Unrepresented Patient Ethics Consultations: An Integrated Process for Decision-making When a Patient's Voice is Absent

Over the past several years organizations across the country have experienced a growing number of patients who are determined by their providers to lack capacity and who, at the same time, do not have an identified decision-making representative. These patients are often referred to as "Unrepresented Patients" (or "Unbefriended Patients", though respect for their dignity and personhood compels the shift in vocabulary to the more compassionate language of "Unrepresented" vs. "Unbefriended"). They are, indeed, one of our most vulnerable patient groups since their voices are nearly or completely absent in conversations about their treatment goals, perceptions of risks and benefits, and values and preferences.

Given the complexities and vulnerabilities inherent in these cases, we have implemented a formalized Unrepresented Patient Ethics Review process (a copy of which you can find at the end of this article). This process, aligned with both the longstanding American Bar Association Consensus Statement from 2003 and the recently revised American Geriatric Society Position Statement from 2024, aims to:

- Acknowledge and address the vulnerabilities of patients without a voice;
- Represent the patient's known or perceived preferences as closely as possible;
- Navigate clinical realities without delaying necessary treatment decisions;
- Uphold the patient's dignity throughout their care experience; and
- Support the care team with multidisciplinary and administrative collaboration and thoughtful deliberation.

This ethics review process is started when the designated care team member (usually a social worker or case manager) identifies a patient without capacity as also being without a decision-making representative. We have found that early activation has increased the efficiency of our process and seems to be reasonable from a logistics perspective. Once activated, the Unrepresented Patient Ethics Review process continues until the patient regains decision-making capacity, a legally authorized representative is identified, the patient is transferred to another facility, or the patient passes away.

In order to facilitate the ethics review process, the Unrepresented Patient Ethics Review

flow sheet includes several key questions for consideration, including:

- What, if any, decisions does this particular patient have the capacity to make at this time?
- Is there a way to ascertain what the patient's values/preferences might be? What the patient might say/is saying?
  - For example, cautious consideration of past behaviors/decisions, or perceptions of acquaintances.
- What are the goals of treatment and how would this intervention move towards those goals? What is the usual treatment plan for patients in this clinical condition (standard treatment/ clinical best interest)?
- How would interventions being considered promote the overall dignity of the patient as defined by the following:
  - Promotion of health and human flourishing
  - Totality & right to bodily integrity (ie., least invasive/restrictive means, reversibility of treatment/outcomes)
  - Maintenance or enhancement of comfort and function
  - Prevention/alleviation of suffering; pain and symptom management
  - Obligatory nature of treatments considered ordinary/standard vs. extraordinary/reaching limit of what medicine can do
- How is this decision aligned with institutional guidance (i.e., the ERDs, Mission Statements, regulatory requirements)?
- What relevant state laws or organizational policies should be considered for this situation?
- What are the potential sources of conflict of interest and bias within the review team and how can we mitigate?
- From whose voice(s) have we not yet heard? Can we hear from them prior to the decision?
- Is there an opportunity if the patient regains capacity to identify a possible surrogate or explore future patient preferences?

We also include a fairly rhetorical question designed to keep us humble within the context of our process:

- What if the patient would disagree with this plan even after careful review?

While there is often limited or no opportunity to follow-up with patients who do not regain capacity or who pass away to determine if they would actually agree or disagree with the decision, we consider inclusion of this type of question important as it calls us to continually consider that each individual patient is unique, and that our deliberation process, though thoughtful and as thorough as possible, does not entirely replace the unique perspective of each person we serve.

While we've had a version of this Unrepresented Patient Ethics Review process in place for several years, we recently identified a need for review and revision. For example, there had been delays in implementing the process because of a misperception that the process was intended only to determine if it would be appropriate to seek outside guardianship. Because public guardian resources are often scarce, and because the appointment of a guardian may impose additional burdens on the patient if and

when capacity is regained, we wanted to include key questions for consideration to help evaluate whether or not a guardianship appointment is the most ethically reasonable option. The revised tool includes questions to help with this evaluation and is required within our ministries as a first step towards moving forward with public guardianship appointment processes.

We also identified a need to re-educate providers and team members about the process, and opportunities to clarify key points within the flow-chart itself. The revised version you see here includes clarification that the process should be implemented as soon as the patient is assessed to lack capacity and identified as not having a representative available to assist with medical decisions. It clarifies that it is typically the responsibility of the case manager or social worker to contact the Ethics Consultation Service to start the process. Finally, it clarifies what to do if urgent (not emergent) medical decisions need to be made before the first meeting or between meetings, by prioritizing due diligence to start the Ethics Consultation process but allowing for decisions made by consensus of at least two providers to avoid unnecessary delays in treatment.

While we believe that this process offers an ethically sound approach to decision-making in these circumstances, there are certainly challenges and limitations. These include the time involved in gathering the review team with the wide scope of key stakeholders, the continual turn-around and attrition of key stakeholders which requires continual education about the process itself, and the inherent conflict of interest resulting from an exclusively organizationally-affiliated review team. While some states served by our organization require community members as participants in their Unrepresented Patient Ethics Review consultations, we chose instead to review the process itself with our Patient and Family Advisory Councils to solicit their broader feedback and community-based perspective. We plan to revisit these groups with updates on the process, to share statistics and trends, and to gather any additional feedback from these groups in the near future.

Overall, we have found the Unrepresented Patient Ethics Review process to be an effective approach to medical decision-making in cases where some of our most vulnerable patients' voices are difficult to hear. We will continually work to improve this process in order to identify opportunities to improve efficiency, effectiveness, responsiveness, and representation for those we serve in this way. ✣

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ENDNOTES

- Dixon, J. D., Josyula, A. V., Javier, N. M., Zweig, Y., Singh, M., Kim, L., Thothala, N. and Farrell, T. W. (2025). American Geriatrics Society position statement: Making medical treatment decisions for unrepresented older adults. *Journal of the American Geriatrics Society*, 73(5),1353-1364.
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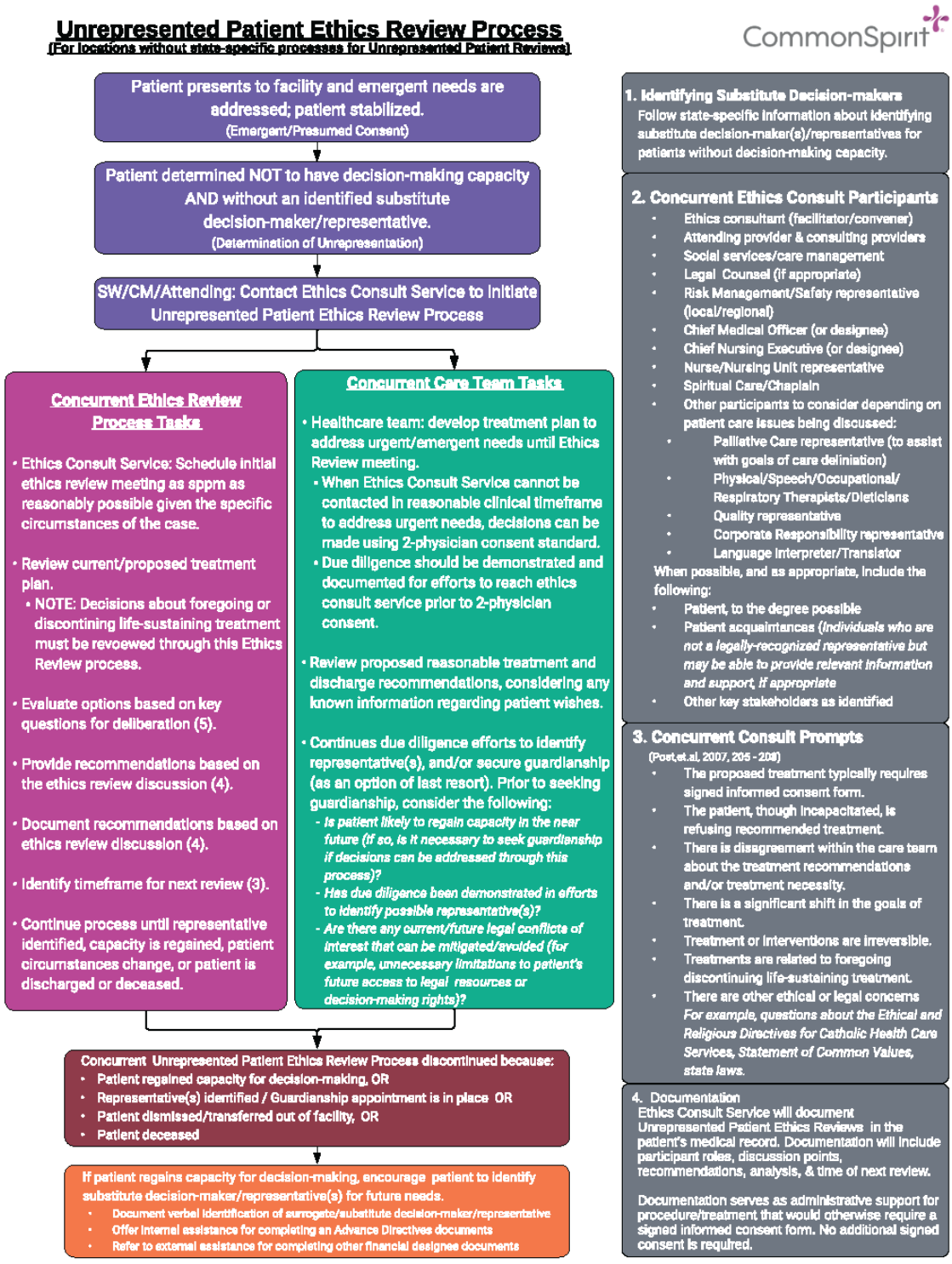

5. Key Questions for Consideration

- What, if any, decisions does this particular patient have the capacity to make at this time?
  Note that decision-making capacity can vary based on the type of decision and over time.
- Is there a way to ascertain what the patient's values/preferences might be? What the patient might say/is saying?
  For example, cautious consideration of past behaviors/decisions, or perceptions of acquaintances.
- What relevant state laws or organizational policies should be considered for this situation?
- What are the potential sources of conflict of interest and bias within the review team and how can we mitigate?
- What are the goals of treatment and how would this intervention move towards those goals? What is the usual treatment plan for patients in this clinical condition (standard treatment/clinical best interest)?
- How would interventions being considered promote the overall dignity of the patient as defined by the following:
  - Promotion of health and human flourishing
  - Totality & right to bodily integrity (ie., least invasive/restrictive means, reversibility of treatment/outcomes)
  - Maintenance or enhancement of comfort and function
  - Prevention/alleviation of suffering; pain and symptom management
  - Obligatory nature of treatments considered ordinary/standard vs. extraordinary/reaching limit of what medicine can do
- How is this decision aligned with institutional guidance (i.e., Mission Statements, regulatory requirements)
  - For Catholic institutions, the **Ethical and Religious Directives for Catholic Health Care Services** (ERDs)
- From whose voice(s) have we not yet heard? Can we hear from them prior to the decision?
- Given all of the information at hand what is the most ethically reasonable option at this time?
- What if the patient would disagree with this plan even after careful review?
- What opportunities might there be to proactively identify a decision-making representative and/or clarify patient preferences if the patient regains decision-making capacity?

Hallmarks of a Well-Designed System

(American Bar Association Consensus Statement – 2003)

- **Focus on the patient.** *Any system should be patient-centered.*
- **Independence and freedom from conflicts of interest.** *There should be sufficient objectivity so that decisions are not subject to undue personal and institutional biases.*
- **Continuity of care.** *Care should not be disrupted or needlessly postponed while the process operates.*
- **Applicability to a full range of decisions.** *While any one mechanism might be limited in scope (for example, specifically excluding end-of-life treatment decisions), the system as a whole should cover the gamut of medical treatment.*
- **Emphasis on least restrictive alternatives.** *Options that stress patient involvement where possible and do not unnecessarily remove fundamental rights are preferred. Thus, guardianship, which strips individuals of basic rights and puts their lives and medical treatment in the hands of the court, is truly a last resort.*
- **Promptness.** *Decisions should be timely. As with justice, care delayed is often care denied.*
- **Cost-effectiveness.** *As states and localities face budgetary crises, they must prove that systems are economical. Careful tracking may show that effective decision-making mechanisms for this at-risk population can actually save public dollars over time.*
- **Accountability.** *Decisions should be tracked and regularly evaluated to ensure a high quality system.*
- **Expertise.** *Decision-makers should have sufficient background and/or receive training on health care law and ethics and on communicating with elderly patients—and should have timely access to sufficient expertise on clinical issues.*
- **Credibility.** *The system should be recognized as a qualified arbiter on health care decisions and have the trust and confidence of professionals and the public.*

Policy & Clinical Practical Advice

(American Geriatric Society Position Statement - Rev 2024)

- *The term "unrepresented" should replace the term "unbefriended" when referring to a person who (1) lacks decisional capacity to provide informed consent to a particular medical treatment; (2) has not executed an Advance Directives document that addresses the medical treatment at hand and lacks capacity to do so; and (3) lacks representation from a surrogate decision maker (ie. family, friend , or legally authorized surrogate.)*
- *Clinicians and institutions should advocate for the inclusion of nontraditional surrogates wherever appropriate.*
- *Clinicians, health care organizations, communities, and other stakeholders should work proactively to prevent older adults without potential surrogates from becoming unrepresented.*
- *Clinicians, healthcare organizations, communities, and other stakeholdesr should develop innovative, efficient, and accessible approaches to promote adequate protections and procedural fairness in decision-making for unrepresented older adults.*
- *Medical decision-making for unrepresented older adults should include adquate safeguards against ad hoc approaches, seek consensus where possible, and ensure procedural fairness.*
- *Clinicians should assess medical decision-making capacity in a systematic fashion.*
- *Clinicians and healthcare institutions should develop, standardize, and systematize methods to make decisions for unrepresented older adults in urgent, life-threatening situations.*
- *Clinicians and healthcare institutions should ensure that patients long-term icapacity have longitudinal access to a decision-making surrogate who is familiar with the patient's medical condition and specific circumstances.*
- *When applying the best interest standard to unrepresented older adults, institutional committees should synthesize all available evidence, and should take steps to guard against perpetuation forms of potential bias in decision-making for this highly vulnerable population.*