A White Paper
by the
Colorado Collaborative for Unrepresented Patients

Addressing Gaps in Healthcare Decision Making for Unrepresented Adults:
A Proposal for the Inclusion of a Public Healthcare Guardian in the Office of Public Guardianship
Colorado Collaborative for Unrepresented Patients consists of the following institutions and individuals:

Center for Bioethics and Humanities, University of Colorado Anschutz Medical Campus
Jean Abbott, MD, MH
   Professor Emeritus, Emergency Medicine; Clinical Faculty Associate
Jacqueline J. Glover, PhD
   Professor, Department of Pediatrics; Director of Clinical Ethics

Center for Ethics and Leadership in the Health Professions, Regis University
Deb Bennett-Woods, EdD, FACHE
   Chair & Professor, Department of Health Care Ethics
   Director, Center for Ethics and Leadership in the Health Professions

Children’s Hospital Colorado
Jacqueline J. Glover, PhD
   Ethics Committee Member
Stefan Mokrohisky, MD
   Clinical Professor of Pediatrics; Ethics Committee Chair
Tracy Price-Johnson
   Ethics Committee Member

Colorado Healthcare Ethics Forum
Jean Abbott, MD, MH
Deb Bennett-Woods, EdD, FACHE
Aaron Snyder, MD, Retired geriatrician and clinical ethics consultant
Kayte Fulton, BA, Clinical Patient Communications consultant

Denver Health and Hospital Authority
Kathryn Witzeman, MD
   Assistant Professor, Department of OB/GYN; Ethics Committee Chair

JFK Partners, University of Colorado School of Medicine
Tracy Price-Johnson

University of Colorado Hospital Authority
Jean Abbott, MD, MH
   Ethics Committee Chair
Jacqueline J. Glover, PhD
   Ethics Committee Member
Acknowledgements:

Sharon E. Caulfield, Esq. and Kristofer M. Simms, Esq.; Caplan and Earnest, LCC; Boulder, CO

Gail Finley, Vice President, Rural Health and Hospitals, Colorado Hospital Association

Carolyn H. Welsh, MD, Ethics Committee Chair, Veterans Administration Medical Center and Professor of Medicine, Division of Pulmonary Sciences and Critical Care Medicine, University of Colorado School of Medicine
Overview

The Elder Abuse Task Force, who were mandated to conduct a review of existing research related to S.B. 12-078 (Colorado State, 2012), recommended that the Colorado General Assembly study the need for and implementation of a public guardianship and conservatorship program, in addition to the mandatory reporting of abuse of at-risk adults (Elder Abuse Task Force, 2012). The Colorado Judiciary responded with the appointment of the Public Guardianship Advisory Committee, who is charged with examining options for creating an Office of Public Guardianship to assure protection for vulnerable adults who need legal guardians but who lack willing and responsible family members or friends to make legal decisions.

County Adult Protective Services (APS) agencies are frequently asked to provide guardianship for the purpose of healthcare decision-making, when patients or residents lack the capacity to make their own decisions and also lack family, friends or other legally authorized representatives to make decisions on their behalf. However, such requests are prohibited by statute and not part of the defined role of APS. Healthcare decisions may be required in the context of acute illness, significant chronic disease or disability, end-of-life decisions, and placement for ongoing treatment. The lack of a decision maker for healthcare can leave Colorado adults without decisional capacity inappropriately institutionalized and can leave health care providers without authorization to make important clinical decisions.

In this white paper, the Colorado Collaborative for Unrepresented Patients (CCUP) seeks to define the problem of “unrepresented” adults in the healthcare system, review Colorado law pertinent to healthcare decision-making, and describe some solutions that have been enacted in other states or systems. The Colorado Collaborative for Unrepresented Patients recommends adding to the public guardianship system a “public healthcare guardian”, with the accompanying training, funding and public support.

I. Definitions (in alphabetical order)

**Advance directive**: A written instruction, such as a living will or durable power of attorney for health care, recognized under state law (whether statutory or as recognized by the courts of the State), relating to the provision of health care when the individual lacks decisional capacity or elects to delegate decision making to another.

**Best interest standard**: A decision-making standard used when it cannot be determined with certainty what the patient would have chosen regarding treatment or setting if he or she had decisional capacity. The standard requires the decision maker to consider the patient’s preferences and values to the extent they are known or discoverable, and the likelihood that benefits will outweigh foreseeable risks and burdens to the patient. Factors that should be considered by a legally authorized representative (LAR) in determining whether treatment decisions are in the best interests of the incapacitated individual include:

- the patient's present level of physical, sensory, emotional, and cognitive functioning;
- the various treatment options and the risks, side effects, and benefits of each of the options;
- the life expectancy and prognosis for recovery with and without treatment;
• the degree of pain and discomfort resulting from the medical condition, treatment, or termination of treatment;
• the degree of dependency and loss of dignity resulting from the medical condition and treatment (adapted from Washington State Hospital Association, 2010).

**Decision-making capacity (DMC):** A patient’s ability to (a) recognize the need for a decision, (b) understand the nature and consequences of the decision; (c) weigh the relative benefits, burdens and risks of available treatment options, (d) and communicate a decision consistent with his or her values. Also referred to as decisional capacity.

**Emergency waiver of consent:** The rendering of medical care to an incapacitated person without the patient’s consent in an emergency situation, using the standard of what a “reasonable person” would want. Emergent surgeries, antibiotic treatments and invasive testing and treatment can be initiated under the “emergency waiver”.

**Health care agent:** Person authorized, verbally or in writing, by a patient at a time when he/she had DMC to be his/her agent in making healthcare decisions when he or she lacks capacity, generally under a medical durable power of attorney (MDPOA) or other document.

**Public healthcare guardian (proposed):** A person appointed via the Office of Public Guardianship and authorized narrowly to make healthcare decisions on behalf of an unrepresented patient who either temporarily or permanently has lost the capacity to make such decisions on his or her own behalf.

**Legally authorized representative (LAR):** An adult authorized (by statute or by common law) to make decisions on behalf of another person. Also referred to as a surrogate decision maker. This adult can either be authorized as a health care agent by the patient or a proxy decision maker according to Colorado statutes.

**Scope of treatment decisions:**

• Routine treatment – medical interventions that do not pose significant risk to the patient’s health or life, and about which major differences in personal, social or religious values are unusual. This generally includes interventions and procedures for which signed informed consent is normally not required or for which signed informed consent is normally required but are considered low risk. Examples of routine treatment may include, but are not limited to: administration of parenteral medications, transfusion of blood products, routine laboratory and radiographic diagnostics, radiographic procedures involving contrast dye, placement of intravenous access, biopsies that do not invade a body cavity, and some invasive diagnostic procedures (paracentesis, spinal tap, etc.).

• Major invasive treatment – medical interventions for which there is substantial risk to the patient for serious injury, significant suffering, or death, or for which there is a reasonable likelihood of major differences in personal, social or religious values. This includes most, but not all, individual interventions for which signed informed consent is normally required. Examples of major invasive treatment may include, but are not limited to: most surgery, most invasive diagnostic and therapeutic procedures, interventions that carry substantial morbidity or mortality risk (such as cancer.
chemotherapy), or lower risk interventions that imply large decisions about overall treatment goals (dialysis, feeding gastrostomy, tracheostomy, etc.).

- Life-sustaining treatment – medical intervention without which there is reasonable medical expectation the patient will die within a brief time period.

- End-of-life treatment – medical interventions intended to provide comfort during the dying process. This includes comfort care, palliative care or hospice.

Unrepresented patient: An adult patient who lacks decisional capacity to give informed consent for medical treatment, does not have an applicable advance directive, and for whom there is no legally authorized surrogate decision maker, family, or friend available, competent and willing to assist with medical decision-making. Also referred to as “unbefriended patient”, “adult orphan”, and “patient without proxy”.

II. Scope of the Problem

The problem of unrepresented patients is increasing. Growing numbers of the elderly and/or chronically ill adults suffer from dementia and have abandoned or been abandoned by family, outlived family and friends, or have lost contact with their community. In addition, homeless persons and the mentally disabled may not have guardians, representation, or a stable community. Several studies have tried to estimate the current scope of the problem. In one study, 3-4% of nursing home residents were unrepresented (Pope, 2012, Part 1) and in another study more than 16% of patients admitted to intensive care units of hospitals were unrepresented (White, 2006). By 2030, it is estimated that more than 2 million adults over the age of 70 will have outlived all of their friends and family members (Weiss, 2012).

In the current legal system, there is a critical gap between clinical treatment that is authorized by the “emergency waiver” and other medical treatment that requires the appointment of a guardian by the courts. While the Probate Court’s public guardianship proposal seeks to eliminate the current time gap of 4-8 weeks, further issues remain. There are also knowledge gaps for guardians when they are called upon to act beyond their standard legal representational role. They must be capable of making difficult healthcare decisions regarding both clinical treatment and treatment setting. Yet, guardians

- are often unprepared or unwilling to make difficult health care decisions;
- may be unfamiliar with the special aspects of decision making in the medical context or of the patient’s values and wishes regarding health care;
- tend to have limited interactions with the medical team or with persons they represent (Bandy, 2010).

III. Risks and Problems for Unrepresented Patients:

Unrepresented patients, often called “unbefriended,” are vulnerable and often socially isolated. Some may be elderly persons who have outlived all of their friends and families, while others may be homeless or estranged from family or friends. Sometimes, friends or family are unable or unwilling to act as guardian (Bandy, 2010). Medical treatment and disposition decisions are
often paralyzed by this lack of a proxy decision maker. The medical care team often does not know the patient’s values, how he or she has lived life, or what he or she would prefer in the current circumstances.

As a result, unrepresented patients may suffer from either overtreatment or undertreatment. Prolonged life-supporting measures may be continued without a process to decide whether such interventions are in the “best interest” of the patient. Providers feel safer continuing treatment than withdrawing it. There are financial incentives to do more interventions, as well as legal fears if treatments are withdrawn. And there is often a bias towards the “status quo” of continuing those interventions that have been started. It has been estimated that patients without representation spend an average of 50% more time in intensive care units than those whose wishes are known. This difference is thought to be due to reluctance of physicians to revert to comfort care or stop treatments of marginal benefit without a representative of the patient with whom to share those difficult but important decisions (White, 2006).

Undertreatment is also a risk, since providers may hesitate to initiate new treatments without knowing the patient’s wishes or in the absence of a consenting party, and they may postpone surgeries or other more elective interventions until they become emergencies. Such delay can increase the risks of these interventions, prolong suffering and pain, as well as compromise the quality of care in an already vulnerable patient.

Unrepresented patients are also at risk from prolonged placements in settings that threaten their well-being and cause suffering. Delayed discharge from acute care hospitals increases the risk of hospital-acquired infections and complications. Institutionalization can jeopardize a person’s financial situation or long-term housing. Transfer to a less restrictive setting reduces suffering and encourages people to live the fullest life that they can, creating opportunities for social contact, experiencing the outdoors, and pursuing activities that make their life meaningful.

IV. The Need in Colorado:

The Colorado Collaborative for Unrepresented Patients came together because ethics committees in each of our hospitals are frequently asked to help healthcare providers when patients remain in acute care settings without acute medical needs or when they continue to receive disproportionately burdensome treatments because they are unrepresented and unable to make decisions. Here are a few actual stories of vulnerable patients caught in this limbo from different healthcare providers in the Denver metro area. A theme of these stories is that patients get stuck in a restrictive environment because they are unrepresented. As a result, they often suffer negative consequences from being in a medically inappropriate setting while awaiting authorization for transfer to a more suitable environment or a decision regarding the continuation of aggressive medical interventions.

- A 59-year-old man was admitted with stroke. He was long estranged from four siblings who were unwilling to be surrogate decision makers. Unable to speak, the patient could only nod, was unable move his right arm or leg and was deemed to lack decisional capacity. The providers were unclear whether they should treat him with long-term intubation and resuscitate him if his heart stopped.
• A man with developmental disabilities came into the emergency department with pneumonia. He lived in a group home and his parents, who were his guardians, had just recently passed away tragically in a car accident. There was no other designated guardian, and he had no siblings to help with medical decisions or to support him through the process of understanding the various medical procedures that might be needed.

• A 66-year-old man with chronic lung disease and alcoholism, but without DMC, presented with a hip infection and received emergent surgery and IV antibiotics under the “emergency exception.” No surrogate decision maker could be found, and the patient needed a supervised setting due to his confusion. It took five months for a guardian to be appointed, a condition necessary for transfer to a long-term care facility, and he remained in the acute care facility (hospital) throughout.

• An elderly patient with dementia from syphilis presented to an emergency department with a bloodstream infection. He was stabilized with six weeks of intravenous antibiotics; however, he remained in the hospital, pleasant but without insight or ability to care for himself, for two more months until a guardianship hearing occurred, a guardian was appointed, and he was transferred to a long-term care facility.

• A young woman sustained permanent brain damage from the rupture of a brain aneurysm. Her kidneys also failed as part of her medical catastrophe and she required kidney dialysis three times a week. Her family refused responsibility and would not authorize her treatment, due to legal concerns and post-stroke behavior that they could not control. She remained in an acute-care hospital for more than a year due to the inability to obtain a guardian because of the complexities of her medical, behavioral and social situation.

• An elderly man, who had not sought healthcare in over 20 years, collapsed with a bloodstream infection on his way to the grocery store. During his treatment in an acute care hospital, he was found to have dementia as well as a need for supervised treatment for tuberculosis. In addition, the healthcare team suspected he had bladder cancer. The patient’s family had not been in touch for several decades and refused to participate in health care decisions due to his past history of abusing them. The patient refused all evaluation or treatments, so he was kept in the acute care setting, without access to the outside environment, in order to receive supervised TB treatment that was mandated by public health officials. He eventually developed hospital-related infections and died in the hospital three months after admission, on the day his guardianship hearing was finally scheduled.

Colorado Revised Statutes have not established a clear and effective process for medical decision making when patients lack capacity and are unrepresented, yet these statutes impose serious restrictions on who may speak on behalf of such patient. In order to avoid a conflict of interest resulting from dual roles, health care facility personnel, physicians and social workers are prohibited by Colorado Statute to petition to be “interested parties” for patients [For example, see C.R.S. 15-14-310 regarding guardianship and prohibition of dual roles].

Figure 1 illustrates a typical process for medical decision making for an unrepresented patient who either does not have decisional capacity at the time of admission, or loses capacity
following admission, or whose preferences cannot be ascertained by health care facility staff. Social workers or case managers attempt to track down relatives or other interested parties, as required by the Colorado statutes (CRS 15-18.5-103), while the patient is treated appropriately for emergent conditions under the “emergency exception” provision while a surrogate is sought.

Protocols for the search for somebody to speak on behalf of an unrepresented patient without decisional capacity vary among hospitals, but include: searches in old medical records, evidence from prescriptions, names solicited from the patient’s primary physician, evidence from the patient’s personal effects, etc. The search process may continue for several days or weeks. If a surrogate cannot be located, a judicially appointed guardian is sought. While Colorado does have a statute allowing appointment of an “emergency guardian” (CRS 15-14-312), this process is not uniformly available when needed. Most adult guardianship petitions related to medical treatment entail a 4-6 week gap. In the interim, significant medical decisions may need to be made (e.g. more elective surgery, such as the placement of kidney dialysis catheters, feeding tubes or tracheostomies), and many of these decisions will not fall within the emergency waiver of consent, as interpreted by the current standard of care and community practice.

Given the high workload of case managers, the labor intensive nature of the search process, and the time required to establish a formal guardianship, patients often endure substantial delays in receiving medically beneficial elective treatments or discharge to a medically more appropriate environment. Critical decisions regarding highly invasive end-of-life treatments are also delayed, often resulting in potentially avoidable suffering and an unnecessarily prolonged dying process.

V. Alternatives – A Review of the Literature

Through most of history, physicians made choices about medical care and treatments for patients under the principles of acting in a patient’s best interest (beneficence) and the assumption that the physician “knows best” (paternalism). Recently, patients have asked for and received more independence in participating in decision-making. The federal 1991 Patient Self-Determination Act (42 USC §§1395cc, 1396a, 1994) promotes the use of advance directives to empower patients by placing them at the center of making decisions about what interventions they do or do not wish to have or who they wish to have represent them if they are incapacitated. Colorado’s medical decision-making law has an expanded list of potential proxy decision makers that includes friends as well as family as potential “interested parties,” which has been very helpful.

Unfortunately, when a patient is not able to speak for him/herself and has no surrogate to express his/her values or wishes, the legal framework for decision-making in medical situations is unclear. Currently, in most published studies, a large number of critical health care decisions fall to the medical treatment team alone because they lack the opportunity to consult with a representative of the patient. Such decisions encompass the full scope of treatments—from routine to life extending. (White, 2007; Bandy, 2010).

Across the country, there are five main processes by which spokespersons can be obtained:

1) Appointing legal guardians: private, volunteer or public to act as decision makers;
2) Authorizing attending physicians caring for individual patients to act as decision makers;
3) Authorizing other clinicians, individuals and entities within the healthcare setting to act as decision makers;
4) Empowering institutional committees, like the ethics committee of the institution, to act as decision makers;
5) Creating and/or empowering external state-authorized committees, beyond the institution, to act as decision makers (Pope, 2012, Part 2).

Table 1 lists various solutions that institutions, organization and states have set up to address this legal gap, as well as the pros and cons of the various solutions.

As noted previously, current statutes in Colorado prohibit any process that gives full decision-making authority to the clinician or health care organization, and the current guardianship process is often too lengthy and unwieldy. While there have been attempts in Colorado to create entities external to the health care institutions to assist in decision making (e.g. Guardianship Alliance and others), these entities have struggled to remain sustainable due to a lack of funding and infrastructure. With the creation of an Office of Public Guardianship comes the potential to create an alternative process that addresses these issues, as well as other barriers to appropriate decision making by guardians as noted in Section II. This alternative is the public healthcare guardian.

VI. Role and Responsibilities of a Public Healthcare Guardian

The role and responsibilities of a public healthcare guardian would be limited to making health care decisions. Clinical decision-making for a patient with impaired decisional capacity by a proxy decision-maker can involve decisions ranging from routine treatment or treatment placement, to major invasive treatment, to life sustaining treatment or end-of-life care. These decisions require working closely with health care providers and, in some cases, an ethics committee. Clinical decision-making differs from other types of proxy decisions that might be made by a court-appointed general guardian. The former are much narrower and include specific issues of timing, complexity, and the necessary clinical knowledge and skills.

Timing

The need for medical decisions can evolve rapidly. A delay of days or even hours in making a decision can result in gaps in appropriate treatment that may cause the patient significant and avoidable suffering or harm, either from delays in initiating treatment or appropriate transfer, or from extended periods of overly aggressive treatment.

Complexity

Decisions involving medical treatment or placement can involve challenging ethical considerations including assessing the potential benefits and harms of each course of action in light of likely clinical outcomes and what is known of the patient’s preferences and values. Such decisions may involve clinical uncertainty, conflicting viewpoints within the clinical care team, religious or cultural dimensions that require interpretation, and/or a lack of clarity regarding patient values and preferences. A public healthcare guardian must be able to understand and
objectively analyze treatment options and potential ethical conflicts with the assistance of health care providers and, if needed, members of the facility ethics committee in order to make decisions that reflect the best interests of the patient in light of the patient’s values and preferences to the extent they are known.

Knowledge, Skills and Abilities

In order to ensure the best possible representation for the patient, a public healthcare guardian must:

- Stay informed of the patient’s current medical condition and prognosis including requesting medical information, asking questions, and discussing treatment options
- Understand any prior advance medical directives the patient may have in place
- Be available to members of the care team by phone or in person to discuss the patient’s condition and treatment options and participate in scheduled care team meetings when requested
- Consult with anyone who might offer insight into the patient’s interests, goals, values and preferences.
- Coordinate medical decision-making with other decisions being made by a public guardian or other interested party acting on behalf of the patient.

In terms of knowledge, the public healthcare guardian ideally has:

- Basic medical knowledge adequate to understanding the clinical issues, asking questions and weighing alternatives.
- Basic working knowledge of the health care system with respect to appropriate care settings
- Familiarity with common bioethical issues, concepts and guidelines.

Healthcare guardianship requires the following skills and abilities:

- Gather relevant clinical, social, cultural, religious and other personal information appropriate to treatment and transfer decisions;
- Communicate effectively with health care providers, social workers, chaplains, ethics committee members and others involved in the patient’s care;
- Differentiate between types of medical advance directives and observe other legal constraints on proxy decision-making;
- Recognize and apply basic bioethical concepts when ethical issues arise;
- Set aside personal bias and preference, especially when dealing with conflicting cultural or religious values;
- Make difficult decisions including those involving end-of-life choices.

VII. Recommendations

The CCUP makes the following recommendations regarding medical decision-making for unrepresented patients.
1. Establish and fund the role of “public healthcare guardian”, as defined in Section I, granting persons in this role the explicit authority to make decisions regarding medical treatment options and appropriate setting choice for unrepresented patients.

2. Establish the required training and preparation needed to support the role and responsibilities of a healthcare guardian, as defined in Section VI, and develop a mechanism for ensuring that appointees meet the minimum requirements for the role.

3. Define a process by which a public healthcare guardian can be appointed by the court through the Office of Public Guardianship within 24 hours of a request by a healthcare provider.

4. Provide education to health care providers regarding the availability and process for requesting a public healthcare guardian on behalf of a patient.
Figure 1: CURRENT DECISION TREE ALGORITHM
MEDICAL DECISIONS FOR ADULTS IN COLORADO

Does the adult patient lack decisional capacity?

Yes
Is there a Patient Representative under a MDPOA or another document?

No
Are there advance directives applicable to this situation?*

Yes
Follow advance directives

No
Are there interested persons?

No
Is it an emergency?

Yes
Perform emergent interventions to save life or prevent severe disability

No
Petition for Guardianship

Determine consent

No
Inform/discuss Risks, Benefits and Alternatives

Yes
Discuss Risks, Benefits and Alternatives, and review in relation to any applicable advance directives

No
Inform/discuss Risks, Benefits and Alternatives

Yes
Follow advance directives

Determine consent**

**Would a reasonable person consent?

If Yes, then treat at minimum

* Types of Advanced Directives in Colorado:
MDPOA: C.R.S. §15-14-503 – 509
MOST Form: C.R.S. §15-18.7-101 et. seq.
Proxy Statute: C.R.S. §15-18.5-101 et. seq.
Guardianship (Incapacitated Person): C.R.S. §15-14-301 et. seq.
Guardianship (Minor): C.R.S. §15-14-201 et. seq.
Table 1: HOW TO MAKE DECISIONS FOR UNREPRESENTED PATIENTS: CURRENT SOLUTIONS

<table>
<thead>
<tr>
<th>TYPE OF AUTHORIZATION</th>
<th>EXAMPLES</th>
<th>PROS</th>
<th>CONS</th>
<th>COMMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>PRIVATE GUARDIANS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Colorado and most other state court laws</td>
<td>Comprehensive – includes property, finances, overall wellbeing</td>
<td>Slow speed, Cost, Competence, Availability</td>
<td>Leaves gap of 4-6 weeks minimum from “emergency exception”. Doesn’t allow for limited-scope or time-limited medical decisions</td>
</tr>
<tr>
<td></td>
<td>Denver Health Hospital Authority</td>
<td>Accelerated assignment of guardian by Probate Court</td>
<td>Need for court cooperation, staffing</td>
<td>Court Assigned Guardian: Affidavit prepared with SW, Petition for Guardianship prepared by hospital counsel.</td>
</tr>
<tr>
<td>PUBLIC GUARDIANS</td>
<td>Guardianship alliance (intermittently in Colorado, Indiana)</td>
<td>More agile, trained for medical decision making</td>
<td>Requires volunteers; requires sustained funding</td>
<td>Has not been sustainable in Colorado.</td>
</tr>
<tr>
<td></td>
<td>Morgan County Colorado; Australia, Ontario, Canada</td>
<td>Public funding and employees</td>
<td>From experience, underfunded, overburdened and understaffed. Requires licensing, training</td>
<td></td>
</tr>
<tr>
<td>ATTENDING PHYSICIANS</td>
<td>12 states: MO, SC, OR, CT; with concurrence: TN, TX, NC, AZ, NY, NJ, AL, GA</td>
<td>Medical expertise, speed of assistance</td>
<td>Perceived conflict of interest, concern about personal bias</td>
<td>Can be unilateral (6 states) or with second opinion via 2nd physician, institutional or external committee.</td>
</tr>
<tr>
<td></td>
<td>Veterans Administration Medical Center</td>
<td>Medical expertise, speed of assistance; separates into types of decisions</td>
<td></td>
<td>Routine: physician Major: physician + Chief of Service Life-sustaining: physician plus multidisciplinary committee serving as patient’s advocate</td>
</tr>
<tr>
<td></td>
<td>San Francisco General</td>
<td>Most knowledgeable about best medical interest of</td>
<td>Not authorized by State of California Statute</td>
<td>Attending, Ethics Committee encouraged</td>
</tr>
<tr>
<td>OTHER CLINICIANS, INDIVIDUALS AND ENTITIES</td>
<td>Florida: social worker</td>
<td>Medical expertise</td>
<td>“clinical social worker...selected by provider's bioethics committee and not employed by provider”</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>Texas: clergy</td>
<td>Surrogate outside of medical system</td>
<td>Unchurched persons excluded</td>
<td>Member of clergy &quot;surrogate of last resort” – required to know patient</td>
<td></td>
</tr>
<tr>
<td>Oregon: health care provider trained in bioethics</td>
<td>Appointment by hospital</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>INSTITUTIONAL COMMITTEE</td>
<td>AMA: Consult Ethics Committee</td>
<td>Avoids ad hoc decision-making; Committee protects against individual biases. More speedy response, more personalized.</td>
<td>Outside the consultant role for ethics committees</td>
<td>Safeguards often increase with more grave decisions. Sometimes ethics committee has informal advisory role.</td>
</tr>
<tr>
<td>Kaiser Permanente, Santa Clara (only), CA – multidisciplinary;</td>
<td>Timely and transparent; Procedure rather than outcome; consistent with community standards</td>
<td></td>
<td>Multidisciplinary subcommittee of ethics committee appointed by EC Chair, includes “non-medical” member, community member, patient’s community; consensus required for WH/WD</td>
<td></td>
</tr>
<tr>
<td>Santa Clara County Medical Association (California)</td>
<td>Process; presentation by physician, decision separate from treating team.</td>
<td></td>
<td>Ethics committee chair convenes 3+ subcommittee to review proposals and act as decision maker(one non-HC and not with organization)</td>
<td></td>
</tr>
<tr>
<td>EXTERNAL COMMITTEES</td>
<td>New York (and TX): Surrogate Decision Making Committee</td>
<td>Patient-centered; faster than courts</td>
<td>Mental disability patients without DMC only</td>
<td>Volunteer panel of 4 (medical, advocates for disability, attorney, individual with expertise)</td>
</tr>
<tr>
<td>IA: local substitute medical decision-making boards</td>
<td>All unrepresented patients</td>
<td></td>
<td>Have been hard to set up and sustain locally.</td>
<td></td>
</tr>
</tbody>
</table>

Based on the references found in the reference list.


Hyun I, et al. When patients do not have a proxy: a procedure for medical decision making when there is no one to speak for the patient. J Clin Ethics 2006; 17: 323-330.


Patient Self-Determination Act, 42 USC §§1395cc, 1396a (1994).


