parents as the legal guardians of the child (unless otherwise specified by law) are entitled and obligated to actively participate in the decision-making process.

A.11.3.c. Health care providers are legally and ethically obligated to act in the best interests of the child patient.

A.11.3.d. Children as patients should be allowed to participate to the extent of their capacity in decisions being made regarding their health care.

A.11.3.e. Decisions to forego a life sustaining treatment do not entail or involve actions intended to end the life of the child (active euthanasia or "mercy killing").

A.11.3.f. Pediatric patients from whom a life sustaining treatment has been withheld or withdrawn will continue to receive competent and compassionate health care including a wide range of supportive

care services such as emotional and physical comforting, management of pain and other discomforts, and other palliative measures as appropriate.

A.11.4. Decision-Making Process: Delegation of Responsibility

A.11.4.a. Health Care Providers

Although orders to forego life sustaining treatment must ultimately be written by the patient's attending physician, these decisions require sustained and effective communication among all of those providing care to the child. The process by which such decisions are made can be initiated by any professional directly involved in the care of the patient and begins with communication between that individual and the attending physician. Providers have the responsibility for ensuring that comprehensive and accurate evaluation of the child's condition has taken place; that the entire range of treatment options has been carefully considered; that appropriate therapeutic trials have been considered and conducted where appropriate; and that the parents and child are fully informed and involved in the decision-making process.

A.11.4.b. Parent(s)/Guardian

As legal guardians, parents have a fundamental interest and obligation to share in the decision-making process. Parents must be informed and provided support necessary for them to actively participate in this process. Parents may initiate this discussion with the child's health care provider(s) and/or request consideration of foregoing a life sustaining treatment. If the parent(s)/guardian concur with the evaluation of the child's condition and request or give permission to the foregoing of the treatment, it may be withheld or discontinued. After allowing sufficient time for deliberation and consultation, if the parents are unwilling to give permission to a recommendation that a treatment be withheld or withdrawn, the attending physician should request formal review of the case by the Pediatric Ethics Committee. Parent(s)/Guardian may also request review by the committee in cases in which they feel that a treatment recommended or being provided to their child should be withheld or withdrawn.

A.11.4.c. Child/Adolescent Patient

The patient should be encouraged and allowed to participate in this decision-making process to the extent of his/her capacity. Providers should solicit the assent of the child to any proposal to forego a life sustaining treatment. Persistent disagreement between the child and his/her parent(s)/ guardian regarding such a decision should prompt appropriate conflict resolution measures and/or review by the Pediatric Ethics Committee.

A.11.4.d. Pediatric Ethics Committee

One of the primary roles of the committee is that of providing a forum in which questions and/or disagreements regarding decisions to forego a life sustaining treatment can be discussed and resolved. Committee consultation and case review will only be undertaken in response to a formal request by a professional directly involved in the care of the patient, parent(s)/guardian or the patient. Requests for consultation and case review with the committee should be communicated directly to the committee chair. The committee will make every effort to provide support for those with the responsibility of making these decisions and for ensuring that conflicts are appropriately addressed and resolved. In the unlikely event that such conflicts could not be resolved, the committee would recommend to the hospital and the involved parties that appropriate legal mechanisms be sought.

A.11.5. Documenting the Decision

All discussions regarding and decisions to withhold or withdraw a life sustaining treatment should be documented in the medical record, including both orders necessary to implement such decisions and appropriate documentation of the rationale for and the process by which the decision was made.

A.11.6. Changing the Decision

All parties to decisions to forego a life sustaining treatment should be aware that such decisions can be changed at any time if such a change is felt to be required in view of a reassessment of or change in the condition of the child. The judgment that such a change is necessary should be communicated to the attending physician who would then facilitate appropriate discussion and re-evaluation of the situation.

A.12. GUIDELINES FOR WITHHOLDING OR WITHDRAWING LIFE-SUSTAINING MECHANICAL VENTILATION

A.12.1. Introduction

The process by which decisions should be made to use or not to use a life-sustaining medical technology involves consideration of a wide range of issues. This statement is intended to serve as an outline for that process when the treatment under consideration is mechanical ventilation, i.e., use of a respirator. The basic ethical values involved are those of patient well-being and patient self-determination. Ethical duties, obligations, rights and responsibilities of the health care providers, patients and families are based on these values. Important considerations include: Is the use of the treatment likely to promote the well-being of the patient? What are the anticipated benefits and burdens of treatment from the patient's perspective? Do the burdens outweigh benefits? How is the patient's right of self-determination to be respected?

Other considerations deal with the decision-making process itself and include:

A.12.1.a. The obligation of health care providers to provide critical on-going evaluation of patients, especially in terms of the chronic use of life sustaining treatments, and to initiate and facilitate discussion with the patient (and family and/or others if the patient wants them involved) regarding the use or continued use of such treatments.

A.12.1.b. Identification of the key decision-maker, i.e., assessing the decision-making capacity of the patient and/or identification of a surrogate. (If the patient is a minor, see "Ethical Guidelines for Decision-Making: Foregoing Life Sustaining Treatment in the Care of the Pediatric Patient.") A surrogate may have been designated by the patient (see policy on "Advance Directives"), appointed by a court ("guardian"), or may need to be identified from amongst adult family members or concerned friends.

A.12.1.c. Making the decision: 1) the roles of providers, patients and surrogates; 2) the criteria for making decisions when the patient lacks the capacity to decide, i.e., the prior expressed wishes of the patient (see section A.6. "Advance Directives"), the known preferences and values of the patient (sometimes called "substituted judgment") or the "best interests" of the patient as they likely would be conceived by a reasonable person in the patient's circumstances; 3) documentation of the basis for the decision; 4) implementation of the decision into the total care plan for the patient.

A12.2. Withholding and Withdrawing Ventilatory Support

Health care providers often find it easier to make a decision to withhold a life-sustaining treatment or to allow a patient to forego its use than to discontinue or withdraw the same life-supporting treatment. This is particularly true in the case of the use of respirators. However, from an ethical point of view it is clear that there is no ethical requirement to continue a treatment merely because it has been started. To continue to impose a treatment against the wishes of the patient or surrogate, when it is felt to be more burdensome than beneficial, is clearly wrong. There is actually strong reason to prefer withdrawal in spite of the psychological difficulties it poses for patient and provider since it allows for time-limited trials of treatments to establish the benefits and burdens of the treatment. A decision to withhold or forego a treatment cannot be made with the same degree of certainty. When there is doubt about the potential benefits of providing respiratory support, it should be started preferably on the basis of a time-limited trial.

A.12.3. Anticipating the Need for Ventilatory Support

In many illnesses--e.g., progressive neuromuscular diseases, cystic fibrosis, chronic obstructive pulmonary disease--the natural history of the disease process includes predictable respiratory insufficiency and eventual failure. Health care providers have the obligation to prepare patients for this phase of their illnesses, especially in terms of initiating and facilitating a dialogue about the possible role of chronic ventilatory support. This dialogue will allow patients to assess the likely benefits and

burdens of such treatment and to provide advance directives regarding such support prior to the onset of respiratory failure.

A.12.4. Ventilatory Support in Emergency Situations

In emergency settings, appropriate time for adequate analysis of the situation as well as important information about the patient's medical condition are frequently unavailable. In the context of acute respiratory failure it is rarely possible to reliably ascertain the patient's wishes regarding the use of ventilatory support. Therefore, in an emergency situation, it is almost always the case that ventilatory support should be initiated. Once the patient's condition has stabilized, the appropriateness of continued use of the respirator should be carefully reviewed.

A.12.5. Communication with the Respirator Dependent Patient

In order to facilitate discussion of the continued use of a respirator, to ascertain the patient's preferences, and to assess the decision-making capacity of the patient, it is imperative that providers utilize all available aids to communicate with a patient who is on a respirator and usually unable to speak. Providers should consider: consultations with communication specialists, use of written communication, use of communication boards, or use of electronic devices to vocalize.

A.12.6. Weaning from the Respirator

Under most circumstances it is appropriate to attempt to wean patients from ventilatory support in order to evaluate the extent to which they are dependent on such support. If the health care provider believes on the basis of such trials that weaning may prove successful, it should be attempted. However, if a decision to discontinue respirator use has been made such trials are not ethically required.

A.12.7. Alternatives to Discontinuing Ventilatory Support

If it is established that a patient has become permanently dependent on ventilatory support, every effort should be made to discuss alternatives to its discontinuation. Since many of these alternatives will involve careful assessment of resources available to the patient following discharge from the acute care setting, consultation with Social Services should be sought. Considerations to be discussed would include at least the following: methods of decreasing the discomfort and burdens of chronic respirator use, alternative forms of ventilatory support, development of home-based treatment plan, and methods to increase mobility such as the use of a portable respirator.

A.12.8. Care of the Patient Foregoing or Discontinuing Life-Sustaining Ventilatory Support

Patients with significant respiratory insufficiency who forego or discontinue ventilatory support will often experience significant degrees of discomfort and difficulty breathing. Often they will experience frightening "air hunger." Maximal supportive care to insure comfort must be provided to such patients including any or all of the following: supplemental oxygen, adequate suctioning, intermittent assisted ventilation, and sedation. If relief of extreme discomfort requires the use of sedation which decreases respiratory effort and/or renders the patient unconscious, it is ethically acceptable to do so with the consent of the patient or surrogate. Provisions should also be made to provide company to such patients. If desired by the patient, family and friends should be allowed maximal access to the patient. They should also be provided the emotional support they may need to participate in this process. If it is anticipated that a patient's death from respiratory failure will occur shortly after discontinuation of the respirator, it is recommended that the attending physician discontinue the respirator and remain at the bedside. If he/she is unable to do so, this important responsibility can be delegated to an appropriately trained member of the professional staff attending the patient.

A.12.9. Care for Bereaved Family and Friends

Adequate consideration should be given to mechanisms to provide support to bereaved members of the patient's family or friends. Decisions to forego or discontinue ventilatory support are often associated with feelings of significant doubt and guilt in addition to those associated with the anticipated grieving process.

A.13. CARE OF PATIENTS IN A PERSISTENT VEGETATIVE STATE

The vegetative state is a clinical condition of complete unawareness of the self and the environment accompanied by sleep-wake cycles with either complete or partial preservation of hypothalamic and brain stem autonomic functions.

A.13.1. Persistent Vegetative State (PVS) can be defined as a vegetative state present at one month after acute traumatic or non-traumatic brain injury, and present for at least one month in degenerative or metabolic disorders or developmental malformations.

A.13.2. Diagnosis: PVS can be diagnosed on clinical grounds in adult and pediatric patients after careful, repeated neurologic examinations. (Note that PVS is different from brain death, and a person in PVS would not meet the criteria for being declared brain dead as set out elsewhere in this Handbook.) The diagnosis of PVS should be established by a physician who, by reason of training and experience, is competent in neurological function assessment and diagnosis. Reliable criteria do not exist for making a diagnosis of PVS in infants under three months of age, except in patients with anencephaly. Criteria for diagnosis include:

- No evidence of awareness of self or environment
- An inability to interact with others
- No evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli
- No evidence of language comprehension or expression
- Intermittent wakefulness manifested by the presence of sleep-wake cycles
- Sufficiently preserved hypothalamic and brain stem autonomic functions to permit survival with medical and nursing care
- Bowel and bladder incontinence
- Variably preserved cranial nerve (papillary, oculocephalic, corneal, vestibulo-ocular, gag) and spinal reflexes

A.13.3. Categories and Clinical Course of PVS: There are four major categories of diseases in adults and children that result in PVS. The clinical course and outcome of PVS patients depends on the specific etiology. The first etiology listed is the only cause due to trauma; the remaining three are considered to be non-traumatic etiologies.

A.13.3.a. Acute traumatic brain injury: PVS usually evolves from (1) a state of eyes-closed coma to (2) a state of wakefulness (without awareness) with sleep-wake cycles and preserved brain stem functions, within one month of injury.

A.13.3.b. Acute non-traumatic brain injury: Ischemic and anoxic brain injury secondary to cardiac arrest or intracranial hemorrhage leads to a condition similar to that of a metabolic or degenerative disorder, described in A.13.3.c, below.

A.13.3.c. Degenerative and metabolic disorders of the brain: Many degenerative and metabolic nervous system disorders in adults and children inevitably progress toward an irreversible vegetative state. Patients who are severely impaired but retain some degree of awareness may lapse briefly into a vegetative state from the effects of medication, infection, superimposed illnesses, or decreased fluid and nutritional intake. Such a temporary encephalopathy must be corrected before establishing that the patient is in PVS. If the vegetative state persists for several months, recovery of consciousness is unlikely.

A.13.3.d. Severe developmental malformations of the nervous system: The developmental vegetative state is a form of PVS that affects some infants and children with severe congenital malformations of the nervous system. These children do not acquire awareness of the self or environment. This diagnosis can be made at birth only in infants with anencephaly. For children with other severe malformations who appear vegetative at birth, observation for three to six months is recommended to determine whether these infants acquire awareness. The majority of such infants who are vegetative at birth remain vegetative; those who acquire awareness usually recover but are severely disabled.

A.13.4. Prognosis for Recovery: The available data indicate that recovery of consciousness from post-traumatic PVS is unlikely after 12 months in adults and children. Recovery from non-traumatic

PVS is exceedingly rare after 3 months in both adults and children and those who recover are almost always severely disabled.

A.13.5. Survival of Patients: The life span of adults and children in PVS is substantially reduced. For most PVS patients, life expectancy ranges from 2 to 5 years. Survival beyond 10 years is unusual. The chance for survival of greater than 15 years is approximately 1/15,000 to 1/75,000. Note that the survival of patients in PVS is strongly influenced by the degree of medical intervention, e.g., the use of feeding tubes.

A.13.6. Management Guidelines:

A.13.6.a. When a patient has been diagnosed as being in PVS by a physician skilled in neurological assessment and diagnosis, it is recommended that a physician skilled in rehabilitation medicine also evaluate the patient to assist in identifying appropriate patient care goals and the level of nursing care required.

A.13.6.b. Physicians have the responsibility to discuss with the family or surrogate the probability of the patient remaining in PVS.

A.13.6.c. Patients in PVS should receive appropriate medical, nursing, or home care to maintain their personal dignity and hygiene.

A.13.6.d. Once PVS is considered to be permanent, a "Do Not Attempt Resuscitation" (DNAR) order is appropriate. Such a decision should, however, be made in a manner consistent with the rules for making health care decisions for an incompetent patient, as discussed elsewhere in this Handbook. The decision to implement a DNAR order may be made earlier in the course of a patient's illness, again assuming such a decision is made in a manner consistent with the rules for making decisions for an incompetent patient.

A.13.6.e. Physicians and the family should determine appropriate levels of treatment relative to the administration, the forgoing, or the withdrawal of:

1. Medications and other commonly ordered treatments
2. Supplemental oxygen and use of antibiotics
3. Complex organ sustaining treatments such as renal dialysis
4. Administration of blood products
5. Medically administered ("artificial") nutrition and hydration, including use of a permanent gastric tube (PEG tube).

A.13.6.f. Many individuals in PVS are candidates for foregoing or withdrawal of any or all of the above interventions. (See appropriate sections of this Handbook with regard to making such decisions.)

A.14. PROCEDURES FOR DETERMINING BRAIN DEATH

There are two well established methods that can be used to determine that death has occurred: (a) use of cardiopulmonary criteria to assess whether circulatory and respiratory functions have irreversibly ceased, or (b) use of neurological criteria to assess whether all brain functions have irreversibly ceased when cardiopulmonary functions are maintained artificially. This policy outlines the procedures to be used for declaring death based on neurological criteria. Additional guidelines pertain to situations involving potential organ donation and when the patient is pregnant.

A.14.1. General Guidelines

A.14.1.a. Definition: Brain death is the irreversible cessation of whole brain function (including the brain stem).

A.14.2. Specific Procedures for the Declaration of Brain Death

A.14.2.a. Policy

This policy defines the criteria for physician determination of brain death. This section 14.2. reflects hospital policy as of 5/25/2010.

A.14.2.a(1). All patients with suspected brain death should be evaluated by a physician intimately familiar with brain death.

A.14.2.a(1)(a). If the primary service attending is unfamiliar with the concepts and procedure for determining brain death, consultation with a service with expertise in diagnosing brain death is mandatory.

A.14.2.a(1)(b). Neurologists, Neurosurgeons, Intensivists and Trauma surgeons often have this familiarity.

A.14.2.a(1)(c). Qualified residents can perform the brain death examination under the supervision of a qualified attending. The degree of supervision necessary for the resident is determined by the resident's attending.

A.14.2.a(1)(d). Even when a consulting service is used, the final determination of brain death is the responsibility of the primary service attending.

A.14.2.a(1)(e). Organ Procurement Organization (OPO) personnel should not be involved in the determination of brain death.

A.14.2.a(2). The diagnosis of brain death requires the irreversible cessation of whole brain function.

A.14.2.a(2)(a). Determination that function of the whole brain has ceased is determined by clinical examination and requires the presence of:

- Unresponsive Coma
- Absent Brainstem Reflexes
- Apnea

A.14.2.a(2)(b). Determination of irreversibility requires:

- That the proximate cause of the brain insult is known.
- That an adequate time has passed since the brain insult to ensure that brain function will not recover.
- The absence of complicating conditions which might reversibly affect brain function (e.g. hypothermia)

A.14.2.a(2)(c). In most circumstances ancillary tests are not necessary to diagnose brain death.

- Ancillary tests are performed when part of the clinical examination cannot be performed or evaluated (e.g. the patient is unable to tolerate an apnea test because of instability).
- Acceptable ancillary tests include:
 - Nuclear medicine brain flow study (showing absent blood flow to the brain)
 - Electroencephalogram (showing electrocerebral silence)
 - Transcranial Doppler (must have had a previous baseline Doppler showing flow)

A.14.2.a(2)(d). Pediatric brain death determination requirements include:

- For a child age **7 days to 2 months:** two examinations and EEG separated by at least 48 hours.
- For a child age **2 months to 1 year:** two examinations and EEG separated by at least 24 hours. A repeat examination and EEG are not necessary if a cerebral radionuclide angiographic study is done and shows no visualization of cerebral arteries.
- For a child **older than 1 year to less than 14 years:** observation period of 12 hours is recommended. The observation period may be reduced if the EEG demonstrates electrocerebral silence or the cerebral radionuclide angiographic study does not visualize cerebral arteries.

A.14.2.a(3). Documentation and communication:

A.14.2.a(3)(a). The primary or consulting service will document the performance of the brain death evaluation on the Examination Criteria Brain Death Determination checklist. Examinations performed by a resident must be co-signed by their attending physician.

A.14.2.a(3)(b). If applicable, the reason for the use of an ancillary test will be documented by the primary or consulting service.

A.14.2.a(3)(c). For patient's meeting brain death criteria, the primary service attending is responsible for signing the declaration of death portion of the completed brain death checklist.

A.14.2.a(3)(d). The primary service is responsible for communicating to the patient's family that the patient has died by whole brain criteria. If involved, the consulting service and palliative care service can assist in these communications.

A.14.2.a(3)(e). Once brain death has been established and the family understands the diagnosis, organ donation management or equipment removal should ensue.

A.14.3. Organ donation

A.14.3.a. Federal regulations require that all deaths and imminent deaths be referred to the designated Organ Procurement Organization (OPO) to be screened for donation potential. Imminent death, for this purpose, is defined as a Glasgow Coma Score of 5 or less.

A.14.3.b. An early screening for donation potential can guide and expedite the process. (Example: If there is no donation potential, confirmatory testing might be deferred and the family need not be offered the option of donation.)

A.14.3.c. To avoid the appearance of a conflict of interest, physicians involved in the determination of death by neurological criteria will not be members of an organ transplant team or involved in the care of a potential organ recipient.

A.14.3.d. Death, based on fulfillment of all diagnostic criteria for brain death and certification by the attending physician, is declared while the artificial respirator is still ventilating the patient. The patient's family is not asked to participate in or to make the decision that the patient is brain dead.

A.14.3.e. Once the family has been informed and a declaration of death has been made, and all decisions and measures relating to possible organ donation have been completed, treatment of the patient should cease. Consent or permission of the family is not required for treatment cessation.

A.14.3.f. Under federal regulations, only trained requestors may offer the option of organ donation (when appropriate). It is hospital policy that a representative of the Midwest Transplant Network, the local Organ Procurement Organization (OPO), will offer the option of organ donation after the attending physician has made a declaration of death and informed the family.

A.14.3.g. It is recommended that the family be told by the attending physician:

- That the attending physician has determined that the patient is dead and that a declaration of death has been made and documented in the patient's medical record.
- That the patient's body is being maintained by mechanical ventilation and pharmacologic measures for a period of time while donation options are considered.
- That resources (such as the local OPO staff) are available to support them and explain their options.

A.14.3.h. The physician will work collaboratively with the OPO coordinator to determine how and when the coordinator will be introduced to the family. The coordinator will offer the option of organ donation and assist the family as needed in making an informed decision.

A.14.3.i. Revised Uniform Anatomical Gift Act (UAGA) statutes in Kansas and Missouri make special provisions in situations of "first person consent," i.e., when a decedent had indicated intent or consent to become an organ donor. In general, such indications constitute legal consent that is irrevocable by anyone other than the person making the gift. In situations of family opposition to donation when the OPO has determined "first person consent," a specific policy and algorithm will be followed that primarily aims to respect donor autonomy in compliance with state laws and federal regulations.

A.14.3.j. If a decision is made that the patient will not serve as an organ donor, interventions being used to maintain the patient's body should be discontinued.

A.14.3.k. Family members should be allowed to accompany the patient's body before, during and/or after these interventions are withdrawn.

A.14.4. Special situations of pregnancy

In the event a determination of brain death is being considered in a patient who is known to be pregnant, obstetrical consultation should be arranged.

Although the determination of brain death itself is not an ethical dilemma, ethical issues commonly coexist in this setting. Consultation with the Hospital Ethics Committee may be appropriate.

A.14.5. References

- American Academy of Neurology (1994) Practice Parameters Determining Brain Death in Adults. Retrieved June 18, 2009 from <http://www.aan.com/practice/guideline/uploads/118.pdf>
- American Academy of Pediatrics (1987) Task Force on Brain Death in Children published guidelines in Pediatrics Volume 80, No 2 August 1987. Retrieved from <http://pediatrics.org>
- The President's Council on Bioethics (2008) Controversies in the Determination of Death: A White Paper by the President's Council on Bioethics. Retrieved June 18, 2009 from [http://bioethics.gov/reports/death/Controversies%20in%20the%20Determination%20of%20Death%20for%20the%20Web%20\(2\).pdf](http://bioethics.gov/reports/death/Controversies%20in%20the%20Determination%20of%20Death%20for%20the%20Web%20(2).pdf)

A.15. RESEARCH INVOLVING HUMAN SUBJECTS

All research activities undertaken with the University of Kansas Hospital or KU Medical Center (or outside of the medical center, if undertaken by or supervised by faculty, staff or students) which involve the use of human subjects must be reviewed and approved by the Human Subjects Committee before they are begun. This requirement applies not only to research which involves direct participation by a human subject, but any activity which involves material derived from or collected from a human subject, and activities which involve use of data, photographs, images or records of human subjects. That committee also has responsibility for continuing review of all on-going research.

A detailed Policies and Procedures Manual is maintained by that committee and will be provided to any investigator upon request. Information regarding human subjects research or that committee may be obtained by calling its office at 913-588-1240, or visiting that office (6020 Wescoe).

B. Policies and Guidelines Adopted by Other KUH and KUMC Entities

Note: Hospital policies are available online via the intranet. Employees who experience problems accessing <http://ukh-appweb1/SiteDirectory/PoliciesProcedures/default.aspx> should contact for assistance the Hospital Helpdesk (913-588-4894) or Marketing (913-588-5728).

B.1. PATIENT RIGHTS

Policies concerning patient rights are included in Volume 2 of Hospital Policies and are accessible through the hospital intranet at <http://ukh-appweb1/SiteDirectory/PoliciesProcedures/default.aspx>. The Patient Rights document is also available on all nursing units and is displayed on inpatient units.

ATTACHMENTS:

- Patient Rights Document (Adult)
- A Rights Statement for Minors with Decisional Capacity
- A Rights Statement for Children with a Developing Capacity for Decision-making

B.1.1. Patient Rights Document (Adult)

The University of Kansas Hospital is committed to respect for and the protection of the rights of its patients. Honoring these rights is an important part of respecting and caring for you as a whole person. We are committed to relating to you in a way that respects your role in making decisions about your care. We will provide care in a manner that is sensitive to cultural, racial, religious and other differences. In providing you this care, we will not discriminate on the basis of race, color, religion, age, sex, sexual preference, national origin, disability or source of payment.

We will respond to your reasonable requests for treatment and to your health care needs. Our response will depend on both the urgency of your situation and on our ability to provide the kind of treatment you may require.

We need you to participate in decisions about your health care. By talking with your caregivers and actively participating in planning your care, you will help to ensure that the care you receive will reflect your dignity and be in keeping with your desires and values.

As an adult patient of this hospital, you have the right:

- * To know the name, identity and professional status of all persons providing services to you and to know the physician who is primarily responsible for your care.
- * To receive complete and current information concerning your diagnosis, treatment and prognosis in terms that you can understand.
- * To access to all information contained in your medical record.
- * To an explanation in terms you can understand of any proposed procedure, drug or treatment. The explanation should include a description of the nature and purpose of procedure, drug or treatment; the possible benefits; the serious side effects, risks or drawbacks which are known; potential costs; problems related to recovery; and, the likelihood of success. The explanation should also include discussion of alternative procedures or treatments.
- * To accept or refuse any procedure, drug or treatment and to be informed of the consequences of any such refusal.
- * To formulate advance treatment directives and to expect that these directives will be honored.
- * To appoint surrogate decision-maker to make health care decision on your behalf in the event you lose the capacity to make decisions.
- * To personal privacy. Care discussion, consultation, examination and treatment will be conducted discreetly.
- * To expect that all communications and records related to your care will be treated confidentially.
- * To supportive care including appropriate management of pain, treatment of uncomfortable symptoms and support of your psychological and spiritual needs even if you are dying or have a terminal illness.
- * To know about the option of organ, tissue or eye donation, when relevant.
- * To have access to protective services.
- * To assistance in obtaining consultation with another physician regarding your care. This consultation may result in additional cost to you.

- * To be transferred to another facility at your request or when medically appropriate and legally permissible. You have a right to be given a complete explanation concerning the need for and alternatives to such a transfer. The facility to which you will be transferred must first accept you as a patient.
- * To know if your care involves research or experimental methods of treatment. You have the right to consent or refuse to participate.
- * To voice complaints regarding your care, to have those complaints reviewed, and, when possible, resolved without fear of recrimination or penalty to yourself. You have the right to be informed of the response to your complaint.
- * To expect reasonable continuity of care and to be informed by care givers of realistic patient care options when hospital care is not appropriate. You have the right to participate in this discharge planning process.
- * To examine your bill and receive an explanation of the charges regardless of the source of payment for your care.
- * To ask about the ownership interests the hospital may have in organizations to which it may refer you.
- * To be informed of any hospital policies, procedures, rules or regulations applicable to your care.

If you are unable to exercise these rights, your legal guardian, next of kin or legally authorized surrogate has the right to exercise these rights listed above on your behalf.

It should be noted that, in certain circumstances, laws or regulations may authorize limitations upon your ability, or that of a surrogate, to exercise any of the above listed rights.

If you have any questions regarding these rights or wish to voice a concern about your rights or treatment, you may contact the nurse or physician responsible for your care. The nurse manager is also available to assist you.

The Patient Relations Office is available to assist you in all matters related to your satisfaction. If you have any questions or concerns, a representative can be reached by calling 913-588-1290.

B.1.2. A Rights Statement for Minors with Decisional Capacity

B.1.2.a. Introduction

The University of Kansas Hospital is committed to respecting and protecting the rights of its patients. Honoring these rights is an important part of respecting and caring for you as a whole person. We are committed to relating to you in a way that respects your role in decisions about your care. We will provide care in a manner that is sensitive to cultural, racial, religious and other differences. In providing you this care we will not discriminate on the basis of race, color, religion, age, sex, sexual preference, national origin, disability or source of payment.

We will respond to your reasonable requests for treatment and to your health care needs. Our response will depend on both the urgency of your situation and on our ability to provide the kind of treatment you may require.

We need you to participate in decisions about your health care. By talking with your caregivers and actively participating in planning your care, you will help to ensure that the care you receive reflects your dignity and is in keeping with your desires and values. You are being treated as a minor who is capable of making your own health care decisions. Therefore, you are being given this information regarding your rights. However, you should be aware that in certain circumstances your ability to act on these rights may be limited by laws, regulations or policies of the hospital. If acting on any of these rights conflicts with the desires of your parents/guardian, you and your parents/guardian may need to work with members of the hospital staff to try to resolve the conflict.

B.1.2.b. As a patient at the University of Kansas Medical Center, you have the right:

- 1.** To know the name, identity, and professional status of all persons providing services to you and to know the physician who is primarily responsible for your care.
- 2.** To receive complete and current information concerning your diagnosis, treatment and prognosis in terms that you can understand.
- 3.** To have access to all information contained in your medical record.
- 4.** To an explanation in terms you can understand of any proposed procedure, drug or treatment; the possible benefits; the serious side effects, risks or drawbacks which are known; potential costs; problems related to recovery; and, the likelihood of success. The explanation should also include discussion of alternative procedures or treatments.
- 5.** To accept or refuse any procedure, drug or treatment, and to be informed of the consequences of any such refusal. If there is conflict between you and your parents/guardian regarding your exercise of this right, you and your parents/guardian may need to participate in conflict resolution procedures.
- 6.** To formulate advance treatment directives and to expect that these directives will be honored.
- 7.** To select a surrogate decision-maker to participate in making health care decisions on your behalf in the event you lose the capacity to make decisions.
- 8.** To personal privacy. Care discussion, consultation, examination and treatment will be treated confidentially.
- 9.** To expect that all communications and records related to your care will be treated confidentially.
- 10.** To supportive care including appropriate management of pain, treatment of uncomfortable symptoms and support of your psychological and spiritual needs even if you are dying or have a terminal illness.
- 11.** To assistance in obtaining consultation with another physician regarding your care. This consultation may result in additional cost to you or your family.
- 12.** To request consultation with the Hospital Ethics Committee regarding ethical issues involved in your care.
- 13.** To be transferred to another facility at your request or when medically appropriate and legally permissible. You have a right to be given a complete explanation concerning the need for and alternatives to such a transfer. The facility to which you will be transferred must first accept you as a patient.
- 14.** To know if your care involves research or experimental methods of treatment. You have the right to consent or refuse to participate.
- 15.** To voice complaints regarding your care, to have those complaints reviewed, and, when possible, resolved without fear of any harm or penalty to yourself. You have the right to be informed of the response to your complaint.
- 16.** To expect reasonable continuity of care and to be informed by caregivers of realistic patient care options when hospital care is no longer appropriate. You have the right to participate in this discharge planning process.
- 17.** To examine your bill and receive an explanation of the charges regardless of the source of payment for your care.

- 18.** To be informed of any hospital policies, procedures, rules or regulations applicable to your care.
- 19.** If you are unable to exercise these rights, your guardian, next of kin or legally authorized surrogate has the right to exercise these rights on your behalf.

If you have any questions regarding these rights or wish to voice a concern about your rights, you may contact the Patient Affairs Office by calling 913-588-1290.

B.1.3. A Rights Statement for Children with a Developing Capacity for Decision-making

B.1.3.a. Introduction

Please read this list of rights. If you need help reading it or need to have some of the words explained to you, ask your mom or dad or any of the people taking care of you.

This is a list of the rights you have, as a patient here at the University of Kansas Medical Center:

- 1.** The right to read or have this list of rights read to you and explained to you as often as you want.
- 2.** The right to be treated with respect by all the people who work at this hospital and to know the name and job of each person taking care of you.
- 3.** The right to be told what you need to know to help you understand why you are at the hospital.
- 4.** The right to have explained to you honestly, in a way you can understand, anything that is going to be done to you while you are here. And, to be told what it may feel like to have those things done.
- 5.** The right to have questions or worries about your treatment answered in ways you can understand.
- 6.** The right to tell your family, doctors, nurses, and other people taking care of you what you think and feel about your treatment and what is being planned for you.
- 7.** The right to help your family and the people taking care of you decide what will be done for you.
- 8.** The right to help in solving a disagreement if you and your family or you and the people taking care of you here at the hospital don't agree about what should be done for you.
- 9.** The right to agree or disagree to anything that is going to happen to you. If you tell the people taking care of you that you disagree, you have the right to know that nothing will be done to you until the people taking care of you talk to you about your worries and questions.
- 10.** The right to know that nothing will happen to you that you do not want unless your family and the people taking care of you agree that you need to have it done.
- 11.** The right to know if your care is part of a research project. You can agree or not agree to be part of any research or stop being part of any research.
- 12.** The right to know that what people taking care of you learn about you will not be told to people who do not need to know.
- 13.** The right to be able to talk freely with the people taking care of you and to know that what you say will not be told to others, including your family, unless it is important to your care if you give permission.
- 14.** The right to know that when the people taking care of you touch your body, they will tell you what they need to do, be gentle and do it in a private way.
- 15.** The right to ask for special things or people that would make you feel more comfortable while you are here
- 16.** The right to have your family with you as much as possible if you want them to be. When this is not possible, the people taking care of you will explain why they can't be with you.

17. The right to have a "safe place" where the doctors, nurses and other people taking care of you at the hospital will not perform treatment procedures. Your nurse will tell you about this special place and show you and your family where it is.
18. The right to know if you are scared, in pain or hurting, the people taking care of you will try to help you.
19. The right to get angry, or to cry, or to say what you don't like about what is happening to you.
20. The right to know that what is being done to you by your doctors, nurses and other people taking care of you is being done to help you and not to punish you.
21. The right to be treated as a growing person and to have times and places to play and to learn while you are here.
22. The right to have the people taking care of you teach you and your family all you need to know about your health care so that you can take care of yourself at home.

If you feel that any of these rights are not being respected, you should tell your parents and the people taking care of you. You can also call a person in a special office called the Patient Affairs Office by dialing 8-1290 on the phone in your room.

B.2. CODE OF ETHICS AND PROFESSIONAL CONDUCT

The Hospital Code of Ethics and Professional Conduct is included in Volume 1 of Hospital Policies and is accessible through the intranet at <http://ukh-appweb1/SiteDirectory/PoliciesProcedures/default.aspx>.

THE UNIVERSITY OF KANSAS HOSPITAL AND ITS SUBSIDIARIES (HEREAFTER KNOWN AS THE "SYSTEM")

CODE OF ETHICS AND PROFESSIONAL CONDUCT

B.2.1. PURPOSE AND POLICY

The System intends to conduct its patient care and business operations within an ethical and legal framework as defined by its mission, vision, values, strategic plan, and Corporate Compliance Plan. This Code of Ethics and Professional Conduct ("Code") describes the System's ethical and legal framework required by the Corporate Compliance Plan.

The Code cannot, nor is it intended to, cover all System employee activities or resolve all System employee ethical or legal questions. The Code will be updated and revised over time to provide guidance and current information to System employees. If you are not sure whether your actions comply with the Code, or if you are aware of a suspected or known Code violation, you should consult with your supervisor or the Chief Compliance Officer as described below.

B.2.1.a. The Corporate Compliance Plan

B.2.1.a(1). *What are the System's Responsibilities under the Corporate Compliance Plan?*

- Develop the Code to provide System employees with ethical and legal guidance on matters of daily business conduct.
- Distribute the Code.

- Establish and maintain training programs to ensure familiarity with and understanding of Code compliance requirements.
- Advise employees, officers and directors as to the proper interpretation and application of the Code.
- Administer the Code and its supporting policies.
- Assure a working atmosphere conducive to compliance and free of retaliation for the reporting of alleged Code violations.

B.2.1.a(2). What are the System Employees' Responsibilities under the Corporate Compliance Plan?

Each System employee has an obligation to assure that the Corporate Compliance Plan is a success by doing the following things:

- Read and regularly review the Code and supporting policies.
- Participate in Code training programs and staff meetings.
- Abide by the Code.
- Ask questions and seek assistance when uncertain about what to do.
- Support employees who report suspected violations of the Code. Recognize that retaliation against persons who report suspected violations is not permitted.
- Be alert to situations that could result in illegal or unethical conduct and encourage other System employees to consult with supervisors or the Chief Compliance Officer when it appears that they may be in danger of violating the law or the Code.
- Immediately report suspected or known violations of the Code.

B.2.1.b. The Code

B.2.1.b(1). Who must comply with the Code?

Each System employee must observe the Code. The System has designated a Chief Compliance Officer to respond to System employees and to help employees understand and comply with the Code. The Chief Compliance Officer administers the Code through a committee and reports on matters of compliance with the Code to the Authority Board of Directors.

All System employees must promptly report any suspected or known Code violations. Failure to report such violations may result in disciplinary action, up to and including loss of employment.

B.2.1.b(2). What if there are questions or suspected or known Code violations?

For questions or to report Code violations contact:

Your Supervisor

OR

The Corporate Compliance Officer at your Subsidiary

OR

The Chief Compliance Officer (Phone: 913-588-5434)

Each Code violation report will be handled confidentially to the extent possible as determined by the Chief Compliance Officer. No retaliation or harassment against System employees who report possible Code violations will be tolerated. System employees may raise concerns anonymously. If an anonymous Code violation report provides enough information to permit investigation, it will be pursued as determined by the Chief Compliance Officer. However, anonymity may make it difficult to

investigate and resolve Code violation reports. For this reason System employees are encouraged to give their identity when asking a question or reporting a possible Code violation.

B.2.1.b(3). *What is the Code Acknowledgment Card?*

Each System employee will be asked to pledge his or her support to and agree to comply with the Code. From time to time System employees will be asked to renew their pledge. Each System employee will be asked to sign the Acknowledgment Card to acknowledge that he or she has received and agrees to comply with the Code.

B.2.1.b(4). *What will happen if the Code is not followed?*

The Code is important and failure to comply with its provisions is a serious matter that may lead to disciplinary action, up to and including loss of employment.

B.2.1.b(5). *What general topics does the Code discuss?*

The Code covers:

- Patient Care Services;
- System Employee Working Environment;
- Business Practices; and
- General Legal Standards.

B.2.2. PATIENT CARE SERVICES

The System's activities encompass such patient care services as the prevention and treatment of illness, education, and research. All such activities will be conducted with integrity, compassion, and a concern for human welfare and dignity. System employees are expected to make a good faith effort to meet or exceed a standard of exceptional service in a courteous manner. It is expected that every individual coming into contact with the System, be they patient, visitor, employee, physician, student, or volunteer, will be able to enjoy an atmosphere which fosters respect, personal safety, and courtesy.

B.2.2.a. Provision of Quality Care

System employees shall follow standards of care based upon the identified needs of the patient without regard to ability to pay. System employees shall seek to avoid the provision of services that are medically unnecessary or ineffective. Every effort should be made to provide high quality health care in an economical manner to patients.

B.2.2.b. Patients' Rights

System employees shall comply with applicable state and federal legislation regarding patients' rights. System employees shall respect patients' rights and assist patients and/or their legally authorized representatives in understanding and exercising their rights and responsibilities. A patients' rights document will be provided in writing to all patients and/or legally authorized representatives upon admission to a patient care unit or treatment area.

The System patient is the primary decision-maker with respect to his or her own health care. The patient has the right to accept, forego or withdraw from offered treatment. Information regarding diagnosis, treatment and/or research options and prognosis should be delivered in language that is understood to ensure that the patient's right to make an informed choice is preserved. System employees will work to provide for the protection of the rights of patients whose capacity to act as their own advocate is diminished by virtue of age or incapacity. Under certain circumstances, a legally authorized representative may have the right to make decisions related to patient care, including the use of life sustaining treatment. The System will work with such legally authorized representatives.

B.2.2.c. Patient Non-Discrimination and Accommodation of Special Patient Needs

The System acknowledges and respects individual patient differences, such as personal background, race, color, ethnic or cultural heritage, national origin, religious/spiritual views, communication needs, sex, age, marital status, veteran status, sexual orientation, handicap, and developmental disability. It is the policy of the System that such differences will be respected in all patient service activities. All patients should be able to expect a high quality of care based on their unique health care needs with respect for and regardless of individual differences. All constituents served must be able to enjoy the same nondiscriminatory System environment.

The System recognizes its responsibility to accommodate the special needs of patients and staff with disabilities. The System will make every effort to comply with all state and federal regulations that apply to such circumstances. These accommodations will be made in a manner that respects the dignity of all parties involved.

B.2.2.d. Patient Admission, Transfer and Discharge

Patient admission, transfer and discharge shall be properly conducted in an ethical manner and in accordance with all applicable local, state, and federal regulations. Patients who are in need of the System's emergency stabilizing services shall not be denied services. Patients whose specific condition or disease cannot be safely treated at the System shall be properly transferred to an accepting facility.

Also, a patient may request transfer to another facility. Such a request will be facilitated when medically appropriate and legally permissible. The patient will receive a complete explanation of alternatives to and risks associated with such a transfer. The receiving facility must first accept the patient. All such activities will be carried out in a respectful and courteous manner.

The System believes patient discharge planning is an integral part of the comprehensive health care plan. Planning for discharge from the System is a multi-disciplinary process involving the patient and family. The patient will be informed by caregivers of realistic care options when hospital care is no longer medically necessary or appropriate.

B.2.2.e. Confidentiality/Release of Patient Information

System employees shall recognize the vital need to maintain patient and business information in a confidential manner. Patient information shall not be released without legal authorization. System employees, physicians, and students are expected to control the informal transmission of confidential information. Sensitive information concerning personnel and management issues shall be maintained in the strictest of confidence and shall be utilized only by those individuals legally authorized to review and act on such information.

B.2.2.e(1). *What is confidential information?*

Confidential information includes any information, or present or planned business, that has not been publicly disclosed by the System. Specifically, System employees are not allowed to release information without legal authorization about:

- Patients, employees or payors
- Pricing
- Financial data
- Marketing programs
- Research

Information such as this is vital to the System's patient care and business operations. It is also a key component of the Code.

B.2.2.e(2). *Why must the System protect confidential information?*

Disclosing confidential information without authorization may violate this Code, applicable law, and System policy regarding:

- Patient confidentiality
- Conflict of interest
- Antitrust
- Employment matters
- Finances
- Intellectual property

B.2.2.e(3). What about confidential medical record information?

System employees pledge to keep medical record information confidential and to respect privacy. This pledge is especially important to the System's patient care and business operations. A medical record or information contained in a medical record should be released only if:

- A valid written authorization for the release of this information is obtained from the patient or legally authorized representative.
- Reporting is required or permitted by law.

Example:

Two employees are discussing a patient's condition in a crowded elevator. A reporter riding in the same elevator realizes the patient is a celebrity with a terminal illness. The reporter uses these facts to run a lead story in the morning paper.

The employees should not have discussed the case in the elevator. All patient conditions are confidential and should not be discussed in casual conversation, even if the patient's name or illness is not specified.

B.2.2.f. Patient Care Ethics Committee Consultation

The System recognizes differences of opinion among those who participate in patient-care decisions. The System will seek to resolve all conflicts fairly and objectively. Ethics Committee consultation is available upon request. The Ethics Committee review will be available within twenty-four (24) hours.

B.2.3. SYSTEM EMPLOYEE WORKING ENVIRONMENT

B.2.3.a. Diversity

The System is committed to equal employment opportunity in the work place. The System seeks a working environment free of prejudice or harassment on the grounds of race, color, religion, sex, age, disability, national origin or any other illegal factor. As is consistent with the high regard the System places upon employee satisfaction and respect, the System is committed to abiding by all federal, state and local laws dealing with employment matters. The System employees shall encourage open communication and a spirit of cooperation.

B.2.3.b. Maintaining Employee Safety and System Environment

The System pledges:

- To continue to develop procedures and conduct training programs to meet legal standards on health, safety and environmental protection.
- To consider the effects that new developments have on the environment.
- To recognize and respond to community concerns about the effects of System business on the environment.

System employees are expected to:

- Learn the procedures for handling and disposal of any hazardous materials used on their job.
- Know the safety procedures that apply to their job.
- Share ideas for improving safety and reducing waste with supervisors.
- Use best efforts to ensure that actions are carried out in a safe and healthy manner.

A commitment to health, safety and environmental protection can be seen in the System's efforts to reduce the generation of waste. Wastes should be recycled or reused whenever possible. Wastes that cannot be recycled or reused should be discarded in a safe manner.

For questions or to report safety violations contact:

- Your Supervisor
- Employee Health
- Safety Officer and the Safety Office

B.2.3.c. System Employee Relief From Participating In Patient Care

The System acknowledges that a System employee may request to be relieved from participating in a patient's care or treatment in a situation where the prescribed care or treatment presents a conflict with deeply held cultural values, sense of ethics, or religious beliefs. The policy on management of staff rights addresses the mechanism for handling these requests and is available upon request. The System shall ensure that patient care and treatment are not compromised if such a request is granted. The Ethics Committee is available for exploration and discussion upon referral.

B.2.4. BUSINESS PRACTICES

B.2.4.a. Business Practices

The System is committed to the delivery of high quality care at reasonable and competitive prices. To that end, the System relies on the ability and professionalism of its employees and representatives to communicate effectively the merits of System services to the patient, physician, and consumer, and expects System employees to use only legitimate competitive practices.

B.2.4.b. Financial Matters

System employees shall work to maintain the financial records of the System in an accurate and complete manner.

The System accounting controls will be sufficient to provide reasonable assurance that:

- Expenditures are made with proper approval and authorization.
- All transactions are recorded to help the System prepare financial statements and account for resources in accordance with established policies.
- Access to assets is permitted only with proper approval.
- Assets are adequately safeguarded, with any discrepancies immediately reported to management.

The financial matters of the System, its employees, physicians and patients are very private. System employees should not reveal these matters to outside parties without permission from the Chief Financial Officer or the President and Chief Executive Officer.

B.2.4.c. Billing for Services Rendered

The System recognizes the imperative nature of accurate and timely billing. Patients and third parties should be billed only for service actually provided to patients and fully documented in the patient's

medical record. Inaccurate records, payments, or billings should be promptly reported to the System administrator or manager authorized to address the situation.

- Initial patient billing should include a summarization of charges and dates of services. Itemized charges should be available to patients upon request.
- When a patient or payor has a question about a specific charge, that inquiry shall be reviewed expeditiously and the response will be timely and courteous and accompanied by a complete explanation of the charges.
- Assistance will be provided to patients and/or the patients' designee who are seeking to understand the cost of their care, or who are seeking to gain information regarding estimated cost of treatment.
- As a service to patients, the System works to bill all third party carriers, including secondary carriers, as appropriate.
- Patients should receive written notice of any balance due on the account.
- Fair Debt Collection Practices shall be adhered to in attempting to collect any outstanding balance from a patient.
- Patients who are unable to pay the balance on their account may be offered a payment plan.
- For patients who have been determined to be financially needy, an assistance program may be available to discount or adjust the patient's responsibility.

B.2.4.d. Conflicts of Interest

The System recognizes that the potential for conflicts of interest exists for decision-makers at all levels. Consequently, the System shall request the disclosure of potential conflicts of interest so that appropriate actions may be taken in advance to ensure that any applicable conflict does not inappropriately influence decisions on behalf of the System. Conflicts may exist with respect to contractual relationships between the System and its staff or other health care providers, educational institutions, and payors as well as referral sources and vendors. System administrators and department managers will submit an annual conflict of interest statement.

B.2.4.d(1). What is a conflict of interest?

A conflict of interest arises whenever a System employee's interest or that of an immediate family member conflicts or appears to conflict with the interests of the System. Each System employee has a duty to avoid conflicts of interest or the appearance of conflicts of interest. If you, or an immediate family member, are faced with a transaction, decision, or situation that you think may create a conflict of interest, report it promptly to your supervisor or the Chief Compliance Officer.

Example 1:

My spouse is an officer of Company B that sells lab supplies. Is it a conflict of interest for me if the System buys supplies from Company B?

This relationship should be disclosed to your supervisor or the Chief Compliance Officer as a potential conflict of interest. If you are not in a position to influence or affect the System's choice of suppliers, the disclosure of this relationship will, in most situations, be sufficient to avoid a conflict of interest.

Example 2:

I have been offered a trip for two to Hawaii if I purchase, on behalf of the System, more than a certain dollar amount of goods or services from Company C. Is such an arrangement a conflict of interest?

Yes, such an arrangement would lead to your personal gain directly from your duties as an employee. You should report the offer to your supervisor or the Chief Compliance Officer.

Example 3:

I wish to buy some land that I learned was for sale through my job at the System. Is the purchase a conflict of interest?

This could be a conflict if the System is still negotiating for the purchase of the real estate. To be safe, you should get confirmation from the Chief Compliance Officer that the System is no longer considering or pursuing the purchase.

B.2.4.e. Marketing and Public Relations

The System will strive to fully and accurately represent itself, its service and its capabilities to the public. Marketing materials should reflect those services available, the current level of licensure and accreditation, and provide communications which are designed to inform and persuade but not to deceive. All comparisons to competitive offerings will be fair. Patient confidentiality and privacy will be respected and protected in any System marketing or public relations activities.

B.2.5. GENERAL LEGAL STANDARDS

Integrity and adherence to the law are basic obligations for everyone. System employees shall uphold applicable laws and regulations. If a System employee has questions about actions, he or she shall seek advice from the Chief Compliance Officer before taking the action. In general, it is illegal and a violation of System policy to:

- Engage in bribery
- Steal hospital property or the property of another
- Commit a fraud or purposely mislead another through the use of false statements
- Injure an individual or his/her property by committing an unlawful act
- Violate any federal, state or local law or regulation

The policy of the System with respect to more specific laws is set forth below, and may be amended from time to time by the System.

B.2.5.a. Copyright & Intellectual Property Laws

Consistent with the high value the System places upon proprietary information, the System pledges to abide by all federal, state and local laws that protect intellectual property. Intellectual property includes patents, trademarks, service marks, trade secrets, and copyrights. Federal and state laws protect intellectual property. Violations of the intellectual property laws may result in civil damages or criminal charges. In addition, the System may be held responsible for the actions of individual employees who break intellectual property laws.

During the course of employment, a System employee may have access to intellectual property owned by other businesses. This information may include patents, techniques, publications or trade secrets. This information is confidential and should not be disclosed to others or used for personal purposes. Licensed computer software is a good example of intellectual property owned by another business. Duplicating computer software or the materials that accompany it may violate the copyright laws and the System corporate policy. The use of illegal copies of software on hospital hardware is prohibited.

The following activities also may violate intellectual property laws:

- Installing software programs on more than one computer when it was sold for only one computer. Find out how many computers can use a multiple unit software package before ordering or installing software.
- Copying (by machine or hand) an entire issue of a journal, magazine or newsletter. Unless permission is obtained from the publisher to make such copies, the original should be circulated within a group or several subscriptions purchased.

B.2.5.b. Antitrust Laws

It is the policy of the System to comply with all antitrust laws that affect the manner in which the System, its employees, or affiliates may do business. Antitrust laws are intended to preserve competition. For this reason, System employees should avoid discussions with competitors concerning:

- Prices or payor rates.
- Decisions to deal with a particular payor or group of payors, or patient or group of patients.
- The granting of membership, privileges, or managed care participation status to any physician, health care provider, or group of providers.

Consult your supervisor or the Chief Compliance Officer if you have questions about the antitrust laws.

B.2.5.c. Medicare/Medicaid Fraud and Abuse

Facilities that receive monies for service provided under Medicare and Medicaid are subject to several laws and regulations designed to prevent fraud and abuse. These laws were created to make certain that federal funds, which finance Medicare and Medicaid, are used only for those purposes. Failure to obey these laws can result in fines, jail or exclusion from Medicare and Medicaid programs. By signing the Acknowledgment Card, System employees pledge to use their best efforts to comply with these fraud and abuse laws. The fraud and abuse laws are complicated and contain numerous exceptions or "safe harbors." If you have specific questions about the fraud and abuse laws, consult the Chief Compliance Officer.

Some of the more important laws relating to fraud and abuse are discussed below:

B.2.5.c(1). Billing and Claims

As described above, honesty and accuracy in billing and in the making of claims for Medicare or Medicaid payment is vital. It is a felony to willfully make a false statement in connection with a claim for payment or an application for certification under Medicare or Medicaid. Using their best efforts, the System and its employees must ensure that all services are properly documented, coded, and billed to the responsible party.

B.2.5.c(2). Anti-kickback Statute

The anti-kickback statute is a federal law. Anyone who willfully offers, pays, seeks, or receives anything of value, including kickbacks and bribes, to bring about a referral for medical services or goods payable by Medicare or Medicaid violates this law. Failure to obey the anti-kickback statute can result in fines, jail, or exclusion from the Medicare and Medicaid programs. The anti-kickback statute also affects the way in which entities carry out a broad range of ordinary business deals.

The following activities may be illegal under the anti-kickback statute and should be reported to the Chief Compliance Officer:

- Offer or acceptance of payment other than fair market value for health care services as a way of getting more business.

- Acceptance of prizes, gifts, cash payments, coupons or bonuses offered for marketing certain products.
- Financial incentives given to physicians that are linked to the number of referrals made by the physician or to the physician's level of billing.

B.2.5.c(3). Ban on self-referral

A physician who receives payment directly or indirectly from, or has an investment interest in, a business should not refer patients to that business for certain services paid for by Medicare or Medicaid. Claims should not be submitted for services performed as a result of improper referrals. The self-referral statute is a complicated law, with numerous legal exceptions. Specific questions regarding the self-referral laws should be directed to the Chief Compliance Officer.

B.2.5.c(4). What if you have additional questions?

The anti-kickback statute and the self-referral ban are subject to numerous legal exceptions. These exceptions, as well as the proper application of these laws, are further explained in other System policies including policies relating to Medicare/Medicaid fraud and abuse. Specific questions regarding any legal standard should be directed to the Chief Compliance Officer.

B.2.5.d. Other Laws

This Code covers many areas; however, your job may involve legal rules not explained here, but explained in detail in other System policies. For example, if you work in the System pharmacy or are responsible for the collection of receivables, other laws may apply to your duties. If your work involves these topics, you should ask your supervisor for additional training, including information about consumer credit protection, garnishments or laws relating to pharmacies. For answers to questions pertaining to other areas, please consult your supervisor or the Chief Compliance Officer.

B.2.6. Conclusion

Underlying each of the above statements is the System's overall commitment to act with integrity in all activities and to treat System employees, patients, physicians, students, and the many constituents it serves with utmost respect. Supporting policies are set forth in the Hospital Wide Policy Manual and/or Department Policy Manuals and are available to System employees upon request. Please review specific policies for additional guidance.

B.3. REQUESTS FOR RELIEF FROM PARTICIPATION IN ASPECTS OF CARE

Hospital policy concerning relief from participation in aspects of care is included in Volume 5 of Hospital Policies and is accessible through the hospital intranet at <http://ukh-appweb1/SiteDirectory/PoliciesProcedures/default.aspx>.

B.4. PRIVACY/CONFIDENTIALITY

Policies concerning patient confidentiality are included in the following sections of Hospital Policies: Code of Ethics and Professional Conduct; Information Management sections of Volume 1; Volume 2, Patient Rights; Volume 5, Human Resources. All are accessible through the hospital intranet at <http://ukh-appweb1/SiteDirectory/PoliciesProcedures/default.aspx>.

B.5. RELEASE OF INFORMATION

Hospital policies concerning release of information are included in the following sections of Hospital Policies: Code of Ethics and Professional Conduct; Information Management sections of Volume 1;

Volume 2, Patient Rights; Volume 5, Human Resources. All are accessible through the hospital intranet at <http://ukh-appweb1/SiteDirectory/PoliciesProcedures/default.aspx>.

B.6. PATIENT DENIAL/NO INFORMATION STATUS

The policy concerning patient denial and no information status is included in Volume 2, Patient Rights section of Hospital Policies and is accessible through the hospital intranet at <http://ukh-appweb1/SiteDirectory/PoliciesProcedures/default.aspx>.

B.7. RESOLUTION OF PROFESSIONAL DISAGREEMENTS

The policy concerning the resolution of professional disagreements is included in Volume 2, Patient Rights section of Hospital Policies and is accessible through the hospital intranet at <http://ukh-appweb1/SiteDirectory/PoliciesProcedures/default.aspx>.

B.8. DONATION OF ORGANS, TISSUES AND EYES

The policy concerning donation of organs, tissues and eyes is included in Volume 2, Patient Rights section of Hospital Policies and is accessible through the hospital intranet at <http://ukh-appweb1/SiteDirectory/PoliciesProcedures/default.aspx>.

An End of Life Resource Handbook is available on nursing units. The End of Life Resource Handbook contains detailed protocols, forms, and resource material to facilitate and support the essential processes for the staff in caring for the patient and family at the end of life. Copies should be located in all patient care areas in which deaths occur.

B.9. INFORMED DECISION-MAKING

The policy concerning informed decision-making is included in Volume 2, Patient Rights section of Hospital Policies and is accessible through the hospital intranet at <http://ukh-appweb1/SiteDirectory/PoliciesProcedures/default.aspx>.

B.10. REFUSAL OF BLOOD TRANSFUSIONS

The policy concerning consent and refusal of blood and blood products is included in Volume 2, Patient Rights section of Hospital Policies and is accessible through the hospital intranet at <http://ukh-appweb1/SiteDirectory/PoliciesProcedures/default.aspx>.

B.11. MANAGEMENT OF PATIENT/FAMILY COMPLAINTS

The policy concerning management of patient and family complaints and grievances is included in Volume 2, Patient Rights section of Hospital Policies and is accessible through the hospital intranet at <http://ukh-appweb1/SiteDirectory/PoliciesProcedures/default.aspx>.

B.12. SUPPORT SERVICES FOR PATIENTS WHO ARE DEAF, HARD OF HEARING, OR DO NOT SPEAK ENGLISH

The policy describing support services for patients who are deaf or hard of hearing and patients who do not speak English is included in Volume 2, Patient Rights section of Hospital Policies and is accessible through the hospital intranet at <http://ukh-appweb1/SiteDirectory/PoliciesProcedures/default.aspx>.

The University of Kansas Hospital and KU Medical Center

HOSPITAL ETHICS HANDBOOK

Revised March 2011

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May/2003 effective date, signed 6/11/03, reviewed 7/1/05, 7/1/07, 2/18/2011; revised 03/15/11

Date signed