**DEFAULT SURROGATE CONSENT STATUTES**

**as of June 2014**

**Explanation:** The descriptors in the chart are generalizations of statutory language and not quotations, so the statutes must be consulted for precise meaning. The default surrogacy statute language varies from state to state and the listed descriptors generally hold the following meanings:

- **Adult** includes any person who is 18 years of age or older, is the parent of the child, or has married;
- **Close friend (Adult friend)** is one who has maintained regular contact with the patient as to be familiar with the patient’s activities, health, and religious or moral beliefs.
- **Provisions in red** are those addressing patients with no qualified default surrogate (sometimes called the “unbefriended” patient).

**CAUTION:** The descriptions and limitations listed in this chart are broad characterizations for comparison purposes and not as precise quotations from legislative language.

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<th>State &amp; Citation</th>
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| **1. ALABAMA**   | Comprehensive Health Care Decisions Act | ▪ Spouse (unless legally separated/divorcing)  
▪ Adult child  
▪ Parent  
▪ Adult sibling  
▪ Nearest adult relative  
▪ Att. physician & ethics committee | Patient must be in terminal condition or permanently unconscious. Certification requirements. | Yes §22-8A-11(c) | Judicial recourse, §22-8a-11 |
| **2. ALASKA**    | Comprehensive Health Care Decisions Act | ▪ Individual orally designated by patient  
▪ Spouse  
▪ Adult child  
▪ Parent  
▪ Adult Sibling  
▪ Close friend | Patient has to be an adult  
N/A to withholding or withdrawing life-sustaining procedures UNLESS patient is in “terminal condition” or “permanent unconsciousness.” Certification requirements.  
Mental health treatment limitations and anatomical gift limitations, see A.S. §13.52.173 and §13.52.193  
Exceptional procedures (abortion, sterilization, psychosurgery, and/or removal of organs) limitations under A.S. §13.52.050. | Yes §13.52.030(g) | Majority rule for adult children, parents, or siblings; and if deadlock, then primary physician decides |
| **3. ARIZONA**   | Comprehensive Health Care Decisions Act | ▪ Spouse (unless legally separated)  
▪ Adult child (if multiple, health care provider will seek a majority opinion from those available)  
▪ Parent  
▪ Domestic partner, if unmarried  
▪ Sibling  
▪ Close friend  
▪ Att. physician in consult with ethics committee or, if none, 2nd physician | N/A to decisions to withdraw nutrition or hydration  
Mental health treatment limitations | Yes §36-3203(C) | Majority rule for adult children |
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<td>4. ARKANSAS</td>
<td>Comprehensive Health Care Decisions Act</td>
<td>A surrogate is designated by the health care provider in the following order of preference conditional on the surrogate being an adult who: (i) has exhibited special care and concern for the principal; (ii) is familiar with the principal’s personal values; (iii) is reasonably available; and (iv) is willing to serve.  - An adult designated orally or in writing  - Spouse (unless legally separated)  - Adult child  - Parent  - Adult sibling  - Adult relative  - Att. Physician in consult with ethics committee or 2nd physician</td>
<td>Certification requirements for withdrawing or withholding of artificial nutrition or hydration A.C.A. §20-6-106</td>
<td>Yes, §20-6-106</td>
<td>Judicial recourse, §20-6-115</td>
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<td>5. CALIFORNIA</td>
<td>Comprehensive Health Care Decisions Act</td>
<td>An individual designated as surrogate. (orally or written)  Note: The surrogate has priority over a concurrently appointed health care agent during the period the surrogate designation is in effect.</td>
<td>Effective &quot;only during the course of treatment or illness or during the stay in the health care institution when the designation is made, or for 60 days, whichever period is shorter.&quot;  N/A to civil commitment, electro-convulsive therapy, psychosurgery, sterilization, and abortion.</td>
<td>Yes</td>
<td>N/A since designated surrogate is presumably one person</td>
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<td>Specialized provision applicable only to medical research</td>
<td>Spouse  Domestic partner  Adult child  Custodial parent  Adult sibling  Adult grandchild  Adult relative with the closest degree of kinship  Note: Different rules apply to emergency room experimental consent  - Next of kin:  - The attending physician and surgeon in accordance with an interdisciplinary team review</td>
<td>Consent restricted to medical experiments that relate to the cognitive impairment, lack of capacity, or serious, or life threatening diseases and conditions of research participants.  This provision N/A to persons involuntarily committed or voluntarily committed by a conservator under the Welfare &amp; Institutions Code</td>
<td>Yes §24178(g)</td>
<td>Consensus required</td>
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<td>Specialized provision applicable only to nursing homes</td>
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<td>Applies when &quot;the attending physician and surgeon of a resident in a skilled nursing facility or intermediate care facility prescribes or orders a medical intervention that requires informed consent&quot;</td>
<td></td>
<td>Not addressed</td>
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<td>6. COLORADO</td>
<td>Comprehensive Health Care Decisions Act</td>
<td>The following &quot;interested persons&quot; must decide who among them shall be surrogate decision-maker:  - Spouse  - Parent  - Adult child  - Sibling  - Adult Grandchild  - Close friend</td>
<td>Certification requirements for withdrawing or withholding artificial nutrition and hydration, §15-18.5-103</td>
<td>Yes, §15-18.5-103(4)(a)</td>
<td>Consensus required on selection of the surrogate. If lack of consensus, judicial recourse (guardianship) §15-18.5-103</td>
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<td>7. CONNECTICUT</td>
<td>Part of Public health chapter on &quot;Removal of Life Support Systems&quot;</td>
<td>Physician, in consultation with next of kin in the following priority: (A) The spouse of the patient; (B) an adult son or daughter of the patient; (C) either parent of the patient; (D) an adult brother or sister of the patient; and (E) a grandparent of the patient (§19a-570) Oral communications re: withholding life support by patient made part of medical record per §19a-570</td>
<td>Limited to the removal or withholding of life support systems, and patient is in terminal condition or permanently unconscious</td>
<td>Yes §19a-571(a)</td>
<td>Judicial recourse, §19a-580c</td>
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<td>8. DELAWARE</td>
<td>Comprehensive Health Care Decisions Act</td>
<td>• An individual orally designated as surrogate • Spouse, unless petition for divorce • Adult child • Parent • Adult sibling • Adult grandchild • Adult niece or nephew • Adult aunt or uncle • Close friend NOTE: Surrogate is disqualified if protective order against the individual is filed or in existence.</td>
<td>Adult patient must be in terminal condition or permanently unconscious, documented in writing with its nature and cause Pregnancy limitation under §19a-574</td>
<td>Yes 16 Del.Code. §2507(b)(6)</td>
<td>If in a health care institution, refer to “appropriate committee” for a recommendation. Judicial recourse, §16 Del. Code §2511</td>
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<td>9. DISTRICT OF COLUMBIA</td>
<td>Durable Power of Attorney for Health Care Act</td>
<td>• Spouse or domestic partner • Adult child • Parent • Adult Sibling • Religious superior if in religious order or a diocesan priest • Close friend* • Nearest living relative * Close friend may not be an individual or facility provider</td>
<td>Incapacity certified in accordance with DC Code §21-2204 N/A to abortion, sterilization, or psycho-surgery, convulsive therapy or behavior modification programs involving aversive stimuli are excluded At least 1 witness must be present whenever surrogate grants, refuses or withdraws consent on behalf of the patient.</td>
<td>Yes 21-2210(b)</td>
<td>Yes DC Code §21-2210 (e)-(f), legal standing to challenge higher priority standard and rebuttable presumption established</td>
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<td>10. FLORIDA</td>
<td>Comprehensive Health Care Decisions Act</td>
<td>• Spouse • Adult child or majority of adult children if more than one • Parent • Adult Sibling or majority of adult siblings if more than one• Close adult relative • Close friend • Licensed clinical social worker selected by bioethics committee, and if decision is to forgo life-prolonging procedures, must be reviewed by bioethics committee.</td>
<td>N/A to abortion, sterilization, electroshock therapy, psychosurgery, experimental treatment not approved by IRB, or voluntary admission to a mental health facility. Pregnancy limitation, §765.113</td>
<td>Yes §765.401(2) and (3)</td>
<td>Majority rule for adult children or siblings. Judicial recourse not addressed.</td>
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| **11. GEORGIA**  | Informed Consent Statute | • Spouse; or any parent, adult or minor of minor child  
• Person standing in loco parentis for minor child or ward  
• Adult child  
• Parent  
• Adult sibling  
• Grandparent  
• Adult first degree relation (niece, nephew, aunt, or uncle)  
• Close friend | Can consent to any surgical or medical treatment procedures not prohibited by law upon physician advice  
Not explicitly applicable to refusals of treatment, but nevertheless should be applicable. | Yes §31-9-2(b) | None provided |
| **12. HAWAII**   | DNR Statute             | • Spouse  
• Guardian (comes after spouse)  
• Adult Child  
• Parent  
• Sibling  
• Physician w/ concurrence of 2nd physician and ethics committee (31-39-4(c)) | Applies only to consent to DNR orders  
Limitation when disagreement between parents of minor child – hospital cannot enter DNR order if parents disagree | Yes §31-39-4(c) | None provided |
|                  | Specialized provision applicable to Temporary Health Care Placement | • Spouse  
• Adult Child  
• Parent  
• Sibling  
• Grandparent  
• Adult grandchild  
• Aunt or Uncle  
• Nephew or Niece | Applies only to decisions regarding admission to or discharge from one health care facility or placement, or transfer to another health care facility or placement.  
Excludes involuntary placement for mental illness (governed by Title 37) | Yes 31-36A-6(b) | None provided |
|                  | Comprehensive Health Care Decisions Act | • An individual orally designated as surrogate  
If none, the following "interested persons" must decide who among them shall be surrogate decision-maker:  
• Spouse (unless separated or estranged)  
• Reciprocal beneficiary  
• Adult child  
• Parent  
• Adult Sibling  
• Adult Grandchild  
• Close friend | None for orally designated surrogate, but an “interested person” may make a decision to withhold or withdraw nutrition and hydration only if two physicians certify that providing it will merely prolong the act of dying and the patient is highly unlikely to have any neurological response in the future. | Yes §327E-5(g) | Consensus required on the selection of the surrogate. If lack of consensus, judicial recourse (guardianship), §327E-5(d) |
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| 13. IDAHO       | Comprehensive Health Care Decisions Act | • Spouse  
• Adult child  
• Parent  
• Person named in a delegation of parental authority executed pursuant to § 15-5-104  
• A relative representing self as appropriate, responsible person  
• Other individual representing self to be responsible for the person’s health care  
• In a medical emergency, attending physician or dentist may authorize and/or provide such care, treatment or procedure as he or she deems appropriate, and all persons, agencies and institutions thereafter furnishing the same, including such physician or dentist, may proceed as if informed, valid consent therefor had been otherwise duly given. | None listed | Indirect in statement of policy: “Any authentic expression of a person's wishes with respect to health care should be honored.” ICS 39-4509(3) | None provided |
| 14. ILLINOIS    | Health Care Surrogate Act | • Spouse  
• Adult child  
• Parent  
• Adult Sibling  
• Adult grandchild  
• Close friend | N/A to admission to mental health facility, psychotropic medication or electro-convulsive therapy (see 5/2-102; 5/3-601.2, amended 1997)  
If decision concerns forgoing life-sustaining treatment, patient must be in terminal condition, permanently unconscious, or incurable or irreversible condition. | Yes §40/20(b) | Majority rule for children, siblings and grandchildren.  
Judicial recourse (guardianship), § 40/25(d) |
| 15. INDIANA     | Health Care Agency (durable power) and Surrogate Consent Act | Any of the following:  
• Spouse  
• Parent  
• Adult child  
• Adult Sibling  
• Religious superior if the individual is a member of a religious order | None listed | Yes § 16-36-1-5(d) | Judicial recourse not addressed |
| 16. IOWA        | Living Will Statute | • Spouse  
• Adult child  
• Parent or parents  
• Adult sibling | Limited to the withholding or withdrawal of life-sustaining procedures, and patient is in terminal condition or comatose  
A witness must “be present at the time of the consultation when that decision is made.”  
Pregnancy limitation, §144A.7(3) | Yes §144A.7(1) | Majority rule for adult children  
Judicial recourse not addressed |
| 17. KANSAS      | Specialized provision, applicable only to consent to medical research | • Spouse, unless legally separated  
• Adult child  
• Parent  
• A relative  
Note: Authority of guardian or agent with authority to make health care decisions is specifically acknowledged. | Consent is restricted to research protocols that have been approved by an institutional review board.  
Cannot consent if contrary to the incapacitated person's permission, expressed orally or in writing | No | None provided |
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<td><strong>18. KENTUCKY</strong></td>
<td>Comprehensive Health Care Decisions Act</td>
<td>• Spouse • Adult child • Parents • Nearest adult relative</td>
<td>N/A to withholding or withdrawal artificial nutrition and hydration unless specified conditions are met</td>
<td>Yes §311.631(3)</td>
<td>Majority rule for adult children and nearest relative Judicial recourse not addressed</td>
</tr>
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<td><strong>19. LOUISIANA</strong></td>
<td>Living Will Statute</td>
<td>• Spouse, if not judicially separated • Adult child • Parents • Sibling • Other ascendants or descendants (direct blood line relatives)</td>
<td>Limited to executing a LW (“Declaration”) for patient in terminal and irreversible condition or comatose</td>
<td>No</td>
<td>Consensus required Judicial recourse not addressed</td>
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<td><strong>20. MAINE</strong></td>
<td>Comprehensive Health Care Decisions Act</td>
<td>• Spouse, unless legally separated • Adult in spouse-like relationship • Adult child • Parent • Adult sibling • Adult grandchild • Adult niece or nephew • Adult aunt or uncle • Adult relative familiar with patient's values • Close friend</td>
<td>If decision pertains to withdrawal or withholding of life-sustaining treatment, patient must be in terminal condition or persistent vegetative state under §5-805(a) N/A to denial of surgery, procedures, or other interventions that are deemed medically necessary Admission to mental health institution</td>
<td>Yes §5-805(f)</td>
<td>Majority rule if more than one member of any class assumes authority Provider may refer them “to a neutral 3rd party for assistance in resolving the dispute”</td>
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<td><strong>21. MARYLAND</strong></td>
<td>Comprehensive Health Care Decisions Act</td>
<td>• Spouse or Domestic Partner • Adult child • Parent • Adult sibling • Close friend or relative who has maintained regular contact with the patient</td>
<td>N/A to sterilization or treatment for mental disorder Applicable to life-sustaining procedure only if the patient as been certified to be in a terminal condition, persistent vegetative state, or end-stage condition</td>
<td>Yes §5-605(c)</td>
<td>If in hospital or nursing home, refer to ethics committee If elsewhere, consensus required</td>
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<td><strong>22. MASSACHUSETTS</strong></td>
<td>None</td>
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<td><strong>23. MICHIGAN</strong></td>
<td>Health Care disclosure and consent act.</td>
<td>“a member of the immediate family, the next of kin, or the guardian” (priority not specified)</td>
<td>Applies when patient has a “reduced life expectancy due to advanced illness”</td>
<td>No</td>
<td>Judicial recourse not addressed</td>
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<td><strong>24. MINNESOTA</strong></td>
<td>None</td>
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| 25. MISSISSIPPI | Comprehensive Health Care Decisions Act | • Individual orally designated by patient  
• Spouse, unless legally separated  
• Adult child  
• Parent  
• Adult sibling  
• Close friend  
• Owner, operator, or employee of residential long-term care institution (but see limitations in next column) | Admission to mental health institution.  
If surrogate is owner, operator, or employee of residential long-term care institution, then the authority does not extend to decisions to withhold or discontinue life support, nutrition, hydration, or other treatment, care, or support. §41-41-215(9) | Yes §41-41-211(6) | Majority rule if more than one member of any class assumes authority  
Judicial recourse not addressed |
| 26. MISSOURI | None | | | | |
| 27. MONTANA | Living Will Statute | • Spouse  
• Adult child  
• Parents  
• Adult sibling  
• Nearest adult relative | Limited to withholding or withdrawal of life-sustaining treatment, and patient is in terminal condition  
Pregnancy limitation, §50-9-106(7) | Yes §50-9-106(4) | Majority rule for adult children and siblings  
Judicial recourse not addressed |
| 28. NEBRASKA | None | | | | |
| 29. NEVADA | Living Will Statute | • Spouse  
• Adult child  
• Parents  
• Adult sibling  
• Nearest adult relative | Limited to withholding or withdrawal of life-sustaining treatment, and patient is in terminal condition  
Pregnancy limitation, §449.626(6) | Yes §§449.626(4) | Majority rule for adult children and sibling  
Judicial recourse not addressed |
| 30. NEW HAMPSHIRE | None | | | | |
| 31. NEW JERSEY | Specialized provision applicable only to medical research | • Spouse or civil union partner  
• Adult child  
• Custodial parent  
• Adult sibling  
• Nearest adult relative | Limited to medical research approved and monitored by an institutional review board, plus certain benefit/risk criteria must be met. | Yes NJ St.§ 26:14-5(d) plus procedural requirements for informed consent | Consensus required  
Judicial recourse not addressed |
| 32. NEW MEXICO | Comprehensive Health Care Decisions Act | • An individual designated as surrogate  
• Spouse  
• Individual in long-term spouse-like relationship  
• Adult child  
• Parent  
• Adult sibling  
• Grandparent  
• Close friend | Admission to mental health facility §24-7A-13(E) | Yes §24-7A-5(F) | Majority rule if more than one member of any class assumes authority  
Judicial recourse. §24-7A-14 |
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<td><strong>33. NEW YORK</strong></td>
<td>N.Y. Family Health Care Decisions Act §§2994-A to -U (McKinney 2014) Specifically, see §2994- D</td>
<td>Specialized Surrogate Consent Statute (applicable to health care provided in a hospital and nursing homes) • Spouse or Domestic Partner • Adult child • Parent • Adult sibling • Close friend • Attending Physician for routine medical treatment or, for major medical treatment, the attending physician must make a recommendation to the hospital for the treatment and have at least one other physician designated by the hospital to independently concur</td>
<td>Even if the patient lacks capacity, a patient’s objection to the surrogate’s decision will prevail unless a court of competent jurisdiction determines the patient is incompetent for all purposes, not just for health care decisions. Decisions to withhold or withdraw life-sustaining treatment for a patient shall be authorized only if certain conditions are met and the attending physician or hospital consents with the decision.</td>
<td>Yes 2994-d(4) and §2994-d(5)</td>
<td>Judicial recourse (guardianship), § 2994-R</td>
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<tr>
<td>N.Y. Pub. Health Law §§2960 to 2979 (McKinney 2014) Specifically, see §§2965 &amp; 2966</td>
<td>Specialized Surrogate Consent Statute (applicable only to DNR orders) • Spouse or domestic partner • Adult child • Parent • Adult sibling • Close friend • Physician, with concurrence by a qualified second physician who personally examines patient that resuscitation is medically futile.</td>
<td>Limited to consent to a DNR order, and patient is in terminal condition, or permanently unconscious, or where resuscitation is futile or extraordinarily burdensome</td>
<td>Yes §2965(3)(a)</td>
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<td><strong>34. NORTH CAROLINA</strong></td>
<td>N.C. Gen. Stat. §90-320 to -328 (2014) Specifically, see §90-322</td>
<td>Living Will Statute • Spouse • Parents • Adult Child • Siblings • Close friend • Att. physician</td>
<td>Limited to the withholding or withdrawal of life-prolonging measures where the patient is terminal or permanently unconscious.</td>
<td>No</td>
<td>Majority rule for parents, adult children &amp; siblings Judicial recourse not addressed</td>
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<td><strong>35. NORTH DAKOTA</strong></td>
<td>N.D. Cent. Code §23-12-01 to -19 (2014) Specifically, see §23-12-13</td>
<td>Informed Consent Statute • Spouse who has maintained significant contacts with incapacitated person • Adult children who have maintained significant contacts with incapacitated person • Parents, including stepparent who has maintained significant contacts with incapacitated person • Adult siblings who have maintained significant contacts with incapacitated person • Grandparents who have maintained significant contacts with incapacitated person • Adult grandchildren who have maintained significant contacts with incapacitated person • Close adult relative or friend who have maintained significant contacts with incapacitated person</td>
<td>Not explicitly applicable to refusals of treatment, but nevertheless should be applicable. A determination of incapacity, over the patient’s objections, can be determined in a court hearing pursuant to chapter 30.1-28. N/A to sterilization, abortion, psychosurgery, and admission to a state mental facility for &gt; 45 days</td>
<td>Yes §23-12-13(3)</td>
<td>None provided</td>
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<td><strong>36. OHIO</strong></td>
<td>Living Will Statute</td>
<td>• Spouse • Adult child • Parents • Adult sibling • Nearest adult relative</td>
<td>Limited to consent for withdrawal or withholding of life-sustaining treatment, and patient has been in terminal condition or permanently unconscious for at least 12 months. Nutrition and hydration may be withheld only upon the issuance of an order of the probate court. Pregnancy limitation, §2133.08(G)</td>
<td>Yes §2133.08(D)(3)</td>
<td>Majority rule for adult children and siblings Judicial recourse not addressed</td>
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<td>Ohio Rev. Code Ann. §2133.01 to .16 (West 2014) Specifically, see §2133.8</td>
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<td><strong>37. OKLAHOMA</strong></td>
<td>Specialized provision applicable only to medical research</td>
<td>• Spouse • Adult child • Parent • Adult sibling • Relative by blood or marriage</td>
<td>Limited to experimental treatment, test or drug approved by a local institutional review board.</td>
<td>Yes §3101.16</td>
<td>Judicial recourse not addressed</td>
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<td>Okla. Stat. Ann. tit. 63 §3101 to 3102.3A (West 2014) Specifically, see §3102A</td>
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<td><strong>38. OREGON</strong></td>
<td>Comprehensive Health Care Decisions Act</td>
<td>• Spouse • Adult designated by others on this list, without objection by anyone on list • Adult child • Parent • Sibling • Adult relative or adult friend • Att. physician</td>
<td>Limited to withdrawal or withholding of life-sustaining procedures for a patient in a terminal condition or permanently unconscious, or who meets other conditions related to pain or advanced progressive illness. Principal’s parent or former guardian’s priority status to withhold or withdraw life-sustaining procedures may be withheld if a court has taken the principal out of their custody permanently or terminated the parental rights.</td>
<td>Yes §127.535(4) &amp; 127.535(6)</td>
<td>Majority rule for adult children and siblings Judicial recourse not addressed</td>
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<td>Or. Rev. Stat. §127.505 to .660 (2014) Specifically, see §127.635, §127.505(13) and 127.535(4)</td>
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<td><strong>39. PENNSYLVANIA</strong></td>
<td>Comprehensive Health Care Decisions Act</td>
<td>• Spouse • Adult designated by others on this list, without objection by anyone on list • Adult child • Parent • Adult sibling • Adult grandchild • Close friend • Att. physician</td>
<td>Pregnancy limitation, Pa. Stat. Ann. tit. 20, §5429 Surrogate health care decision maker may not execute an advance health care directive or name a health care agent on behalf of an incompetent individual.</td>
<td>Yes Tit. 20, §§5456 &amp; 5461</td>
<td>Majority rule if more than one member of any class assumes authority Judicial recourse not addressed</td>
</tr>
<tr>
<td><strong>40. RHODE ISLAND</strong></td>
<td>None</td>
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<tr>
<td>State &amp; Citation</td>
<td>General Type of Statute</td>
<td>Priority of Surrogates (in absence of an appointed agent or guardian with health powers)</td>
<td>Limitations on Types of Decisions</td>
<td>Provides Standard for Decision-Making</td>
<td>Disagreement Process Among Equal Priority Surrogates</td>
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<td><strong>41. SOUTH CAROLINA</strong>&lt;br&gt;S.C. Code Ann. §44-66-10 to -80 (2014)&lt;br&gt;Specifically, see §44-66-30</td>
<td>Separate Surrogate Consent Act</td>
<td>• Person given priority to make health-care decisions for the patient by another statute&lt;br&gt;• Spouse, unless separated or divorced&lt;br&gt;• Parent or adult child&lt;br&gt;• Adult sibling, grandparent, or adult grandchild&lt;br&gt;• Other close relative&lt;br&gt;• Person given authority to make health-care decisions for the patient by another statutory provision</td>
<td>N/A if patient's inability to consent is temporary and delay of treatment will not result in significant detriment to the patient's health</td>
<td>Yes&lt;br&gt;§44-66-30(F)</td>
<td>Consensus required&lt;br&gt;Judicial recourse. Specifically, see §44-66-30(D)</td>
</tr>
<tr>
<td><strong>42. SOUTH DAKOTA</strong>&lt;br&gt;S.D. Codified Laws §34-12C-1 to -8 (2014)&lt;br&gt;Specifically, see §34-12C-3</td>
<td>Separate Surrogate Consent Act</td>
<td>• Spouse&lt;br&gt;• Adult child&lt;br&gt;• Parent&lt;br&gt;• Adult sibling&lt;br&gt;• Grandparent or adult grandchild&lt;br&gt;• Aunt or uncle or adult niece or nephew&lt;br&gt;• Adult cousin&lt;br&gt;• Close friend (An authorized surrogate may delegate authority to another person in same or succeeding class)</td>
<td>None listed</td>
<td>Yes&lt;br&gt;§34-12C-3</td>
<td>Consensus required&lt;br&gt;Judicial recourse not addressed</td>
</tr>
<tr>
<td><strong>43. TENNESSEE</strong>&lt;br&gt;Tenn. Code Ann §68-11-1801 to -1815 (2014)&lt;br&gt;Specifically, see §68-11-1806</td>
<td>Comprehensive Health Care Decisions Act</td>
<td>Supervising health care provider selects from the following order of preference under criteria provided:&lt;br&gt;• Individual designated by patient&lt;br&gt;• Spouse&lt;br&gt;• Adult child&lt;br&gt;• Parent&lt;br&gt;• Adult sibling&lt;br&gt;• Other adult relative&lt;br&gt;• Close friend&lt;br&gt;• Primary Physician, in consultation with ethics committee or independent 2nd physician&lt;br&gt;Disqualified surrogates:&lt;br&gt;• Indiv. Provider&lt;br&gt;• Facility Provider&lt;br&gt;• Person who is the subject of a protective order that directs the person to avoid contact with the patient&lt;br&gt;• Any matter governed by the mental health code.</td>
<td>Except for individual designated by the patient, other surrogates cannot make decision to w/h or w/d artificial nutrition &amp; hydration without certification by 2 physicians of medical prerequisites.</td>
<td>Yes&lt;br&gt;§68-11-1806(d)</td>
<td>Provider selects surrogate using criteria provided under §68-11-1806(c)(4)</td>
</tr>
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<td><strong>44. TEXAS</strong>&lt;br&gt;Tex. [Health &amp; Safety] Code Ann. §166.031 to .053 (Vernon 2013)&lt;br&gt;Specifically, see §166.039</td>
<td>Comprehensive Health Care Decisions Act</td>
<td>Physician and:&lt;br&gt;• Spouse&lt;br&gt;• Adult children&lt;br&gt;• Parents&lt;br&gt;• Nearest relative&lt;br&gt;• Att. Physician, with concurrence of independent 2nd physician or physician member of ethics committee</td>
<td>Pregnancy limitation, §166.049</td>
<td>Yes&lt;br&gt;§166.039(c)</td>
<td>Judicial recourse (guardianship), §166.039(g)</td>
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<tr>
<td>State &amp; Citation</td>
<td>General Type of Statute</td>
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<tr>
<td>Tex. [Health &amp; Safety] Code Ann. §166.081 to .101 (Vernon 2013) Specifically, see §166.088(b)</td>
<td>Specialized provision (applicable to DNR orders)</td>
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<td>Tex. [Health &amp; Safety] Code Ann. §313.001 to .008 (Vernon 2013) Specifically, see 313.004</td>
<td>Specialized provision applicable to patients in home &amp; community support services or in a hospital or nursing home</td>
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<td>45. UTAH</td>
<td>Comprehensive Health Care Decisions Act</td>
<td></td>
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<tr>
<td>Utah Code Ann. §75-2a-101 to -125 (2013) Specifically, see §75-2a-108</td>
<td>Spouse</td>
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<td>46. VERMONT</td>
<td>None</td>
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<td>47. VIRGINIA</td>
<td>Comprehensive Health Care Decisions Act</td>
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<tr>
<td>Va. Code §54.1-2981 to -2993 (West 2013) Specifically, see §54.1-2986</td>
<td>Spouse</td>
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<td>48. WASHINGTON</td>
<td>Informed Consent Statute</td>
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<td>Wash. Rev. Code Ann. §7.70.010 to .160 (West 2014) Specifically, see §7.70.065</td>
<td>Spouse or registered domestic partner</td>
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<td>Priority of Surrogates (in absence of an appointed agent or guardian with health powers)</td>
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<tr>
<td>Spouse</td>
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<td>Adult child</td>
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<td>Parent</td>
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<td>Adult sibling</td>
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<td>Adult grandchild</td>
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<td>Grandparent</td>
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<td>Close friend</td>
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<td>Surrogate may not admit the adult to a licensed health care facility for long-term custodial placement other than for assessment, rehabilitative, or respite care over the objection of the adult</td>
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<td>Pregnancy limitation, §75-2a-123</td>
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<td>Provides Standard for Decision-Making</td>
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<td>Pregnancy limitation, §166.098</td>
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<td>Yes §166.088(c)</td>
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<td>Judicial recourse (guardianship), §166.039(g)</td>
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<td>Yes §313.004(c)</td>
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<td>Consensus, in the case of adult children surrogates</td>
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<tr>
<td>Judicial recourse, §313.004(b)</td>
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<td>Yes §75-2a-110(1)</td>
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<td>Majority rule inside the highest available priority level.</td>
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<td>Judicial recourse, §75-2a-120</td>
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<tr>
<td>Yes §54.1-2986(A)(7)</td>
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<tr>
<td>Majority rule</td>
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<td>Not explicitly applicable to refusals of treatment, but nevertheless should be applicable.</td>
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<td>Yes §7.70.065(1)(b) and (c)</td>
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<tr>
<td>Consensus required</td>
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</table>
| 49. WEST VIRGINIA | Comprehensive Health Care Decisions Act | Att. Physician or Advanced Nurse Practitioner selects from the following order of preference under criteria provided:  
• Spouse  
• Adult child  
• Parents  
• Adult sibling  
• Adult grandchild  
• Close friend  
• Any other person or entity according to DHHR rules | None listed | Yes §16-30-8(b)(1)(A), -9 and -5(d) | Not applicable since provider selects surrogate. |
| 50. WISCONSIN | Specialized Surrogate Consent Statute applicable to certain facility admissions | • Spouse  
• Adult child  
• Parent  
• Adult sibling  
• Grandparent  
• Adult grandchild  
• Close friend | Limited to consent to admission to nursing home and certain community-based residential facilities for up to 60 days, with 30 day extension possible, and only if:  
1. The incapacitated person is not diagnosed as developmentally disabled or having a mental illness at time of admission  
2. Petitions for guardianship and protective placement are filed prior to admission | No | Consensus required |
| 51. WYOMING | Comprehensive Health Care Decisions Act | • Individual designated by personally informing the supervising health care provider  
• Spouse, unless legally separated  
• Adult child  
• Parent  
• Grandparent  
• Adult sibling  
• Adult grandchild  
• Close friend | None listed | Yes §35-22-406(f) | Majority rule if more than one member of any class assumes authority  
Judicial recourse, §35-22-415 |
| UNIFORM HEALTH-CARE DECISIONS ACT | Comprehensive Health Care Decisions Act | • Individual orally designated by patient  
• Spouse  
• Adult child  
• Parent  
• Sibling  
• Close friend | None listed | Yes §5(f) | Majority rule if more than one member of any class assumes authority |

**CAUTION:** The descriptions and limitations listed in this chart are broad characterizations for comparison purposes and not as precise quotations from legislative language.

**Provisions in red** are those addressing patients with no qualified default surrogate (the “unbefriended” patient)

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The ABA acknowledges Thomson Reuters Westlaw for providing access to on-line legal research.
MEDICAL DECISION MAKING FOR PATIENTS LACKING AN ADEQUATE SURROGATE

EXECUTIVE SUMMARY

When patients with limited or no decisional capacity lack a surrogate and need to make a significant medical decision, caregivers should consider calling for an ethics consultation in addition to seeking opinions from Partners Office of General Counsel or BWH Risk Management as an alternative to seeking a court appointed guardian. The goal of the consultation process is to reach consensus about the most appropriate course of action. The chosen course should be made based on an estimate of what the patient would be likely to choose based on evidence concerning his or her values from among the medically available options.

BACKGROUND

Over the past three decades, medical decision-making has become progressively more patient-centered. As a result, it is now standard practice to involve patients thoroughly in their treatment decisions. Many medical decisions have a strong qualitative or subjective component so that equally informed patients make different choices based on their personal values. However, a patient’s decisional capacity may be limited by decline in cognitive function (e.g. Alzheimer’s disease) or by the circumstances of serious illness (e.g. delirium). In these instances it becomes necessary to rely on a surrogate decision maker for a substituted judgment.¹ (see VIII-13, Policy on Patients with Limited Decision Making Capacity).

With the advent of advance directives such as the Massachusetts Health Care Proxy, patients can identify and document a person to act as their health care agent in the event the patient loses decisional capacity. In those circumstances, the agent has the same legal authority as the patient with respect to health care decisions. In the absence of a Health Care Proxy, the patient’s next of kin serves as a surrogate. It is standard medical practice to counsel the health care agent or surrogate to make a decision based on what he or she believes the patient would choose because it is knowledge of the patient and his or her preferences which gives the agent or surrogate the moral and legal authority to decide on the patient’s behalf.

When there is no clearly identified surrogate, this approach to patient-centered decision making will not work. Another valid legal and ethical standard for medical decision making is based on what is in the patient’s best interest from a purely objective, medical perspective (e.g. gives the best chance of survival, the least pain and suffering, and what most people would choose in such a circumstance). Combining this knowledge with any available information about the patient “as a person” is the ideal way to make a patient-centered decision when there is no surrogate. The following process, implemented by an ethics consultation, is designed to gain such a perspective.

PROCESS

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¹ Surrogate is a general term meaning “substitute”. In this setting it refers either to someone designated by a health care proxy document or the next of kin. Only surrogates can make a substituted judgment. When there is no surrogate medical decisions should be based on the patient’s “best interest”. This policy describes the elements of a “best interest” decision that incorporates specific details concerning an individual patient.
1. Thorough investigation of the patient's background should be undertaken. Living arrangements, friends, community involvement, religious affiliation, prior health care decisions and discussion with previous care providers gives a sense of the patient's life story and medical priorities. The patient's primary care physician should always be contacted in this regard.

2. The patient's current response to his/her illness and treatment should be assessed: freedom from pain, outlook, and satisfaction with treatment already initiated.

3. Statements the patient previously made regarding medical treatments should be taken into account, especially concerning interventions that are relevant to the patient's current situation (e.g., ventilators, nursing homes, feeding tubes, ostomies, etc.)

4. All available treatment options should be considered. These can be offered by any current caregivers: attending physicians, consultants, house staff, nurses, social workers, etc.

The goal of this process is to reach a synthetic (as opposed to a substituted) judgment of what the patient would probably choose or want. This should not represent the judgment of a single caregiver but should be a consensus of what a group of people from multiple disciplines directly connected with the patient's care believe that the patient would be likely to choose. If, following this process, there is no consensus on a care plan and the options include invasive treatment or withholding life-sustaining treatment, consultation with the Office of General Counsel is necessary to determine whether a court-appointed guardian should be obtained.

SPECIAL SURROGATE CATEGORIES

1. Limited Surrogate. In this circumstance there is no legal representative (assigned healthcare agent, next of kin or legal guardian) but there are friends, neighbors, or more distant relatives who no longer play an active role in the patient's life but want to be helpful. These people can provide useful information about the patient's beliefs and values and their information may assist caregivers in thinking about what the patient would choose. Input from limited surrogates should be integrated with medical information concerning prognosis, treatment options and likely outcomes.

2. Impaired Surrogate. Family members are in a position to play a role in medical decision making but they may be unable or unwilling to fully participate. Alternatively, they may be impaired by virtue of physical distance, emotional or psychological incapacity or evidence that the patient would not want them as a surrogate. When this is the case, the caregivers should attempt to integrate relevant information provided by the impaired surrogate, but must ultimately make decisions based on a shared perspective about what is in the patient's best interest.

3. Multiple Conflicting (Potential) Surrogates. Several family members of equal kinship may want to be surrogates, but they may disagree or have limited knowledge of the patient's wishes. If possible, it is best to identify one person to act as the surrogate, document that person's role and notify the other family members. Factors that would favor someone as surrogate include: closeness to and knowledge of the patient, concern for the patient's welfare, evidence of responsible decisional capacity in other settings and availability for emergency decisions. If family members resist the designation made by the care providers of the person to act as surrogate, it may be necessary to seek a court-appointed guardian.

This policy describes a process, implemented by an ethics consultation, for making medical decisions for decisionally incapacitated patients. The ideal process will integrate the medical facts of the case with knowledge of the patient's values, to reach a treatment decision that is most likely to represent the
patient’s choice. This process will help caregivers reach a more timely and objective decision and can often avoid the need for a court appointed guardian.

**SPONSOR:** Anthony Whittemore, M.D.

**APPROVED:**
- Medical Staff Executive Committee, **12/05**
- Senior Management Group, **12/05**
- Care Improvement Council, **12/05**
MEDICAL DECISION-MAKING FOR
UNKNOWN and UNREPRESENTED PATIENTS
A Report Submitted to the Harvard Ethics Leadership Group
by the Community Ethics Committee

March 2016

The Community Ethics Committee was created under the auspices of the Harvard Ethics Leadership Group and functions as a part of the nonprofit Community Voices in Medical Ethics, Inc. The Committee was developed to serve both as a policy-review resource to the teaching hospitals affiliated with Harvard Medical School and as an educational resource to the varied communities from which the members come.

The volunteer members of the Committee are diverse as to age, socio-economic status, religious affiliations, cultural and language groups, and educational backgrounds. Committee members, during all or part of this study, included:

Carol L. Powers, Chair and Principal Author
Christine Mitchell, Advisor and Liaison to the Harvard Ethics Leadership Group

Herman Blumberg
Talia Burstein
Yvonne Joyner
Neville Lee
Shukong Ou
Patrick Smith
Shehla Syed
Julian Willard

Barbara Foot
Molly Johnson
Kathleen Kaditz
Paul C. McLean
Gayle Robertson
Adam Sonnenschein
Frank Tipton

Please address correspondence to:
Carol L. Powers, c/o Harvard Medical School, Center for Bioethics
641 Huntington Avenue #207, Boston, MA 02115,
or email at carollpowers@gmail.com.

Please visit our website to read our blog and review our prior Reports.
medicalethicsandme.org
**SETTING**

Hospitals and the caregivers within them are facing an increasingly frequent ethical challenge – who should make medical treatment decisions for Patients unable to speak for themselves and who are unknown and unknowable to the hospital staff, even after diligent search efforts are made and no one is found either to represent them or to describe their values and goals of care? Especially when, after the initial medical emergency has passed, medical treatment decisions must be made that may either prolong or curtail a life, who should make those decisions and how should those decisions be made? An attendant question arises from those forced to make these hard choices – “What does the wider community think about such complex questions?”

A good example of this challenge is presented in a narrative published in a Perspectives piece in the February 2015 issue of the Lancet. Using a prepaid cell phone, a gentleman called 911 twice from a boarding house where he had lived for less than a week. Emergency medical services found him gasping for air; treatment for an allergic reaction did not help; and attempts to intubate him failed. He had been without a pulse for ten minutes before emergency access to his airway was established. After the medical team stabilized him, he spent two weeks in the hospital’s ICU before being transferred to a medical floor of the hospital. He had lost all cortical function, confirmed by repeated brain imaging and brain activity scans. Having had a tracheostomy, he was sustained by a vent but no other life-sustaining interventions were required. His care – his food, clothing, housing, medications, direct care services, social connections, indeed his very life – was supported entirely by the hospital and the individual caregivers there. Careful and protracted efforts were made to find co-workers, family, and friends who would be able or willing to speak for the Patient. Those efforts failed thoroughly and completely. For the purposes of medical decision-making, he was friendless and, although some family members were located on a distant continent, they were not willing to speak to the medical team or make any medical decisions. No one professed to know him well enough or felt a strong enough personal connection to make medical treatment decisions on his behalf. He was unknown and unrepresented.

Discussion among medical team members roiled about whether he should be transitioned to “comfort measures only.” What would he have wanted? Are an individual’s values preserved or compromised by continuing to provide mechanical supports when all cortical function is lost? Is the institutional statement “we err on the side of life” always ethically supportable? Should the institution continue to provide arguably burdensome medical care to avoid any liability for “giving up too soon?” What is owed to this Patient? What kind of society do we aspire to be? Is there anything solid upon which to base a medical decision or is it all shifting sand?

In this case, and in others presented to the CEC as it considered this issue, the Patient had absolutely no one to make decisions for him and the medical team had no way of finding out anything about what values might have supported a particular medical decision. Although one could not say the Patient held no values, what those values might have been as they applied in general to medical decision-making and in particular to life-sustaining treatment decisions were unknowable and not discoverable by cultural research or conjecture. The hospital social support team members spent significant amounts of time and resources speaking with those who knew him, even those who knew him only in passing, in an attempt to obtain some insight into his possible values, even if only a glimmer. He had successfully gone “off grid” in every way a person can be “invisible” in this society and that became the only glimmer of insight gained into what was important to him and what he was successful doing. He was unknown and unknowable.
Without a surrogate or Representative decision-maker, the medical team is “stranded” and must proceed to treat the Patient based upon institutional and professional biases. It is true the Court system provides a process for appointing a surrogate decision-maker through a Guardianship proceeding. The Guardianship process in Massachusetts is challenging, however, and is avoided to the extent it can be avoided. Both because of a limited pool of trained and available Guardians (there is no funded Public Guardianship system within Massachusetts) and because of the delays inherent in any deliberative Court process, the appointment of a Court-appointed Guardian to make decisions for an unknown and unrepresented Patient is a solution of last resort.

In situations where the Patient is unable to communicate, the question “What would the Patient have wanted?” is answered by a representative or surrogate – someone who has standing to speak for the individual Patient if s/he cannot. Typically, Patients enter the hospital setting with a decision-making surrogate already named – either a formal proxy who is appointed in an advance directive document or an informal decision-maker who is deemed suitable by default due to blood relation or relational proximity. On rare occasions, a Patient already has a Court-appointed Guardian in place to make medical treatment decisions when s/he cannot. No matter how they obtain their authority to decide, all surrogates are required to make decisions based upon a “substituted decision-making” standard, meaning they are not to make decisions based upon what they would want for themselves but, rather, they are to make decisions based upon what they believe the Patient would have wanted. Such a substituted decision-making standard assumes the surrogate knows the individual and knows the medical decisions which would have been made by him or her. Those decisions are often, although not always, based upon religious, cultural, educational, and experiential perspectives. When the Patient’s individual wishes are unknown either because the treatment option to be decided upon was unanticipated or the individual never had decision-making capacity, a different decision-making standard is employed. The question to be answered transitions from “what did this person say s/he wanted?” to “what would be in the best interests of this person in this particular situation?” It is a decision-making standard which requires imagination and empathy in addition to careful thought.

No matter which decision-making standard is applied, both are predicated upon knowledge of the individual. Substituted judgment requires some understanding or memory of the individual’s articulated desires while best interests requires some understanding of the individual’s values and social structure. These standards are excruciatingly difficult to apply when there is some consanguinity or affinity with the Patient. These standards are perhaps impossible to apply when there is absolutely no knowledge of the individual who is in medical extremis and for whom a life-or-death medical decision must be made.

Again the question arises - is there anything solid upon which to base a medical decision or is it all shifting sand? We are confronted by this question during one of the most challenging of situations: a Patient is no longer responsive; his or her medical condition is often changing and always tenuous; and individual values to be applied to a particular medical decision are, more often than not, unknowable.
This Report describes what the Community Ethics Committee thinks about how medical decisions should be made for individuals who are unknown and unknowable and who have no one to make medical decisions for them. Should such individuals receive life-sustaining treatments as an ethically supportable default decision? Should Patients with no decision-making Representative be treated differently from those with a Representative? Should the mere possibility of medical benefit be the primary justification for medical interventions based upon a Patient’s “best interests”? Who should make medical decisions for a Patient who is unknown and unknowable?

The question of “who” should decide is asked in the context of limited Court resources – if the process to appoint a Guardian is unreasonably delayed and/or results in the appointment of an inadequately trained Guardian, who should be the one to make medical decisions when timeliness and medical sophistication are required? The question of “what should be done” is asked in the context of limited institutional resources – does it matter if the careful stewardship of medical resources becomes a salient factor in making medical treatment decisions for unknown and unrepresented Patients, and in that context, which life-sustaining treatment options are ethically supportable and which are not?

INTRODUCTION

The Community Ethics Committee (CEC) is a group of volunteers living in the Boston metropolitan area who are members of the broad demographics of the populations served by the Harvard-affiliated teaching hospitals. The CEC provides reports and opinions on topics brought forward by members of the Harvard Ethics Leadership Group – representatives of the various ethics services within the Harvard teaching hospitals. The need for such a consultative group has been evident for a long time, since the few community members on hospital ethics committees are unable to represent multiple communities. Solicitation for membership on the CEC has been cast widely through community, business and religious groups, with a specific application process to ensure selection of a dissimilar but effective working group.

CEC members are diverse as to age, socio-economic status, religious affiliations, cultural and language groups, and educational backgrounds. Eight members are women and eight are men; we range in age from our teens to our seventies. Some of us have advanced degrees, some have high school diplomas. Among members past and present are a high school administrator, a high school teacher, and a high school student; a rabbi, an imam, a Muslim female attorney, and a professor at a Protestant seminary. Some of us are individuals with disabilities and others are parents with disabled children. Two are retired, one from a large Boston law firm. We are students and writers and small business owners. We volunteer in our communities, including on an Institutional Review Board and in local health care facilities. We belong to eight different religious traditions, including atheism, and we are fluent in several different languages. Most of us have attended the annual Harvard Clinical Bioethics Course, where the original members first met in 2007 and began the conversation as the Community Ethics Committee. Since 2011, the CEC has been part of the nonprofit corporation, Community Voices in Medical Ethics, Inc., which was established in order to enhance the CEC’s mission to bring the issues of medical ethics into the community as well as to include the community’s voice in the dialogue already occurring in health care institutions, government, and academia.
PROCESS

The Committee met throughout 2014 and most of 2015 to educate ourselves about the dilemma created by Patients entering the health care system who are unknown and unknowable and who have no one to make decisions for them. We heard narratives from many different sources – several of the Harvard teaching hospital medical team members shared their dilemmas in treating Patients without representatives and the moral distress that arises when trying to make decisions congruent with a Patient’s values and goals of care when those values and goals of care are completely unknown and unknowable. We heard from care team members working in inner city clinics as well as those providing services to the developmentally disabled. We also heard from those working in the Veterans’ Administration hospital setting. Lastly, we had the privilege of discussing the development of a special mental health court in the Maryland judicial system with the Honorable Gail E. Raisin (Retired) who initiated a separate docket of cases to help those who had no personal advocate. The Committee was able to hear care team members’ real and troubling anguish at doing their best to treat individual Patients, most with complex medical needs, all in the context of institutions with differing approaches and with limited financial resources resulting from free care requirements under the Hill-Burton Act. Based on our group discussions and in order to obtain everyone’s viewpoints in an anonymous format, we developed a survey that solicited Committee members’ thoughts on the questions asked by the various medical teams who had presented and on the questions raised at our meetings. Some of the responses from that survey are included in this Report. The Committee also distributed a survey among the public and some of those responses are also included in this Report. The Committee benefited from the special insights of one of its members, Paul McLean, who was focused on this issue as a project of his Fellowship year with the Center for Bioethics. (His individual conclusions, which differ from the CEC’s group recommendations, are posted on the blog found at medicaethicsandme.org.)

TERMINOLOGY

Although our response will highlight some of the additional complexities of this topic, the CEC was presented with two questions – WHO should make medical decisions for Patients who are unable to communicate their wishes and who have no one to make medical decisions on their behalf and HOW should those decisions be made?

The CEC has found that the first step in any review of a topic must involve defining our terms. Surprisingly perhaps, the Committee struggled with the question “who are we talking about?” We concluded the most comfortable and concise phrase to use in this Report was “Unknown and Unrepresented Patients.” The Patients we were focused on are those who are unknown both to the medical staff providing care and to the community from which these individuals come; unknowable even after a diligent search to obtain information; and unrepresented without anyone willing or able to step forward to make medical treatment decisions during their hospitalization and continued care.

When focusing on who we were talking about, “patients without surrogates” and “incapacitated and alone” were phrases that we also considered but “surrogates” was a word with child-bearing connotations and “incapacitated” was a word with legal connotations that made it inaccessible to many. Although the phrase “unbefriended patients” is used widely in the literature on this topic, we concluded the term “unbefriended” carried a pejorative sense that was not helpful. In many ways, “unbefriended elders” were those who actually had friends and family years ago but who had the misfortune of outliving them all.
The Committee found that deciding upon the best word to describe the substitute decision-maker was also problematic. The individual or group chosen to make decisions was not necessarily acting in the role of “friend.” Instead, our discussions frequently focused on the need for someone who could advocate for the Patient’s interests — an individual or group who would actively promote the Patient’s welfare, someone who would be on the Patient’s “side.” We were talking about a Patient needing a substitute decision-maker who would make medical decisions in the same way the Patient would have — in a word, a representative of the Patient. In the end, we felt most comfortable using the phrase “Unknown and Unrepresented Patients” when addressing this topic.

**ANALYTIC FRAMEWORK and DISCUSSION**

To answer the questions “who should make decisions?” and “how should medical decisions be made for unknown and unknowable Patients who have no one to speak for them?” the Committee used a loose analytic framework of “who,” “what,” “when,” ”where,” and “how.” The discussion which follows tracks our conversation over the months that we spent on this topic.

**WHO are the Stakeholders?**

The Patient needing a medical treatment decision is unknown and unknowable. She is not necessarily elderly. She has not always been unknown or socially invisible. She was someone who had a family life at one time, lost now to the alienating effects of mental illness or substance abuse, trauma or just old age. She might have been incarcerated; she might be carefully living “under the radar,” perhaps as an individual without documentation. In all events, as she comes to this medical decision-making moment, she is a Patient who cannot express either her needs or wants and cannot make an informed medical decision; she has no one to speak for her or act on her behalf; she is unknown and unknowable.

The law goes to great lengths to ensure no one loses their autonomy when making medical decisions and statutory structures are in place to ensure a Representative can be identified to make medical decisions for an individual who is incapacitated and unable to speak for themselves. The law in all fifty states allows any competent individual to appoint someone to make healthcare decisions for him or her. With a document called a Health Care Proxy or an Advance Directive or Health Care Power of Attorney, an individual while competent can appoint a representative to make decisions in situations of temporary or permanent incapacity. On occasion, specific directions are given within the document to help the Representative make difficult medical decisions. When such a document does not exist or is not found, a decision-maker can sometimes be identified and empowered based upon a statutory hierarchy of interested persons. Such a listed hierarchy does not exist in Massachusetts and physicians here usually rely upon the informal input of family members and close friends as those individuals are identified by the treating physician and care team members.

Every state has a statutory procedure in place to appoint a Guardian to represent another person who is incapable of making medical decisions for themselves. Those Guardianship proceedings vary but little across state lines, with many states adopting a Uniform Probate Code providing standardization both in the procedures required to obtain appointment as a Representative and in the scope of authority granted to that Representative. Unfortunately, due in part to budget constraints within the Massachusetts Court system, the procedural delays (sometimes months and
months) and lack of trained Guardians (Massachusetts has no public guardianship system in place) result in many hospitals and institutional caregivers eschewing the pursuit of a Guardianship appointment for a Patient who is unknown and unrepresented. And because many end-of-life medical treatments fall into the category of “extraordinary medical procedures” in Massachusetts, a Guardian may be required to seek additional Court approval before a decision can be made to withdraw artificial nutrition and hydration or ventilator support and sometimes before a DNR order can be entered. While the statutory protections are in place to protect individuals from losing their autonomy entirely, the result is that a Guardian in Massachusetts has limited authority to make medical decisions.

The **Representative** of a Patient who needs a medical decision to be made is not necessarily an individual. The best substitute decision-maker for this unknown and unknowable Patient may be an individual or it may be a group of individuals. The Committee acknowledged that whoever steps in as a Representative decision-maker will be biased – whether that decision-maker is appointed by the Patient beforehand or is authorized by a Court or is acknowledged by relational proximity or is a separate decision-making body. A fully-informed Patient makes decisions that are necessarily affected by the Patient’s knowledge of their disease, their confidence in the medical prognosis, and the breadth of their experience. Medical team members are biased by their individual caregiving experiences as well as by the requirements of their professional standards of conduct. They are also affected by the sometimes unspoken institutional biases of “we always err on the side of life” or “remember to steward our resources carefully.” Court-appointed Guardians typically are accountable to uphold a governmental mandate to preserve life. Biases abound among those involved in medical decision-making and most assuredly, the Patient’s Representative is no exception.

The integrity of the Representative is premised upon their ability both to know their medical treatment biases and to disclose those biases. In a “shared decision-making model,” all the stakeholders – medical team members and the Patient or Representative – work together to balance the benefits and burdens of treatment options in the context of prognostic uncertainties. Typically the purview of the Patient/Representative is to articulate the individual’s overall goals of care (based upon cultural, religious, familial, and ethnic values) and the expertise of the medical team is to present medical treatment options which best accomplish those goals of care (based upon professional expertise and experience). In the case at hand, when the Representative does not have any way to know the Patient, the Representative must become an advocate for the Patient in his or her most vulnerable moments. Most certainly, the burden on the Representative decision-maker is heavy.

The **Physician** who is providing medical care for the unknown and unrepresented Patient must often provide that care within an emergency or ICU setting and frequently is called upon to make extemporaneous decisions without the ability or time to consult with others. The physician’s role in helping Representatives make medical treatment decisions rests on his or her medical expertise. The physician’s judgment is required to make both prognostic determinations and treatment recommendations upon which medical decisions are based. Arguably it is the physician’s professional assessment of the feasibility of obtaining good medical outcomes that determines what is in the best interests of the Patient. It is for this reason, many conclude the unknown and unrepresented Patient’s treating physician is the logical default decision-maker and some states have statutorily named the treating physician as the decision-maker in these situations. Although relying upon the treating physician to be the default decision-maker
arguably makes for an “easy” answer to the question “who should decide?,” other interests are at stake which must be addressed including the need to maintain public trust through transparency and accountability. The Committee was also concerned about the effectiveness of medical decision-making residing in one individual, where checks and balances to individual biases do not exist.

Other Care Team Members are stakeholders in how medical decisions are made for unknown and unrepresented Patients. They are the caregivers who must provide sometimes intrusive medical treatments for a Patient who, without a Representative, may be maintained for long periods of time in an ICU or in a consciousness-deprived state because of an institutional bias to prolong a Patient’s life, regardless of its quality. Or they are the caregivers who acknowledge that vulnerable unknown and unrepresented Patients often have no advocate for continued therapeutic care and are, as a result, perhaps allowed to die prematurely. The moral distress on both ends of the spectrum is real and troubling.

And lastly, Society has a stake in how these medical decisions are made. We as a community must contend with at least two primary social interests in this area of decision-making for unknown and unrepresented Patients – how we treat the least among us affects us all and we should treat Patients without decision-making Representatives the same as we treat Patients with Representatives. Both societal interests fall under the umbrella of “due process” – substantive due process where fundamental rights must be protected and procedural due process where fairness must be protected. The issue of how medical decisions are made for unknown and unrepresented Patients affects society as a whole and mechanisms must be in place to protect our societal values of justice and mercy.

“As a person with a severe disability (quadriplegia), I would not be able to trust any stranger to value my life as much as I do . . .”  

Public Survey Respondent

**WHAT**

Medical treatment decisions must be made by someone during the time when institutional care is provided to an unknown and unrepresented Patient. The CEC discussed at length what the context of those medical decisions would most likely be. We acknowledged that the legal requirements for and the primary goal of emergency medicine are to save and stabilize all individuals in medical need, whether a decision-making Representative is present or not. Only “when the dust settles” and the treatment decisions are either therapeutic (with the primary goals of prolonging life and restoring prior or acceptable functionality) or palliative (with the primary goal of comfort care), does the question arise of what medical treatment decisions are best for this particular Patient. Frequently, as the medical care “steps down,” the next tier of decisions must be made in an intensive care unit.

Based upon the numerous narratives that the Committee heard from caregivers, the medical decisions being made for the unknown Patient which create the greatest moral distress fall into three categories – life-prolonging, life-sustaining, and palliative treatments. Life-prolonging medical treatment decisions include treatments with a discernable burden and a limited benefit. Examples of such life-prolonging treatment decisions include excising a malignant tumor when the life-expectancy after the surgery would remain less than six months or authorizing toxic medications such as chemotherapy, again when a life-expectancy remains at less than six months. Life-sustaining medical treatment decisions include treatments with a significant burden and an
indeterminate benefit. Examples of such life-sustaining medical treatment decisions include initiating long-term dialysis or performing a tracheostomy with the expectation that the Patient will need long-term ventilator supports. **Palliative care** includes treatments without a primary goal of therapeutic cure or long-term physical maintenance but instead are undertaken with the goal of diminishing the unknown Patient’s pain and suffering, both physical and existential, while forgoing burdensome medical interventions. No matter in what category these treatment options fall, medical decisions must sometimes be made quickly and they must always be made knowledgeably and with the Patient’s best interests at the forefront.

A concern expressed by Committee members was the interventional “creep” that occurs even with the best of intentions – one medical treatment decision leads to another that leads to another. A life-prolonging decision can provide the time needed for the Patient to respond to therapeutic interventions, through a “trial of therapy.” Such life-prolonging treatment decisions can, unfortunately, lead to life-sustaining treatment choices which can strand Patients, both those known and unknown, on mechanical supports for prolonged periods of time, well past when the therapeutic benefit might have been attained. For example, the decision to provide artificial nutrition and hydration for a Patient may seem innocuous enough. A Representative might well receive a recommendation to remove a naso-gastric tube (a short-term measure) and give consent to the surgical insertion of a g-tube (a long-term measure). While on first glance, that escalation of medical treatment is a “good” decision, motivated by the Patient’s best interests to prolong his or her life, the placement of a g-tube often leads to the need for other interventions such as antibiotics to fight infections and physical restraints to limit self-extraction of the tube. And, although academic ethical discourse concludes that withholding and withdrawing medical treatments are ethically equivalent, the two actions are not emotionally equivalent and, once a life-sustaining treatment is begun, the stopping of that treatment is fraught with significance for caregivers and Representatives alike.

In the world of institutional Patient care, the transition from therapeutic interventions to palliative care can be challenging. The institutional ethos is clearly to save lives, often by intervening with the best technological resources at hand. The institutional goal of care is to rescue and to restore. Transition to palliative care stops the technological mandate to intervene and redirects those salvific goals of care into the provision of “comfort measures.” Such a transition seems to signal defeat and failure. It is no wonder that the choice to transition to palliative care is sometimes challenged by caregivers and perceived as premature or unnecessary.

In an ideal world, a decision-making Representative must possess: (a) the ability to understand the benefits and burdens of accepting and rejecting the proposed medical treatments (to provide true informed consent) and (b) knowledge of the Patient sufficient to advocate for his or her values (to achieve the Patient’s individual goals of care). Representative decision-making is challenging enough when the Patient is known and loved and an essential part of a functioning family unit. Such decision-making when the Patient is unknown and unknowable is well-nigh an impossible task, completely without comfort or confidence.

“... we are talking about any patient who lacks decision-making capacity who requires care that needs informed consent – whether that is life-sustaining treatment, end-of-life care options, or other treatment situations – chronic or acute.”

CEC Internal Survey Respondent
**WHEN**
Although the immediate medical crisis may have passed and the unknown Patient may be physically stabilized, the Representative must often make therapeutic treatment decisions quickly. Life-prolonging and life-sustaining interventions are not usually those which can wait for protracted Court proceedings or on formal institutional mechanisms to provide decisional certainty. The fluidity of the Patient’s medical situation necessitates a decision-making Representative who is informed and available to make a complex medical decision quickly and thoughtfully.

The straightforward answer to “when” these ethically challenging decisions must be made is whenever the medical treatment decisions mark a transition. When life-prolonging treatment converts into life-sustaining treatment and when life-sustaining treatment converts into palliative care, those are the points at which Patients who are unknown and unrepresented most need someone to advocate on their behalf. Certainly at the earliest possible moment, but no later than these transition moments, this is when the Committee’s recommended Medical Decision-making Team should be included, informed, and involved. (The Committee recommends that a formal ethics committee consult be initiated at the same time.)

**WHERE**
The decisions which we are discussing – medical treatment decisions for an unknown and unrepresented Patient – are most frequently but not always made in an institutional setting. The Committee learned that without a Representative, unknown Patients cannot be transferred outside of a hospital setting because less intensive settings such as a skilled nursing facility or medical group home do not receive governmental funding to treat a Patient without a Representative. As a result, unknown and unrepresented Patients who have complex medical needs are sometimes stranded in hospitals for months at a time, pending Court appointment of a formal Representative or until the Patient’s situation changes. Unknown and unrepresented Patients whose care needs are not as complex face dangerous discharge decisions, sometimes discharged and abandoned to the streets. In either setting – hospital or street - the lack of a Representative can result in a sub-optimal place of care.

“I know our discussions have focused primarily on the hospital setting but it seems like the same issues would arise in nursing home, group home, and home care situations as well. I think wherever the need for informed consent and the lack of decision-making capacity intersect would be situations where a decision-maker is necessary.”  

CEC Internal Survey Respondent

**HOW**
Once a Representative decision-maker is identified and agrees to serve, the medical decisions to be made must be made according to established legal and ethical standards. The legal and ethical standards uniformly applied to medical decision-making focus on a Patient’s autonomy as exercised through informed consent. Without informed consent granting prior permission for the invasion of an individual’s personal space, most medical care would be categorized as an “unauthorized touching” (the tort of battery). When someone other than the Patient makes medical decisions, that interest in autonomy continues and the requirement of “substituted judgment” is mandated of Representatives, no matter how they are appointed. What did the Patient say he or she wanted?
But of course, when a Patient is unknown and unknowable and without a formal decision-making Representative, the Committee recognized that there can be no “substituted judgment.” By definition, this Patient has no one to step forward and shed light on what he or she liked or disliked; what sensitivities may have been held physically, culturally, religiously, emotionally; what personal connections existed at one time to make life meaningful and rich. Without “substituted judgment,” the Representative must rely on a determination of what is in the unknown Patient’s “best interests.” From a purely medical perspective, that “best interest” decision-making standard examines what treatments would give the Patient the best chance of survival, with the least pain and suffering. From a Patient-centered perspective, however, without any information about what the Patient “as a person” would choose, the best interests decision-making standard is impossible to apply in these cases.

The Committee considered numerous methodologies that have been used to ascertain and advocate for an unknown Patient’s “best interests.” A policy promulgated by Brigham and Women’s Hospital proposed a decision-making standard they call “Synthetic Judgment” which stated in pertinent part –

the goal being “to reach a synthetic (as opposed to a substituted) judgment of what the patient would probably choose or want. This should not represent the judgment of a single caregiver but should be a consensus of what a group of people from multiple disciplines directly connected with the patient’s care believe that the patient would be likely to choose. If, following this process, there is no consensus on a care plan and the options include invasive treatment or withholding life-sustaining treatment, consultation with the Office of General Counsel is necessary to determine whether a court-appointed guardian should be obtained.”

The Committee concluded that the Brigham & Women’s policy reflected the best standard for medical decision-making for unknown and unknowable Patients and based its recommendation on this kind of “composite” judgment standard.

RECOMMENDATIONS

As has been noted above, the Committee focused its review on two particular aspects of medical decision-making for unknown and unrepresented Patients – who should serve as a decision-making Representative when no one can be found and how should medical decisions be made for someone unknown and unknowable once a Representative decision-maker is in place?

WHO SHOULD DECIDE?

The Committee concluded that a small group within the institutional setting should be the unknown Patient’s Representative decision-maker. We called that group the Medical Decision-Making Team.
During our many discussions about the topic, we acknowledged that, even though most Representative decision-makers rely almost exclusively upon the recommendation of the treating physician, that physician should not make those key decisions alone. We concluded the best methodology for reaching a balanced, well-considered, and unbiased decision lies in a Representative composed of a team (the unknown and unknowable Patient’s Medical Decision-Making Team) making medical treatment decisions based on consensus after synthesizing their several different perspectives, reaching a “composite judgment” on which to base the decision on the unknown Patient’s behalf. The Committee then discussed at length what kind of group should make these decisions and what decision-making tools may already be in place or could become alternative recommendations.

We looked at what other states have done to address this issue and found that many solutions have been suggested but few have been given the funding mandate needed to accomplish the lofty goals of adequate representation of unknown and unknowable Patients. Some states have developed Public Guardianships so that there is a well-trained pool of advocates to represent these Patients. Many states (but not Massachusetts) have a default surrogate list to facilitate identifying a Representative for the Patient. (The Committee chose not to address specific concerns about the Massachusetts Guardianship process in this Report.) In some states, the physician becomes the decision-maker of last resort based upon such a surrogate list. “Transition authorization panels,” “interdisciplinary teams,” and “limited healthcare fiduciaries” have been proposed to make limited decisions for Patients, including decisions about transitioning Patients who are ready to be discharged from an acute care setting to a skilled nursing facility and transitioning Patients to hospice care. (Thanks are due to Thaddeus Pope, J.D., for sharing his expertise in this regard.)

The Committee looked at other creative avenues of specialized decision-making. We examined the medical decision-making process instituted in Massachusetts for disabled children in foster-care, technically under the custody of the Department of Children & Families. In those cases, an ethics committee consult is required along with a second medical opinion. We also discussed whether a specialized docket could be created within the already-existing Probate Court system so that unknown and unknowable Patients would have a “fast track” to experienced Guardians and judges who are not squeamish ruling on medical decision-making cases. We also were attracted to a recommendation that included the creation of a Medical Decision-Making Court which would stand within the existing Superior Court system and operate much like the Superior Court Business Litigation Session which was established in Massachusetts to facilitate the Court’s disposition of complex business cases. The creation of a specialized Court-within-a-Court was an attractive way to address a broad spectrum of medical decision-making cases, including cases involving unrepresented Patients and cases involving medical futility.

After lengthy discussion and much self-education, our recommendation finally came down to four over-arching societal interests: expediency, cost, effectiveness, and justice. Creating a Medical Decision-Making Team from within the hospital’s human resources addressed expediency – these are people already on-site and available to make decisions in a timely way. Including professional caregivers on the Medical Decision-Making Team addressed concerns about cost and effectiveness as well – other than paying for the time needed to consult on the unknown Patient’s care decision, no new costs would be required since no “outside” staff or systems would be involved. The Team would include staff already involved in the unknown and unknowable Patient’s care, familiar with the issues surrounding that individual’s transitions and the likely repercussions of the medical treatment decisions to be made.
The societal interest remaining for the Committee to consider was justice. Recognizing that without a formally appointed Guardian involved in the decision-making process, the Patient’s interests were in danger of being overlooked, the Committee discussed at length how best to incorporate the unknown Patient’s perspective. The challenge was to ensure the Patient’s “voice” could be heard – finding someone who could speak for the Patient as a strong advocate, sensitive to articulating what the individual’s values might have been. We looked at the possibility of including a member of the hospital’s Patient and Family Advisory Council but, in the end, the Committee concluded that the best internal advocate on the Medical Decision-Making Team for the unknown and unknowable Patient would come from the hospital’s chaplaincy program.

Why chaplains? Chaplains provide not only “life cycle counsel” to Patients and families but they possess the professional skills necessary to be an integral member of an interdisciplinary team. They are trained not only in the spiritual needs of a particular Patient but his or her psycho-social and emotional needs as well. They regularly address a Patient’s fears, anxieties, and guilt, in the context of oftentimes complex family relationships. As one of our atheist-identified members noted, chaplains maintain their integrity by being value-neutral. The Committee acknowledged that spirituality is broader than religion and chaplains are trained in diverse world views. The Common Standards for Professional Chaplaincy focus not on denominational or specific religious world views but rather on the elements of pastoral care. These standards require chaplains to “provide effective pastoral support that contributes to the well-being of Patients, their families, and staff;” and “provide pastoral care that respects diversity and differences including, but not limited to, culture, gender, sexual orientation and spiritual/religious practice.” Finally, the standards require chaplains to “support, promote and encourage ethical decision-making and care.” Perhaps of most importance, chaplains are outside of the primary revenue source of the institution, meaning a medical decision made by a chaplain on behalf of an unknown and unknowable Patient is not tied to the hospital’s financial “bottom line”. The chaplain does not get paid more or less if the Patient lives or dies. That freedom from institutional bias was significant to the Committee in seeking to maintain trust in the integrity of the decision-making process.

The Medical Decision-Making Team, as envisioned by the Committee, would be ad hoc – a team called upon early in the unknown and unknowable Patient’s care to become a participant in decision-making as soon as necessary medical treatment decisions are required. (The Committee understands that consent is not required during emergency care nor is it required during routine medical care. Consent is required, however, when medical treatment decisions are being made that involve invasive, life-prolonging, life-sustaining, or palliative interventions.) The Medical Decision-Making Team would ideally be composed of (1) the Patient’s attending physician and (2) a healthcare professional who is not directly involved in the Patient’s care (preferably another physician to provide peer review) and (3) a member of the hospital’s chaplaincy office. The Committee recommended that any hospital policy which would establish such an ad hoc Medical Decision-Making Team would explicitly state that the chaplain’s voice carried great weight, as he or she is speaking on behalf of the unknown and unknowable Patient.

“Two doctors, one palliative, one standard. One hospice nurse. One medical social worker.
No lawyers. No one religious.” Public Survey Respondent

“I would never trust a group that was non-religious. Their interest would only be cost savings.
I want all Herculean measures.” Public Survey Respondent
HOW SHOULD MEDICAL DECISIONS BE MADE?

Once the Medical Decision-Making Team is assembled, the actual medical decisions should be made from the perspective of “doing right” by the unknown and unknowable Patient. Being an idealistic group, the Committee holds that one of the primary goals of any personal interaction, including in medicine, should be to treat each other well - with respect and compassion. As we have discussed earlier in this Report, a Patient comes to a doctor with certain goals of care based upon their values, experiences, and understanding of their condition. The treating physician comes to the Patient with medical treatment options available to accomplish those goals of care. The dilemma here is that an unknown and unknowable Patient does not articulate any goals of care – he or she is, however, in need of health and healing. Such an unknown Patient’s care team comes to the bedside with a full armamentarium of medical treatment options - many of which may be life-prolonging and life-sustaining but not necessarily life-enhancing.

As has also been addressed earlier in this Report, the standards a Representative must use to make medical decisions on behalf of someone else are legally mandated – the Patient’s substituted judgment must be employed when wishes are known and the Patient’s best interests standard must be used when explicit prior decisions have not been articulated but the Patient’s values and interests are known. The conundrum escalates when even best interests are impossible to discern. What then?

The standard for medical decision-making for an unknown and unknowable Patient must include a mechanism for their voice to be heard, even if it is a guess, a composite view based upon whatever small glimpses of values and interests can be gained from an examination of the unknown Patient’s life. Such a composite decision-making standard would be predicated on procedural due process – considerable efforts must be expended to obtain information about the unknown Patient and to locate people who are or were involved in that Patient’s life. Substantive due process must be protected as well – considerations must be taken into account to ensure biases are minimized and medical treatment decisions are made with a view of protecting the unknown Patient’s physical integrity.

The Committee was impressed by the stories of hospital social work staff who are given the task of tracking down any and all possible leads to glean some information about the Patient. This due diligence included entry into now-abandoned apartments, contacting people with even the remotest of ties to the unknown Patient, making repeated calls to absent family members if they are found. And the effort to create some composite picture of the unknown Patient often continued for weeks and months! The sustained effort to obtain some glimpse into the individual’s values and interests is valuable and valued in the quest for creating this composite decision-making standard. It provides the procedural due process needed to protect the unknown Patient’s physical integrity – the right to informed consent before medical interventions are performed. (This sustained due diligence to find out as much as possible about the Patient also provides a level of protection from liability which the Committee understood was needed for good decisions to be made.)

Substantive due process prohibits the government from infringing on fundamental constitutional liberties. In this context, the difference in medical decision-making between a court-appointed Guardian and an ad hoc Medical Decision-Making Team is profound and vitally important. The Guardian must uphold the government’s bias toward sustaining life at all costs. The Medical Decision-Making Team is attempting to replicate the individual’s constitutional liberty to autonomous consent, free of bias to the extent possible. The Committee was troubled upon
learning that Patients without Representatives are far more likely to spend a longer time in an ICU, receiving more aggressive care, than those Patients with Representatives. The Patient’s medical circumstances were not as determinative of the length of an ICU stay as was the presence or absence of a Representative. Like Patients are not being treated alike.

As a result, representation for medical decision-making becomes key to protecting the physical integrity of the unknown and unknowable Patient. The recommended Medical Decision-Making Team’s composite decision-making standard is necessary so that treatment decisions for unknown Patients are not governed by the technological imperative to treat at all costs. The option of allowing an unknown and unknowable Patient to stop treatment and begin palliative care (with hospice care implied) must be available, just as the oversight to ensure adequate treatment is necessary to protect those who could benefit and recover.

The Committee understands it is not looking primarily at legal standards for decision-making. We are, in fact, an ethics committee! While the law sets the floor for decisions and behavior, establishing the minimum of what must be done, ethics opens the skylight and looks at what should be done. In a Green Paper Technical Report for the Essex (UK) Autonomy Project entitled “Best Interests decision-making under the Mental Capacity Act,” Justice Hedley is quoted in a decision saying:

“...If one asks what has to be taken into account in considering the best interests of any human being, the answer is a very wide ranging one: his health, his care needs, his need for physical care, and his needs for consistency. There is, of course, more to human life than that, there is fundamentally the emotional dimension, the importance of relationships, the importance of a sense of belonging in the place in which you are living, and the sense of belonging to a specific group in respect of which you are a particularly important person.”

The consideration of emotional ties and relational connections is perhaps the most important basis for a composite decision-making standard. In the end, the Committee was protective of the unknown and unknowable Patient – wanting to be sure that the evaluation of an unknown Patient’s best interests includes more than the status of their medical condition, but also includes an ethical standard of medical decision-making that ensures such a one’s relational life is taken into account. The Committee concluded that an ad hoc Medical Decision-Making Team, using a composite decision-making standard, would best be able to assess the unknown and unknowable Patient’s needs and to advocate for those needs to be met, so that what should be done is done.

“I would hope that an advocate would work closely with the care providers to determine the best course of care for my situation. This advocate could be within the hospital setting but not a medical provider (perhaps a social worker, clergy, etc.), or could be a neutral person outside of the hospital setting – assigned by the courts or some outside board. In any case, I would hope the person advocating for me would be thoughtful and thorough in their decision-making, reasonable in their expectations of treatment cost/benefit ratios, and motivated by what is best for me (without financial or other institutional pressures).”

CEC Internal Survey Respondent
THREE SIDE NOTES
The Committee’s discussions included three additional side notes that are important to include in this Report. First, we understand the puzzlement that might arise at the Committee’s recommendation to specifically include chaplaincy with a weighted voice on an unknown Patient’s Medical Decision-Making Team. Second, although not explicitly stated in our recommendation, the Committee encourages the initiation of an ethics committee consult early on in the unknown Patient’s treatment. And third, we note the close ties between our discussions regarding medical decision-making for unknown and unrepresented Patients and Medical Futility, with lessons learned that carried a particular impact our recommendation. These three aspects of our discussions were weighty enough to deserve separate treatment here.

Chaplaincy
A short narrative might be in order. The Committee was asked to present its views on medical decision-making for unknown and unrepresented Patients at a May 2015 conference on “Making Decisions for Others” at the University of Arkansas Medical School and three Committee members attended and spoke. We met others wrestling with these challenging issues and we were struck by the composition of several of the ethics committees outside of our limited geographic area. Many institutional ethics committees located outside of the bioethicist-rich Northeast corridor are headed by and comprised primarily of chaplains. These individuals are compassionate, knowledgeable, value-neutral, and innovative representatives of both their institutions and the Patients within their communities. We were struck by their professional skill at advocating for Patients’ needs while working within the institutional system. These encounters opened our eyes to the value and the strength of incorporating the chaplains’ voice into those ethics discussions where the Patient’s voice is unheard and unknown.

In making its recommendation to specifically include a representative from the chaplaincy office, the Committee assumed a non-judgmental professionalism and a value-neutral stance could be maintained. The weighted voice of the chaplain on the Team was meant to enhance the creation of the “composite judgment” standard which we thought would be most effective in ensuring an unknown and unknowable Patient would be treated with mercy and justice.

During a recent Harvard forum on decision-making, Charles Bosk discussed his recent book “What would you do? Juggling Bioethics and Ethnography,” and noted that writing the book:

“grew out of my puzzlement: where did ethics experts come from, what made them legitimate, how is it that the secular ethics experts never acknowledged the religious ethics experts? What role in fact did chaplaincy play? . . . [Most patients] don’t say “Get me a bioethicist;” they do say “Get me a chaplain.””

Ethics Committees
Without any reservation, the Committee respects the work the Harvard teaching hospitals’ ethics committees do to address ethical complexities which arise in the context of the provision of patient care within an institutional system. More often than not, the ethics committee members are trained in bioethical discourse and understand the philosophical underpinnings of bioethical analysis. Most are health care workers within the institution. Some are community members and some are chaplains. An ethics committee consult is an invaluable tool when ethical dilemmas arise and an ethics committee consult often provides another “voice” to the discussions surrounding treatment options and accomplishing a Patient’s or families’ goals of care. Our Report recommends enlisting the aid of the ethics committee as soon as transitional medical decisions are needed for unknown and unrepresented Patients – the perspectives of the committee will only enhance and strengthen the care provided to such a Patient. The Committee did not explicitly suggest an ethics committee member participate on the Medical Decision-Making Team but there is no reason to presume
exclusion from the Team if that were necessary or advisable. The roles are arguably different and the Committee chose a representative from chaplaincy as a way to be sure there was an institutional participant on the Team whose voice could be weighted to speak to what the Patient would likely have wanted.

Medical Futility Lessons
We found the dilemmas surrounding medical decision-making for unknown and unrepresented Patients are related to dilemmas surrounding medical decision-making for Patients subjected to treatments which are medically futile. Both situations involve the need for a strong Patient-centered voice and both involve situations where care-giving decisions are sometimes overwhelmed by the technological imperative to treat at all costs. The Committee spent a great deal of time and effort analyzing both situations. We learned something from our recommendation with regard to Medical Futility that affected our recommendation here.

At the time of our Report on Medical Futility, we recommended the creation of an independent decision-making panel that would exist outside of the institutional setting. We noted when we reviewed the issue of Medical Futility,

“...Unless an effective and efficient [] dispute resolution mechanism is in place, our society will continue to suffer. And most importantly patients suffer – their dying process is prolonged for no apparent therapeutic or curative purpose with substantial harm done to caregivers, family members, and patient alike. No matter whether decisions are made by court or committee, even if all cases [] could be decided reasonably and well, with the patient’s best interests protected, efficient resolution by any authoritative institutional group may come at the potential expense of public trust and confidence. Decisions made by either courts or medical institutions’ internal review boards are suspect because the stakes are high, core values differ, and the power disparity of the stakeholders is extreme. Rarely does anyone feel particularly comfortable when a court or authorized expert panel or ethics committee mandates withdrawal of life-support for a terminally ill child, for example, against the wishes, hopes, and demands of frantic and grief-stricken parents. Another approach must be found that includes safeguards and provides an open process that considers cultural, religious and patient values and welcomes participation by surrogates acting in the patient’s best interest.”


Over time, the Committee has found our recommendation for the creation of an outside decision-making body to be “ideal” but not practical. With limited governmental and institutional resources available to fund a separate decision-making panel, the hospitals are left to rely on institutional policies and their own internal decision-making practices. The Committee felt strongly that we did not want our recommendation on medical decision-making for unknown and unrepresented Patients to lie fallow. By recommending an in-house Medical Decision-Making Team, we have to some extent stepped away from the “ideal” to ensure a practical solution that can address decision-making for these most vulnerable of Patients. It is our hope that the chaplain’s participation on the Medical Decision-Making Team will provide a weighted voice of advocacy and compassion, taking into account factors in addition to physical well-being.
In all the years of its existence, the Community Ethics Committee’s discussions and recommendations have focused on the “Patient in the bed.” This inquiry was no different. An effective and efficient voice needs to be found for each unknown and unknowable Patient and we trust the creation of an ad hoc Medical Decision-Making Team, comprised of the attending physician, another care team member, and a hospital chaplain, will provide that voice. Even if “only” a composite of the Team’s understanding of this unknown and unknowable Patient, the medical decisions made by the Team will provide a previously voiceless Patient with a voice and that is precisely what the Committee hopes for.

A NOTE OF THANKS
To the physicians, nurses, social workers, and medical staff who so generously gave their time and invaluable insights to the Committee, we are grateful.

REFERENCES and RESOURCES
A bibliography of articles, books and resources used by CEC members in our discussions and review of this topic will be provided separately.
EXECUTIVE SUMMARY –  
Report on Medical Decision-Making for Unknown and Unrepresented Patients

Throughout 2014 and most of 2015, the CEC met with many different health care providers who posed two questions: Who should make decisions and how should decisions be made for patients who are unknown, whose values are unknowable, and who have no representative?

Typically the purview of the Patient/Representative is to articulate the individual’s overall goals of care (based upon cultural, religious, familial, and ethnic values) and the expertise of the medical team is to offer treatment options which best accomplish those goals of care (based upon professional expertise and experience). When the Representative does not have any way to know the Patient’s express wishes or personal values, the Representative must become an advocate for the Patient in his or her most vulnerable moments. The Committee concluded that, although the treating physician’s perspectives and recommendations carry great weight, leaving a crucial medical decision to the treating physician alone was not supportable. In answer to the question who should make a medical decision for an unknown and unrepresented Patient, the Committee recommends the Patient Representative should be a three-member Medical Decision-Making Team. The Team would be comprised of the treating physician, a medical professional not directly involved in the Patient’s care, and a representative from the hospital’s chaplaincy office. Weight should be given to the chaplain’s perspective, whose pastoral value-neutral professional training would enable them to be an effective advocate for the Patient.

For Patients who have expressed their wishes regarding particular medical decisions, Patient Representatives must make decisions based upon a substituted judgment standard. For Patients who have never been competent or who did not express their wishes with regard to particular medical decisions, Patient Representatives must make decisions based upon a best interest standard. Using either a substituted judgment or best interest standard to make medical decisions for someone else is challenging. When that “someone else” is completely unknown and their values are completely unknowable, the decision-making standard is not firmly established and is especially challenging. The Committee suggested that a “composite decision-making standard” be employed by the Medical Decision-Making Team, based upon the distinct perspectives of the treating physician (providing a medical prognosis, balancing treatment benefits and burdens), another medical professional (providing peer review of sorts and a balance to a technological imperative to treat), and a chaplain (providing advocacy for the Patient based primarily upon compassion). The recommendation is based, in part, on the Synthetic Judgment Standard promulgated by policy at Brigham & Women’s Hospital.

The Committee recognizes its recommendation is based upon assumptions about chaplaincy training and the ability of chaplains to be effective Patient advocates as participants on a Medical Decision-Making Team. To bring in someone outside of the institutional medical setting to serve on a Medical Decision-Making Team was beset with practical challenges including expediency, transparency, and liability. The chaplaincy service offers the best alternative to provide a person “in house” who is trained in both medical decision-making and compassion. The composite decision-making standard to be applied to the medical decisions made by the Team will provide a previously voiceless Patient with a voice and that is precisely what the Committee hopes for.
Addressing Gaps in Healthcare Decision Making for Unrepresented Adults: A Proposal for the Inclusion of Medical Proxy Decision-Makers into an Office of Public Guardianship

July 31, 2013

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Acknowledgements:

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Overview

The Elder Abuse Task Force, 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 Denver Probate Court has responded with a proposal to create 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.

As noted in the Court’s proposal, county Adult Protective Services (APS) agencies are frequently asked to provide guardianship for the purpose of healthcare decision-making, when patients or residents lack 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 treatment placement. The lack of a decision-maker for health care can leave adults in Colorado 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 medical proxy decision maker”, 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 is incapacitated.

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 are initiated under the “emergency waiver”.

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

**Public medical proxy decision maker (proposed):** A person appointed via the Office of Public Guardianship and authorized to make healthcare decisions on behalf of an unrepresented patient who either temporarily or permanently has lost 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 intervention that does 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 individual 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 intervention 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 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 authorized by the “emergency waiver” and 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 between their standard legal representational role and understanding of difficult healthcare decisions required regarding both clinical treatment and treatment setting. Specifically, 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. They may be elderly persons who have outlived all of their friends and families. They 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 wish 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, in the absence of a consenting party, may hesitate to initiate new treatments without knowing the patient’s wishes and may postpone surgeries or other more elective interventions until they become emergencies. Such delay can increase risk of the 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 continuing to receive disproportionately burdensome treatments because they are unrepresented and unable to make decisions. Here are a few actual stories, from different healthcare providers in the Denver metro area, of vulnerable patients caught in this limbo. A theme of these stories is that patients are stuck in a restrictive environment because they are unrepresented and they often suffer consequences of being in that setting while awaiting authorization for transfer to a more appropriate environment or a decision regarding continuation of aggressive medical intervention.

☐ A 59 year old man was admitted with stroke. He was long estranged from 4 siblings who were unwilling to be surrogates. Unable to speak, the patient could only nod and was unable move his right arm or leg. The providers were unclear whether they should treat him with long-term intubation and resuscitate if his heart stops.

☐ 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 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” because it was in his best interest. No surrogate decision-maker could be found, and the patient needed a supervised setting due to his confusion. It took 5 months for a guardian to be appointed, a condition necessary for transfer to a long term care facility, and he remained in the acute facility (hospital) throughout.

☐ An elderly patient with dementia from syphilis presented to an emergency department with a bloodstream infection. He was stabilized with 6 weeks of intravenous antibiotics;
however, he remained in the hospital, pleasant but without insight or ability to care for himself, for 2 more months until a guardianship hearing could occur and allow him to go 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 3 times a week. Her family refused responsibility and would not authorize her treatment, due to legal concerns and behavior that they could not control. She remains in an acute-care hospital after 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. He was treated in an acute care hospital and found to have dementia as well as require 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 healthcare 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, to receive supervised TB treatment mandated by public health officials. He eventually developed hospital-related infections and died in the hospital, 3 months after admission, on the day his guardianship hearing was finally scheduled.

Colorado Revised Statutes lack clarity about the process for medical decision making when patients lack capacity and are unrepresented. 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. If a patient does not have decisional capacity at the time of admission, or loses capacity following admission, or if the healthcare facility is otherwise unsuccessful in ascertaining the patient's wishes regarding treatment, 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). 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 for the patient 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. If a surrogate cannot be located, a judicially appointed guardian should be obtained. 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, during which significant medical decisions may need to be made (e.g. more elective surgery like placement of kidney dialysis catheters, feeding tubes or tracheostomies), with many decisions not qualified for use of the emergency waiver of consent as applied according to current standard of care and community practice.

Gaps in this system due to the high workload of case managers, the time intensity of the search process, and delays in establishing formal guardianship mean that patients are often substantially
delayed in receiving elective treatments or in discharge to a medically more appropriate and free environment for days or weeks. Critical decisions regarding highly invasive end of life treatment 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 protect 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 surrogates that includes friends as well as family as potential "interested parties," which has been very helpful.

Unfortunately, when the patient is not able to speak for his/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 treatment medical team alone because they lack the opportunity to consult with a representative of the patient. Such decisions encompass the full scope of treatment (White, 2007; Bandy, 2010).

Across the country, there are 5 main processes by which spokespersons can be obtained:

1) Appointed guardians: private, volunteer or public;
2) Attending physicians caring for individual patients;
3) Other clinicians, individuals and entities within the healthcare setting;
4) Institutional committees, like the ethics committee of the institution;

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 statute in Colorado prohibits 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, these entities have struggled to remain sustainable due to 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 creation of a public medical proxy decision maker.

VI. Role and Responsibilities of a Public Medical Proxy vs. a Public Guardian

Unlike the broader authority of a public guardian, the role and responsibilities of a public medical proxy are limited to the scope of health care decision-making. 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 treatment. 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 guardian. These differences include specific issues of timing, complexity, and the necessary 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 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 medical proxy decision-maker 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 medical proxy decision-maker 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 medical proxy decision-maker 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.
Medical proxy decision-making 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 category of "public medical proxy decision-maker", as defined in Section I, with the explicit authority to make decisions regarding medical treatment and appropriate setting for unrepresented patients.

2. Provide the basic training and preparation needed to support the role and responsibilities as defined in Section VI.

3. Define a process by which a public medical proxy decision-maker can be appointed by 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 medical proxy decision-maker on behalf of a patient.
Figure 1: DECISION TREE ALGORITHM
MEDICAL DECISIONS FOR ADULTS IN COLORADO

Is the patient an incapacitated

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

Inform/discuss Risks, Benefits and Alternatives

Are there advance directives* applicable to this situation??

Yes

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

No

Inform/discuss Risks, Benefits and Alternatives

Determine consent**

Are there interested persons?

Yes

Follow Proxy Statute and identify proxy

Inform/discuss risks, benefits and alternatives

No

Perform emergent interventions to save life or prevent severe disability

Petition for Guardianship

Is it an emergency?

No

**Would a reasonable person consent?

Yes

If Yes, then treat at minimum

Determine consent**

*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>
<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>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 for 4-6 weeks, 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</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: SX, MO, NC, OR, CA, CT; with limits: NY, NJ,</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</td>
</tr>
<tr>
<td></td>
<td>San Francisco General</td>
<td>Most knowledgeable about best medical</td>
<td></td>
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<table>
<thead>
<tr>
<th>OTHER CLINICIANS, INDIVIDUALS AND ENTITIES</th>
<th>interest of patient</th>
<th></th>
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</table>
| Florida: social worker | Medical expertise | "..."

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<tr>
<th>Texas: clergy</th>
<th>Surrogate outside of medical system</th>
<th>Unchurched persons excluded</th>
<th>Member of clergy &quot;...&quot; - required to know patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oregon: health care provider trained in bioethics</td>
<td>Appointment by hospital</td>
<td></td>
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<thead>
<tr>
<th>INSTITUTIONAL COMMITTEE</th>
<th></th>
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<tbody>
<tr>
<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>
</tr>
<tr>
<td>CA Kaiser – multidisciplinary;</td>
<td>Timely and transparent; Procedure rather than outcome</td>
<td></td>
</tr>
<tr>
<td>California Consortium (Santa Clara)</td>
<td>Process; presentation by physician, decision separate from treating team.</td>
<td>Ethics committee chair convenes 3+ subcommittee to review proposals (one non-HC and not with organization)</td>
</tr>
</tbody>
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<tr>
<th>EXTERNAL COMMITTEES</th>
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<tbody>
<tr>
<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>
</tr>
<tr>
<td>IA: local substitute medical decision-making boards</td>
<td>All unrepresented patients</td>
<td>Have been hard to set up and sustain locally.</td>
</tr>
</tbody>
</table>

Based on the references found in the reference list.
References


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).


Date: September 17, 2013

To: Frank W. Gold  
Manager/Chaplain – Spiritual Care Services  
Exempla Lutheran Medical Center

From: Jackie Glover, Ph.D.  
Member, Colorado Collaborative for Unrepresented Patients

For several years, the Colorado health care community has struggled with how to effectively and ethically make treatment decisions for unrepresented patients within the constraints of Colorado law. The Colorado Collaborative for Unrepresented Patients (CCUP) emerged from a group of representatives of the Colorado healthcare ethics community, led by the Center for Bioethics and Humanities at the University of Colorado at Anschutz Medical Campus, the Center for Ethics and Leadership in the Health Professions at Regis University, and the Colorado Healthcare Ethics Forum. The goal of the CCUP was to investigate best practices from around the country and develop a concept paper to address the growing issue of unrepresented patients in the Colorado health care system.

The early efforts of the CCUP coincided with the passage of Senate Bill 12-078 and the report of the Elder Abuse Task Force. Members of the CCUP learned that the Honorable Elizabeth Leith of the Denver Probate Court was, in response to the recommendations of the Elder Abuse Task Force, preparing an analysis related to the establishment of an Office of Public Guardianship. A representative of the CCUP met with Judge Leith to determine whether an Office of Public Guardianship would provide a viable option for addressing the issue of unrepresented patients, and it was determined the two projects were mutually supportive.

Over the next several months, the Collaborative developed the enclosed white paper entitled, **Addressing Gaps in Healthcare Decision Making for Unrepresented Adults: A Proposal for the Inclusion of Medical Proxy Decision-Makers into an Office of Public Guardianship.** At the same time, Judge Leith was able to gain approval for the establishment of the Public Guardianship Advisory Committee, which is charged with assessing the need for public guardianship services in Colorado and making recommendations for a model to address that need. Healthcare decision-making is one of the needs the Committee will consider. It is anticipated that a legislative proposal may result from the work of the advisory committee, most likely in the 2015 session.

At this time, the CCUP is soliciting input from interested stakeholders on their proposal to include the role of a medical proxy decision-maker as an element of the larger issue of public guardianship. While it has always been our intention to solicit broad stakeholder support for any proposal and subsequent legislative action, the coincidental timing of the Public Guardianship Advisory Committee has accelerated the time frame. Your organization has been identified as a key stakeholder. The CCUP white paper is attached. We are very interested in hearing your thoughts, concerns and/or endorsements regarding the paper.

As a representative of the CCUP, I would be happy to attend a meeting, engage in a conference call or receive individual emails regarding your comments. I can be reached at Jackie.Glover@ucdenver.edu or by calling 303/724-3992. Alternatively, please feel free to contact any of the CCUP members listed on the following page. Thank you for your consideration. We look forward to continued dialogue regarding options and a potential solution to the dilemmas we all face in caring for this very vulnerable population.
COLORADO COLLABORATIVE FOR UNREPRESENTED PATIENTS

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Guardianship Proceedings in Massachusetts Probate Courts for Health Care Facilities: The Not-so-Uniform Probate Code

by William A. Mandell and Suzanne M. Fuchs

Introduction

On January 15, 2009, Massachusetts joined 18 other states in adopting the Uniform Probate Code ("UPC"). Article V of the UPC went into effect on July 1, 2009, making sweeping substantive and procedural changes to guardianship law, aiming to grant greater protections to the civil rights of incapacitated persons. Further changes to the UPC were adopted in April of 2012, mostly relative to intestate succession and estate administration.

In theory, Article V of the UPC was designed to streamline procedural requirements for appointing surrogate decision makers while protecting the civil rights of the incapacitated by crafting decrees and orders specifically tailored to address particular areas of incompetency. In practice, however, so far the UPC has led to a significant increase in petitions, motions and return appearances being filed by health care facilities for incompetent patients at a time of diminished Probate Court system resources. Under the UPC, health care facilities are more frequently securing the appointment of guardians and seeking specific and modified court orders for admission to skilled nursing facilities, treatment plans for patients unable to give informed consent, non-routine medical decisions and end of life decisions. They are doing so for a broader scope of medical conditions and transfer situations, and finding that: Probate Court judges, in applying the UPC, are often limiting the authority of guardians to give consent for treatments unless further court review and approval are secured.

The UPC instructs Probate Court judges not to confer more authority over a person than is necessary. The balance between an incapacitated patient’s civil rights and the altruistic discretion of hospitals and other treating facilities has been fundamentally altered by the UPC as Probate Court judges are now clearly required to make orders only to the extent necessitated by the protected person’s limitations and other conditions.

Furthermore, the variability of the Massachusetts Probate Courts in applying the UPC often adds delay and unnecessary cost for health care institutions and consequently their ability to efficiently and effectively treat the very individuals that the UPC was intended to protect. For example, the cost effective health care system is designed to move patients out of an acute care setting as quickly as possible when sub-acute level care is more appropriate and a bed placement has opened up for the patient. In order to authorize the transfer of an incompetent patient, who has no involved family members and never appointed a health care agent before becoming incompetent, Massachusetts acute care hospitals are often forced to keep such a patient in the acute care setting pending the appointment of a guardian or the modification of the existing guardianship to authorize transfer to a skilled nursing facility, which is specifically required under the new law. This new aspect of the law results in extended stays in acute settings for extra weeks or months, exposing patients to greater risk of infection and relapse, often without access to needed rehabilitation and long term care services. This occurs while the hospital counsel or family attorney navigates the various courts’ processes, subject to the courts’ overburdened schedules and lack of personnel.

Additionally, health care institutions pursuing guardianships will often encounter the challenge of being in the middle of a dispute with or among the incapacitated individual’s family members about whether a guardian is needed, who will serve as guardian, and decisions as to treatment or treatment discontinuation. More often than not, a facility facing adversarial family members especially needs to petition for guardianship to secure a court order approving the recommended treatment plan. The facility is forced to bear the financial burden of pursuing a guardianship that is significantly delayed by the objecting family members.

Venue limitations under the UPC and inconsistent guardianship proceedings among Massachusetts Probate Courts also challenge health care facility petitioners who must obtain guardians and court orders for treatment and transfers for the growing number of incapacitated
patients lacking duly appointed surrogates as decision makers and/or any involved family members. Clearly, the demographic trends of people in the U.S. living longer are impacting the number of patients in Massachusetts who need a legal surrogate to make health care decisions. The current backlog of cases pending in the underfunded and overburdened Probate Courts across the Commonwealth further delays guardianship proceedings and can lead to great variation of process among the Probate Courts.

General Overview Of Guardianship Law and Procedure Under The UPC

A. Understanding Guardianship Substantive Requirements:

Under the UPC, a guardian may be granted an array of general powers that effectuate the guardian’s ability to act as a medical decision maker on behalf of an incapacitated person. The guardian’s powers fall into three broad categories, and each category necessitates distinct procedural and substantive requirements under the Code. Generally, the first category is known to practitioners as “ordinary medical decision making,” the second is “placement authority,” and the third is referred to as “extraordinary medical decision making” or “substituted judgment” proceedings, which necessitate the appointment of a public defender paid by the Committee for Public Counsel Services who is specifically trained to advocate for the patient in these types of cases.

With regard to the first category, a guardian appointed without any additional authority is generally authorized to make decisions about routine, non-invasive medical procedures. Once appointed by the court, such a guardian may have the authority to “make decisions regarding the incapacitated person’s support, care, education, health and welfare . . . and the guardian shall act in the incapacitated person’s best interest and exercise reasonable care, diligence, and prudence.” Such “ordinary decision making” authority generally gives consent to treatment and arranging appropriate medical inpatient or outpatient care that does not involve any antipsychotic medications. A guardian need not seek explicit orders for each “ordinary” decision, as long as the guardian is appointed by the court and is acting in the incapacitated individual’s best interest. Also, guardians are the duly appointed legal surrogates who have authority over the use and disclosure of the health information for the “person in need of services.”

The second category, placement authority, requires an explicit court order allowing the guardian to consent to placement in a skilled nursing facility or other health care facility. The court, rather than the guardian, after a hearing on the matter, will apply the “best interest” standard in determining whether such authority, and thereby placement, is appropriate. This authority is required for admission of any person under guardianship to any facility licensed as a skilled nursing facility, whether for long term care or any short term rehabilitation, even if only for several days. The requirement also applies regardless of who the guardian is, including those who are spouses, children or other family members as opposed to professional or institutional guardians. Issues also arise regarding persons from out of state and whether the foreign decrees authorize admissions to skilled nursing facilities in the Commonwealth.

Finally, a guardian can only make “extraordinary medical decisions” upon an explicit court order authorizing the specific treatment in question. Extraordinary medical procedures generally fall into two categories: (1) administration of antipsychotic medication, known as “Rogers authority,” and (2) all other invasive treatments. For both types of extraordinary medical procedures, probate courts apply the “substituted judgment” standard, whereby the Court weighs various factors in order to determine the decision that the incapacitated individual would have made if competent. The drafters of the UPC did not specify an exhaustive list of such extraordinary authorities, accounting for and leaving flexibility to adapt to evolving medical techniques and standards. The UPC has, however, codified the following common examples of extraordinary treatment: “[t]reatment with antipsychotic medication, sterilization, abortion, electroconvulsive therapy, psychosurgery and removal of artificial maintenance of nutrition or hydration.” The UPC is not clear as to whether a guardian may consent to a “Do Not Resuscitate,” “Do Not Intubate” or “Do Not Hospitalize” order without specific court authority. Prior to the adoption of the UPC, Massachusetts courts suggested that a substituted judgment finding was required for the guardian to enter a DNR/DNI order. An exception to this requirement may exist when the patient is in acute medical distress, the guardian/family/physician all agree that there is no choice to be made, and avoiding resuscitation or lifesaving measures will not hasten death.

B. Understanding Guardianship Procedural Requirements

Any person “interested in the welfare of the incapacitated” may petition for a determination of incapacity and/or the appointment of a guardian over the incapacitated person (hereinafter “Respondent”).
UPC contains venue rules that require the petitioner to file in the Probate Court of the county where the Respondent resides at the time the proceeding is commenced. Pre-UPC guardianship procedure was more lenient in permitting Massachusetts health care facilities to file petitions of permanent appointment and motions for temporary appointment in the Probate Court located in the County where the facility was located.

Upon receiving a petition for guardianship, the Probate Court issues a citation, which is to be served in hand upon the Respondent as well as the heirs at law at least two weeks prior to the return date listed on the cited. Where there are no heirs at law or the interested parties do not receive notice, a publication must occur in the County where the proceeding is pending at least seven days prior to the return date. G.L. c. 190B §1-401(3). The “return date” is, in effect, a deadline by which interested persons to the case may file an objection. This date is usually about 4-6 weeks from the date of filing of the petition with the Court. A permanent guardianship cannot be completed until this date passes and proof of service upon all interested parties and/or publication is filed with the Court.

While the permanent petition is pending, a petitioner may file a verified motion for the appointment of a temporary guardian if “an incapacitated person has no guardian, and the court finds that waiting during the longer time frame to secure a permanent appointment under UPC procedures will likely result in immediate and substantial harm to the person alleged to be incapacitated occurring prior to the return date, and no other person appears to have authority to act in the circumstances.” A temporary guardian appointment is effective for 90 days, at which time it will be reviewed and new medical documentation will be required. On a temporary motion, the Petitioner must give seven days in-hand notice to the Respondent and the same by mail to any heirs at law. If the Court finds that an immediate emergency exists requiring the appointment of a guardian, it may waive or shorten the notice requirements, provided that the Respondent is notified of the proceeding as directed by the Court, and the Respondent and heirs at law receive notice after the proceeding instructing them that they may vacate the order.

If a petitioner requests ordinary authority or skilled nursing home authority, the court must determine whether such placement is in the best interest of the Respondent. The Court may appoint counsel to represent the interests of the incapacitated person, or a guardian ad litem (GAL) to investigate and provide a report to the Court. If a petitioner seeks extraordinary authority or authority to consent to administration of antipsychotic medication (“Rogers authority”), the court will always appoint counsel for the Respondent.

### Variability of Guardianship Proceedings Among Massachusetts Probate Courts

After a new guardianship petition and motion for temporary guardian is filed it can take two weeks to several months to have the first hearing date depending on where Probate Court the guardianship petition is filed. This length of time, particularly for petitions filed by acute care hospitals, is extremely problematic, costly, and can pose imminent harm to Respondents. The lack of sufficient funding for the Massachusetts Probate Courts has caused cuts to staff and most recently, a limitation on the hours that the Courts are open to consider petitions and motions. This contradiction of service is happening at the same time that the UPC is requiring the Probate Courts to adapt to entirely new rules and process on estate administration while still handling the normal work load. The increasing amount of incapacitated patients is also resulting in significantly more demands on the Probate Courts with more guardianship case filings.

### A. Venue Requirements

The UPC provides that a guardianship petition shall be filed where the Respondent resided prior to hospitalization. This venue requirement seems warranted if the patient has family or friends residing in the same County who are involved with the patient’s care and can provide information about the patient’s preferences prior to his incapacity. However, a growing number of patients are homeless or have resided alone without any known heirs or acquaintances prior to hospitalization. Requiring health care facility petitions to file in a Court that may be a long distance from the facility, causes undue delay, burdens the facility, the guardian the court appointed counsel, and testifying physicians. Further, an incapacitated individual has the right to attend any hearing, and in Rogers cases, must attend a hearing absent extraordinary circumstances. As written, the UPC does not acknowledge exceptions to the venue rule where the patient has no ties to his previous residence.

For example, a Boston tertiary care hospital that must seek a guardianship appointment to secure an order to approve a discharge plan to a sub-acute facility for a patient found homeless in Barnstable County is expected to file the matter in Barn-
hurdles, the method for docketing a file and obtaining a hearing significantly varies with each Probate Court and presents further delays and expense. One common trend is that few of the Probate Courts will now process a file and assign it a docket number and hearing date on the day of filing. In the best case scenario, new matters are docketed within a few days and hearing dates are generally being scheduled ten days from filing. Guardianship cases, even those including motions for temporary appointments, will languish in some Probate Courts. If not pushed as life or death emergencies, these cases will be placed in a pile of backlogged cases and not processed for several weeks, nor heard for several months.

In other cases, the court will not assign a case a court date. Instead, the petitioner must determine which Judge will hear the matter and when that Judge is available, and then attempt to contact the Probate Court to obtain a court date. A date obtained in this manner is often times weeks out, if at all.

C. Appointment of Counsel

Even if a petitioner is successful in docketing within a few days of filing, most of the Probate Courts will not mark-up a hearing date until approximately seven to ten days from filing, which is consistent with proper notice under Mass. G.L. c. 190B §1-401(3). Although judges hold weekly motion days, clerks in many of the busiest Probate Courts are unable or unwilling to schedule new cases less than a few weeks after the docketing of the case, if at all.

When an expeditious hearing date can be obtained, inconsistencies among the Probate Courts in counsel appointment can further delay the process and lead to vast differences in the time it takes to secure the requisite legal authority to implement a discharge and/or treatment plan. Patients needing rehabilitation or long term care services and treatment can remain unnecessarily in acute care settings.

As previously mentioned, all Probate Court judges will appoint Rogers counsel or counsel for the Respondent when consent to treat with antipsychotics or extraordinary authority is sought. Counsel must be notified of their appointment, accept the court appointment and have the opportunity to visit with the Respondent prior to the hearing on a proposed treatment plan. There is a limited list of Committee for Public Counsel Services (“CFCS”) attorneys who can accept Rogers appointments. Again, due to the courts’ backlog, counsel are often not appointed until days or even weeks after the filing of the petition. Often the appointed counsel for the patient does not receive notice of appointment in time for a hearing, cannot visit the patient in time, or cannot accept the appointment at all. In such instances, the initial hearing date on a motion for a temporary guardian and immediate approval of a treatment plan is continued.

Additionally complicating matters are the inconsistencies among judges in appointing counsels and GALs in non-Rogers cases. Where a guardian is needed to authorize the transfer out of an acute care hospital to a home care or non-acute facility setting, currently there are huge and unpredictable variances in the process among the Probate Courts and even the judges within each County. Because the UPC calls for judicial discretion for counsel appointment, some judges routinely choose to appoint counsel, or even a GAL, while others do not. Without knowing judicial preference beforehand,
clerks may fail to appoint counsel, and the petitioners may prepare for a hearing date only to receive an order requiring a counsel appointment on the day of the hearing.

**D. Shortage of Guardians**

In guardianship cases involving patients who have no living or involved family members and never appointed a health care agent while competent, petitioning health care facilities need to identify and secure the services of some suitable person to serve as guardian. Overburdened Probate Court clerks and judges are unlikely to find a willing attorney or social worker to serve as a guardian in patient care cases filed by hospitals and nursing homes. The involvement of the Courts in helping secure guardians varies greatly from County to County. By separating the guardianship function over health care decisions from the conservator functions over financial affairs into two separate legal proceedings, the UPC makes it difficult to find willing volunteers to serve as guardians in cases involving incompetent patients with no involved family or friends who are willing to serve as guardian. For hospitals and other facilities that regularly seek guardianship appointments it has become a constant challenge to secure the services of guardians for incompetent patients. The shrinking pool of guardians is in part attributable to the increasingly complex annual reporting required under the UPC, coupled with the convoluted manner in which professional guardians are compensated for indigent patients. Under the current scheme, a professional guardian can only seek payment for serving a MassHealth patient by seeking approval from the Court to order MassHealth to adjust the amount of the patient’s contribution for her care from external income sources (social security or pension). This adjustment must be authorized by the Court on an annual basis, and it is a mechanism that precious few attorneys will tolerate to serve as guardians. This is a situation that will get worse and warrants a systematic fix.

**E. Process to Affirm Health Care Agents**

As currently written, the UPC provides that a properly designated health care agent’s authority under M.G.L. c. 201D takes priority over the authority of a guardian, and cannot be revoked absent court order. Further, the comments to M.G.L. c. 190B §5308, state that the language of the revised UPC “should aid in preventing the mere institution of a guardianship proceeding from upsetting an arrangement for care under a health care proxy.” Accordingly, it is clear that the drafters of the UPC intended to prioritize designated health care agents and respect an individual’s right to prepare an advance directive.

Under M.G.L. c. 201D §5, a health care agent has broader decision making authority than a court appointed guardian. “The agent has authority to make any and all health care decisions on the principal’s behalf that the principal could make, including decisions about life-sustaining treatment, subject, however, to any express limitations in the health care proxy.” An agent’s powers are not limited to non-antipsychotic treatment plans or consenting to non-extraordinary authority, as are the guardians. Further, an agent may admit an incapacitated individual to a locked psychiatric facility, whereas the under G.L. c. 190B §5-309, a guardian explicitly lacks such authority.

Despite the UPC’s clear intent to uphold the broad authority of health care agents without the need for court intervention. M.G.L. c. 201D §7 makes it easier for the patient who executed a proxy when competent to render it unreliable for the health care provider by refusing treatment or to undergo a procedure authorized by the agent. M.G.L. c. 201D §7 states that “[a] principal may revoke a health care proxy by notifying the agent or a health care provider orally or in writing or by any other act evidencing a specific intent to revoke the proxy.” In such circumstances, this section of the Massachusetts Health Care Proxy Law requires a physician who is informed of or provided with a revocation of a health care proxy to immediately record the revocation in the principal’s medical record and to notify orally, and in writing, the agent and any health care providers known by the physician to be involved in the principal’s care of the revocation.

Thus, hospitals encountering patients who refuse treatment over the authority of their agents often have no choice but to file a guardianship petition or seek a court order affirming the authority of the agent in order to secure the requisite legal authority over treatment decisions. The UPC does not provide for any process to resolve such cases. The Health Care Proxy Law does provide a process through which a petitioner, including a hospital or health care facility, may “commence a special proceeding in a court of competent jurisdiction, with respect to any dispute arising under [M.G.L. c. 201D].” This language suggests that a petitioner may seek to affirm the powers of the agent, but neither M.G.L. c. 201D nor the UPC provide any further guidance on when affirmation of a proxy is appropriate or any procedural guidelines regarding affirming an agent’s continuing authority under a proxy despite a pa-
tient’s refusal to voluntarily submit to treatment.

Some hospitals have been successful in petitioning Probate Court judges to affirm an agent’s authority on the basis of the Probate Court’s general authority. Other hospitals have adopted the practice of seeking a guardianship appointment of the agent in such cases. Currently, there is a lack of uniformity on how to most expeditiously secure the minimum necessary judicial intervention while protecting the patient’s rights. Arguably the patient’s rights would be best served by honoring the prior broad agency appointment. But if there is evidence of unfitness of the agent or a question of sufficient competency by the patient to have the informed capacity to refuse the treatment, then some level of an evidentiary hearing may be required in many of these cases to sufficiently adjudicate the matter.

F. Short Order on Notice

One mechanism that can be attempted by health care facility petitioners, and should be more widely accepted by all Massachusetts Probate Court clerks and judges, is to file motions for short orders of notice due to an exigent medical situation and the necessity of expediting the proceedings. A short order of notice allows the moving party to be heard on its motion within a period of time shorter than the required 7 days notice. Further, it allows a motion to be heard on a day that may otherwise be blocked out by those who schedule motions for the Judge due to the number of already marked up matters. There is a great variance currently among the Probate Courts as to their willingness to permit short orders of notice. In all venues, Court staff and case managers alike are understandably resistant toward any cases filed on emergency status, as it burdens an already strained system. Emergency motions are now almost always met with scrutiny and some push back.

Moreover, each County differs in its procedure to expedite appointment of counsel for matters that may be marked up more quickly. Some judges permit petitioner’s counsel to propose CPC’s counsel who is available on short notice. Other Judges forbid proposing counsel in a motion and instruct that counsel is appointed “off the list” where too often counsel is not appointed in time for the scheduled hearing. In some Counties, depending on the nature of the circumstances, temporary guardianship appointment may be made without appointment of counsel, and subsequent appointment is made with short review date in order to reassess the emergency order. A broader adoption of this approach among more Counties would be helpful.

G. Out-of-State Patients/Jurisdictional Questions

Another major challenge many Massachusetts health care facilities face now under the UPC is with out-of-state incompetent patients. Facilities located near the border of neighboring states, as well as Massachusetts teaching hospitals and centers of excellence, regularly treat out-of-state patients and inevitably many of them are not competent to make informed health care decisions. Many Massachusetts hospitals and sub-acute facilities have service areas that include large portions of Rhode Island, Connecticut, New York, New Hampshire and Maine.

Many out-of-state incompetent patients present without having made out an advance directive recognized by their state of residence. This leaves a major question of jurisdiction and applicable law. Clearly, a Massachusetts hospital cannot treat and discharge such a patient on a non-emergency basis without seeking the appointment of a guardian and would need to do so by filing a petition in a Massachusetts Probate Court. Many Probate Courts, however, will not accept such petitions and instruct Massachusetts health facility counsels to seek an appointment in the state court of the patient’s residence.

In other situations, a patient does have a surrogate in place from another state but additional questions come up as to that out-of-state surrogate’s authority to consent to antipsychotic treatment and other invasive treatments being rendered in Massachusetts.

The American Bar Association has proposed adoption by the states of the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act (“UAGPPJA”). This Act would address jurisdictional issues such as transfer, out of state jurisdiction, and multi-jurisdictional guardianships. Massachusetts could resolve many of these jurisdictional issues by joining the 30 other states that adopted the Act.

H. Consequences of the Variability in Procedure Among Probate Courts

The increasing length of time under current UPC Probate Court practice before a temporary or permanent guardianship is heard is problematic and does not serve the interests of the incapacitated individuals that the UPC was drafted to protect. It is important to understand that most cases initiated by health care facilities are, by their very nature, urgent situations. For patients who do not have a surrogate decision-maker but
are medically stable and ready for discharge, the current Probate Court system is causing acute care hospitals longer than is medically advisable to discharge. These patients are often at greater risk of acquiring healthcare-associated infections, also referred to as nosocomial, hospital-acquired or hospital-onset infections. These patients also remain unable to obtain appropriate rehabilitation or post-acute care, facing the likelihood that his or her condition will deteriorate. Further, proper placements cannot be held indefinitely and are often lost by the time a temporary guardian appointment with the discharge approved by the Court can be secured. Patients who must wait one month for a guardianship order will not be accepted by the originally available post-acute care facility or program as the bed or placement has been filled. Moreover, the patient in a locked psychiatric facility awaiting a guardianship appointment and an order approving a treatment plan must remain in the most restrictive setting, suffering the symptoms of a psychiatric illness without the ability to commence an antipsychotic treatment plan.

Conclusion

The variability of Massachusetts Probate Courts in applying UPC requirements is currently causing unnecessary financial costs to the Massachusetts health care system, inconvenience and uncertainty to litigants and their counsel, and most importantly, is not serving the interests of the incapacitated. Some of the current challenges stem from the financial shortfalls and lack of resources in the system. Many, however, could be easily rectified by UPC amendments and/or more consistent application of procedural steps by all of the Massachusetts Probate Courts in handling guardianship petitions and motions filed by health care facilities. A re-examination of the UPC as applied by the Probate Courts and the handling of all health care intervention matters is due and should be undertaken by the Chief Administrative Justice of the Massachusetts Probate Courts. Such a process could hopefully result in more efficient, fair standardized procedural rules to ensure that the UPC’s intent to create uniformity of procedure and greater rights for the incapacitated is effectively carried out in practice.

(Endnotes)

2 The UPC defines an “incapacitated person” as “an individual who for reasons other than advanced age or minority, has a clinically diagnosed condition that results in an inability to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self care, even with appropriate technological assistance.” Mass. G.L.c. 190B § 5-101(9).
3 Mass. G.L.c. 190B, § 5-106. Under the UPC guardians no longer have any authority over the funds or estate of a person, but rather no authority only over the person’s personal health care decisions. Court appointed surrogate authority over the financial affairs of an incapacitated person is limited to a conservator, who must be appointed through a separate legal process from a guardianship under the UPC.
4 Mass. G.L.c. 190B, § 5-467 (a), (d).
5 Mass. G.L.c. 190B § 5-309 (g).
6 No guardian shall have the authority admit an incapacitated person to a nursing facility except upon a specific finding by the court that such admission is in the incapacitated person’s best interest.” According to the note for § 5-309(g), the requirement of specific authority for admission to a nursing facility is an important new protection for the elderly.
8 7-45 C.F.R. § 164.502 (g)(1) and (2); Mass. G.L.c. 111, §70; Mass. G.L.c. 112, §12C.
9 The UPC replaces the reference of “ward” to “person in need of services” for adult incapacitated individuals.
10 Mass. G.L.c. 190B § 5309 (g).
11 The Court in Rogers et al v. Commissioner of the Department of Mental Health et al., 300 Mass. 489 (1943) held that specific court authority must be sought to administer antipsychotic medication, whereby the court applies a “substituted judgment” standard in order to determine whether an incapacitated individual would have refused treatment if they were not incapacitated.
12 Brophy v. New England Sinai Hospital, 398 Mass. 472 (1986) (At least six factors are weighed in making substituted judgment: the individual’s express preferences regarding treatment; the strength of the individual’s convictions in relation to their refusal of treatment; the impact of the decision on the individual’s family; the probability of adverse side effects; the prognosis with and without treatment; and any other relevant factors); Mass. G.L.c. 190B § 5306A.
13 Massachusetts Comment to Mass. G.L.c. 190B § 5-303.
20 Id.
21 Mass. G.L.c. 190B § 5308 (c).
22 Mass. G.L.c. 190 § 5308 (d).
23 Often urgent and potentially life-threatening circumstances call for even more immediate court intervention which can be availed through the Emergency Injunctive Response System.
24 Mass. G.L.c. 190B § 5309 (g).
26 The current hours for Massachusetts Probate Courts are 8:00am - 3:00pm.
29 See 130 C.M.R. 520.026 (E)(3).
30 Mass. G.L.c. 190B §5-309 (e).
31 Mass. G.L.c. 190B §5-309.
33 Mass. G.L.c. 190B §7 (emphasis added).
34 Mass. L.c. 190B §7.
35 The National Guardianship Association describes UAGPPA on their website, http://www.guardianship.org/uagppa.htm
(Endnotes)

1. All references in this article to ACA are derived from Title 2 of the Patient Protection and Affordable Care Act (PL. 111-148) and the Health Care and Education Reconciliation Act of 2010 (PL. 111-152). All references to Chapter 58 are derived from Chapter 58 of Acts of 2006. For ease of reading, we have not footnoted every instance when the law is referenced.


4. Implementation of many other features of ACA, including development of Exchange rules, is a joint venture between the Massachusetts Health Connector, tax changes, and insurance market rules, are well worth consideration. These features have all been put into effect.

5. ACA provides a limited number of exceptions, for instance, on the basis of immigration status, religious beliefs, or membership in an Indian tribe.

6. Such legislative action will not be necessary if the United States Supreme Court strikes down the individual mandate in Department of Health and Human Services v. Florida, Supreme Court Docket No. 11-338.


8. See ACA, at §1513 and §1016.

9. See id. See also chapter 302, sections 16 and 19 of the Acts of 2006 (establishing quarterly testing instead of annual).

10. See id. See also 145 CMR 16.00 et seq.

11. See id. See also 145 CMR 17.00 et seq.

12. See id. See also 145 CMR 18.00 et seq.

13. For instance, the Chapter 58 defines “full-time” as 35-hour work week, whereas ACA uses a definition of 30-hour work week. See supra.

14. ACA, § 2707 (a).

15. Chapter 58 of the Acts of 2006 required individuals to purchase coverage that meets minimum requirements in order to avoid paying a tax penalty to the Massachusetts Department of Revenue pursuant to M.G.L. c. 62H, Section 2. The Connector Authority defined the requirements for MCC, see 956 C.M.R. 5.00.

16. Subtitle D – Affordable Coverage Choices for All Americans, Part I – Premium Tax Credits and Cost Sharing Reductions, Section 1401. The Connector Authority has established Section 12 of Subchapter D of Chapter 58 of the Acts of 2006. [Specific statutory citation required]

17. Self-insured plans that are not subject to state insurance regulation pursuant to Section 514 of the Employee Retirement Income Security Act (ERISA) are exempt.

18. ACA, § 1302 (a)(1).

19. ACA, § 1302 (b).

20. Limitations on annual cost sharing are capped at Section 225(c)(2)(A)(i) of the Internal Revenue Code of 1986 (Currently $6,050 for an individual and $12,100 for a family). Section 1302(c)(2)(A). ACA contains provisions for indexing of annual limits.


22. Cost sharing requirements are defined in a separate bulletin, Internal Value Cost Sharing Reductions (Feb. 24, 2012).

23. Should a state not select a benchmark plan, the default benchmark plan for the state will be the small group plan with the largest enrollment in the state.


25. ACA, § 1311(d)(3)(B).

26. See DOI presentation on results of survey of potential benchmark plans presented to ACA Stakeholder Working Group, March 12, 2012. Examples of differences between the small group plans include routine eye care exams, dental services, physical and occupational therapy, coverage, and speech generating devices. Differences between the small group coverage and the state employees’ Group Insurance Commission (GIC) include: skilled nursing and rehabilitation therapy, private duty nursing, assisted reproductive technology, early intervention, hearing aids, chiropractic therapy, and physical and occupational therapy. Most differences relate to number of visits.

27. See id. Massachusetts’ mandates on Autism Coverage and Infertility not part of FEHB.

28. 956 CMR 5.00: Minimum Creditable Coverage


31. See Department of the Treasury, Proposed Rule on Health Insurance Premium Tax Credit, 26 CFR Part 1, 76 Fed. Reg. 50931, August 17, 2011. The monthly credit amount is equal to the lesser of either the premium for the month for one or more QHPs covering the individual or family, or the excess of the adjusted monthly premium for the “benchmark” plan offered through the exchange. See Proposed 26 CFR Part 1, 36B-1.


33. Provided of course that the state does not implement a Basic Health Program, which provides coverage to individuals earning between 133% and 200% FPL.

34. ACA §1421 - Small Business Tax Credit. Credit for Employee Health Insurance Expenses of Small Businesses. Amending Subpart D of Part IV of Subchapter A of Chapter 1 of the Internal Revenue Code of 1986 by adding a new Section 45R.
Making Medical Decisions for Patients without Surrogates

Thaddeus Mason Pope, J.D., Ph.D.

People who are decisionally incapacitated but haven't provided advance directives for their health care and have no health care surrogates — sometimes called the “unbefriended” or “unrepresented” — are some of the most powerless and marginalized members of society. Most of the unrepresented are elderly, homeless, mentally disabled, or socially isolated. Yet medical decision making for these vulnerable patients often lacks even minimally sufficient safeguards and protections. Consequently, health care decisions made on their behalf are at risk of being biased, arbitrary, corrupt, or careless.

Most U.S. states have similar processes for making treatment decisions on behalf of patients without capacity (see table). In an emergency, clinicians can treat patients without their consent. For nonemergency situations, patients may have completed a Physician Orders for Life-Sustaining Treatment (POLST) form or advance directive with instructions that clearly address their current circumstances, or they may have appointed a health care agent or durable power of attorney. But most patients have taken neither of these steps, so 43 states have “default surrogate” laws specifying who can make decisions. In most of these states, a spouse is designated first, followed by adult children, parents, siblings, and often other relatives and friends.

None of these decision-making mechanisms, however, can help the unrepresented. They have no POLST forms, no advance directives, no agents, and no default surrogates. And the unrepresented are a big group — including some elderly and mentally disabled patients, as well as many who are homeless or socially isolated. In many states, lesbian, gay, bisexual, or transgendered patients may have same-sex partners who could serve as decision makers but are not legally recognized as surrogates. Experts estimate that 3 to 4% of the 1.3 million people living in U.S. nursing homes and 5% of the 500,000 per year who die in intensive care units are unrepresented.

Who can consent to treatment on behalf of these unrepresented patients? In almost every state, the only legally authorized decision maker is the court-appointed guardian. But that solution is usually inadequate, for several reasons: the judicial process is too slow and cumbersome relative to the need for treatment decisions, it’s expensive, and guardians often lack time, given their heavy caseloads, to learn about the patient. The biggest problem, though, is that guardians are often unavailable. Most court-appointed guardians are family members, but unrepresented patients have no available family. Professional guardians are unwilling to serve if the patient has no resources. In many states, not even the use of public guardians is practicable. For example, in 2010, Georgia enacted a new medical-guardian statute specifically to help the unrepresented, but a recent survey of Georgia probate judges indicates that the law is ineffective because there’s a shortage of people willing to serve.

So what happens to unrepresented patients when there is nobody authorized to consent to medical decisions? Clinicians exercise substituted judgment to the extent that that’s possible. Otherwise, they aim to make decisions that are in the patient’s best interest. But when clinicians do not hear the “voice” of the patient, they may provide treatment discordant with his or her preferences, values, and best interest.

We can do better. Most model and institutional policies start with prevention, by promoting measures that aim to keep patients from becoming unrepresented in the first place. That means, first of all, protecting and promoting patients’ ability to make their own health care decisions to the greatest extent possible. Capacity is not all or nothing; it fluctuates and can often be preserved through “supported decision making,” such as assisting the person to make and communicate preferences and choices. Second, while patients still have capacity, they should be helped to complete an advance directive appointing an agent and an alternate agent, so that when they really do lose capacity they will have someone to make treatment decisions. Third, in cases in which no agent or default surrogate is initially available, a thorough and diligent search should be conducted. Often, a surrogate can eventually be found.
— and even if that turns out not to be the case, casting a wide net to include friends and pastors can at least provide evidence of the patient’s values and treatment preferences.

But for many patients, even improved preventive measures won’t work. If we can’t keep the patient from becoming unrepresented, who should make treatment decisions? Who should play the role of surrogate and apply the substituted-judgment standards as the individual physician decision maker. But the committee has greater ability to discover and diligently represent the patient’s wishes, to offer and consider various perspectives, and to weigh both medical and nonmedical considerations.

Ideally, this ethics committee would be external to the health care facility, like the committees used for unrepresented patients in the New York and Texas mental health systems. Many areas of the country already have citywide or regional ethics committees that could assume this role. But even an intramural committee would be a substantial safeguard, at least until novel solutions are developed. This solution should not be resource-intensive, since almost all hospitals already have an ethics committee.

Unfortunately, only five states have formally empowered existing institutional multidisciplinary committees to make treatment decisions for unrepresented patients. The remaining states have no clear legislative or regulatory guidelines, so in order to ensure transparency and fair process for unrepresented patients, it is up to facilities to develop their own institutional policies. So long as legally sanctioned mechanisms are nonexistent or inadequate, I believe that providers have both the duty and the discretion to design these policies.

The best approach would carefully balance due process and efficiency. Clearly, we need a decision-making process that not only is accessible, quick, convenient, and cost-effective but also provides the important safeguards of expertise, neutrality, and careful deliberation. Ideally, the mechanisms we develop would not only increase the quality of decisions but also provide a greater sense of social legitimacy.

Disclosure forms provided by the author are available with the full text of this article at NEJM.org.

From the Health Law Institute, Hamline University School of Law, Saint Paul, MN.
Railways, Industry, and Surgery — The Introduction of Risk Management

Thomas Schlich, M.D.

Trains sometimes derail, planes crash, factories collapse — yet we take trains and planes and keep building factories. We have learned to live with risk. The notion of risk is so common that it has been described as a defining feature of modern societies. Modern risk management has made risk calculable and to some extent controllable. It is also a central feature of medical intervention, most notably in surgery. But when risk management was initially introduced into surgery, in the 1870s, it was not only because of developments in medicine (such as antisepsis) but also because of precedents in the railroad and manufacturing arenas. This new attitude toward risk led to greater use of surgical interventions and, I would argue, was at least as important as antisepsis for the development of the field.

Before the late 19th century, surgeons had engaged in what might be called the “management of chance.” A particularly instructive example of this approach is encapsulated in an 1854 essay by the Russian surgeon Nikolay Pirogov, aptly titled “On Luck in Surgery.” As Pirogov knew, surgeons had always been particularly vulnerable to being blamed for bad outcomes, since the link between an operation and the death of a patient is normally obvious and hard to deny. Pirogov assumed that the reason why surgeons had always had to cope with this problem was that outcomes in surgery were essentially beyond the practitioner’s control. Surgeons needed a certain “practical tact,” explained Pirogov, to judge whether or not to operate in a situation in which the odds could neither be completely known nor influenced. Such decisions had to take into account a whole economy of risk, involving the influences of both medical and nonmedical factors. Surgeons incurred particularly high risk to their reputations and future work, for example, when operating on a patient of high social standing. Some patients, Pirogov advised, should therefore be referred to colleagues. Others should be dissuaded from undergoing surgery altogether. Involving several doctors in a given case could disperse responsibility. One could also try to perform as many safe operations as possible so that the occasional failure would not spoil one’s mortality statistics. However, at the end of the day, all these strategies had their limitations. The power of hidden factors and pure chance was too strong. Pirogov explicitly rejected the idea of using statistical calculations to deal with this uncertainty because, he explained, the chance element in probability calculations made them inapplicable to the surgeon’s day-to-day work.

In 1881 the German surgeon Richard von Volkmann suggested that the traditional surgeon resembled a farmer who could only cultivate his land and wait to see how his harvest turned out, whereas the modern surgeon, with antisepsis at his disposal, resembled a manufacturer from whom the public expected consistently high-quality products.1 Volkmann had adopted Joseph Lister’s antisepsis a decade earlier and had become Germany’s most influential proponent of the antiseptic method, an innovation that had engendered an unprecedented expansion of surgery. Operations whose performance would have been considered insane or criminal just 15 years earlier were now performed routinely. The decisive advantage of antisepsis, however, was the predictability of good results so...
How chaplains are a valuable part of the health care team

REV. SUE WINTZ / EDUCATION | MARCH 31, 2016

As health care settings become more focused on patient experience and care for the whole person, issues of culture, diversity, personal beliefs, and values have come to the forefront. Staff are expected to deliver not only high-quality clinical care but to do so with compassion and care. Neither of these elements are new, but they are gaining attention as health care is increasingly measured on a number of quality indicators, including patient satisfaction and outcomes.

As health care leaders and administrators face these challenges, unfortunately, many are unaware of a valuable resource that can contribute to their clinical care and organizational goals: professional chaplains. At the same time, they can do their share to help advance optimal spiritual care, to benefit their patients and their families, staff, and organization.

Professional chaplains have been part of hospitals and other health care settings for decades: spiritual care specialists who contribute a unique expertise to interdisciplinary teams. The credentials of a professional chaplain demonstrate a rigorous training similar to other disciplines: graduate degree, clinical residency, demonstration of competency, national certification or credentialing, and annual continuing education.

They bring expertise that is essential to patient and family care, including: assessing, responding, documenting and communicating issues of spiritual distress and interventions to other members of the team; acting as cultural brokers, ensuring beliefs and practices are identified and integrated into care; participating in invaluable conversations when ethical issues arise and consultations are needed; and educating physicians and other clinical staff on spiritual, religious, existential or cultural components that influence beliefs and values, as well as how they can respond as “spiritual care generalists.”

Yet, at a time when perhaps health care chaplains can be more of an asset than ever, there are several issues that have been inhibiting the profession. They are issues that cannot be ignored, not just within the discipline of chaplaincy but by health care leaders.

While professional chaplains, like other disciplines, have graduate education and clinical training, they are also trained in a specialized model, partly because of the expertise they bring, the issues they address and facilitate, and the uniqueness of their role as members of the health care team. For the most part, the current method of training chaplains has remained the same for decades, despite the changes in not only health care but also in the educational advances that other disciplines have incorporated: standardized patients, online learning, and a set of outcome-focused competencies that are validated not only by subjective evaluation but objective testing.
As a result, rural and small town health care settings often find themselves addressing spiritual care needs by hiring untrained chaplains or community religious leaders, which impacts both the quality of care provided and the sensitivity to diversity that is required. In addition, the other members of the clinical team aren’t able to receive the training and support they need — and ask for — in providing generalist spiritual care.

An accompanying issue is the need for a consistent continuing education pathway for chaplains to increase their skills as they grow in the profession and to be able to respond alongside other disciplines to changes in health care delivery.

Health care organizations, administrators, physicians, nurses, and other professionals, as well as the patients and families served, deserve better. It is long past time to determine how to bring training to those who wish to become professional chaplains, those who want to continue to advance their knowledge, and those from other health care disciplines who want to include attention to spiritual needs as a component to their scope of practice.

Also blocking chaplaincy from being on par with other disciplines and, thus, perhaps on the radar of administrators, has been the lack of specific quality indicators and scope of practice in this field. This has now changed.

A distinguished, international panel of experts recently developed and released quality indicators, the field’s most comprehensive evidence-based indicators that demonstrate the quality of spiritual care in health care, along with the metrics that indicate such care is present and suggested evidence-based tools to measure that quality. The set of 18 indicators include spiritual care that reduces spiritual distress, increases client satisfaction, and facilitates meaning-making for clients and family members.

On the heels of this, a separate panel of interdisciplinary experts developed and released the first evidence-based scope of practice, or set of competencies, for professional chaplaincy. They describe how chaplains can help their organizations meet the quality indicators and “effectively and reliably” provide best quality spiritual care.

The statements most directly impact professional chaplains, but they have broad ramifications for spiritual care and health care in general. They give spiritual care specialists, other providers, and administrators a framework in which to provide quality spiritual care in health care settings while also informing the training and ongoing education of chaplains. With them, organizations can better access and guide the provision of spiritual care and demonstrate its value to health care outcomes.

As the profession continues to evolve, there are several actions health care leaders can — and should — do now.

The first step is determining whether your organization has a chaplain(s) on the team. If not, an essential element of whole-person care is missing.
Next, ensure that the chaplain has the education, training and credentialing that is recognized within the profession, and advocate for competency for best patient outcomes.

Encourage other members of the interdisciplinary team to obtain basic knowledge of spiritual care to incorporate into their scope of practice and to facilitate interactions with and referrals to chaplains.

Read the quality indicators and scope of practice documents, and, in collaboration with the organization’s chaplaincy department, commit to the suggested quality indicators and competencies. Make your voice known that you value chaplains as members of the interdisciplinary team, and support the move within the profession to explore new avenues of training, standardization of practice, and commitment to research and quality.

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