



**Organizing an ICU Palliative Care Initiative:
A Technical Assistance Monograph from The IPAL-ICU Project**

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Introduction. In prior monographs, in the [IPAL-ICU Portfolio](#), we have described models for structuring an ICU palliative care initiative, potential standards that could serve to guide such an initiative, and measures to evaluate results and identify opportunities for further improvement of palliative care quality in ICUs. The present monograph focuses on practical steps for organizing an initiative that will succeed and endure in improving palliative care for critically ill patients and their families. Specifically, we address: 1) convening an interdisciplinary workgroup to plan and lead the effort; 2) assessing needs and resources for improving palliative care in a particular ICU; 3) developing an action plan to address existing needs in the context of available resources; and 4) engaging the interdisciplinary ICU team to create a culture supporting palliative care improvement.

1. Convene an Interdisciplinary Planning/Implementation Workgroup. The first step in organizing an ICU palliative care initiative is to identify a core group of individuals who will collaborate to plan and lead implementation of the effort. This workgroup should represent “key stakeholders” including leaders from the ICU, the palliative care consultation service (if present, as in the majority of US hospitals), and hospital administration. Representation of both physicians and nurses is essential, and involvement of other disciplines is optimal. A list of potential participants in the workgroup is presented in **Table 1**.

Table 1. Potential Members of ICU Palliative Care Planning/Implementation Workgroup
●ICU Medical Director
●ICU Nurse Manager
●Director of Palliative Care Consultation Service
●Nursing educator
●Social worker
●Chaplain
●Hospital leadership: administration and finance
●Case manager
●Information Systems specialist
●Other individual(s) believed to be important to success for specific initiative (e.g., ethics consultant, mental health professional, pharmacist)

Ideally, the workgroup will include both the ICU physician and nurse directors, since these individuals, if committed to the effort, are in the best position to address needs realistically, allocate resources and staff to effect change, and engage broader support from institutional leadership and ICU colleagues. In addition, they have the clearest understanding of systems and processes for ICU care, on which design of the improvement effort must focus. They can make specific assignments to other members and track completion of assigned tasks. If the ICU uses an “open” care model without an intensive care physician as director or full-time attending, a physician leader from a service that frequently admits patients to the ICU should be included in the workgroup. Participation by physician and nurse leaders from the palliative care consultation

service helps to cement the collaboration across specialties and disciplines. Representation of other disciplines that contribute to ICU patient and family support, such as social work, psychology, and chaplaincy, promotes consideration of the full range of palliative care needs and incorporation of appropriate strategies to meet these needs. The staff of some ICUs includes a case-manager and/or quality monitor, who can also provide useful input. Since changes in clinical practice and work processes usually require educational support, staff educators should be included. Other individuals who may be important to success of an initiative in a specific ICU or institution include ethics consultants and pharmacists. Finally, improvement efforts in palliative care and other areas of ICU practice have been greatly strengthened by participation of hospital leaders, who can help the team to conceive the initiative for optimal effect in its institutional context. Although the work of this group will vary according to the unit, the institution, and the project's scope, workgroup members should be prepared to commit to attendance at frequent (ideally, at least every two weeks) meetings over a sustained (6 to 18 month) period.

2. Conduct a Needs Assessment. An improvement effort should be designed to address specific needs of ICU patients, families, and/or providers, using resources that are or can be made available for this purpose. Although such needs may be felt intuitively by staff, it is important that they be defined and demonstrated as clearly as possible. Appropriate needs assessment identifies opportunities and priorities for improvement, highlights the importance of the initiative, justifies the investment of resources including staff effort, helps to build support and collaboration within the ICU, and provides a baseline for evaluating results. In addition, the initial evaluation can be used to engage hospital leaders in the initiative and strengthen the case for institutional support. Even in a single institution, each ICU has its own profile of needs and resources. Thus, the needs assessment should be conducted within a local context, focusing specifically on the unique profile of the ICU in which a palliative care initiative is planned. This assessment should be completed at the outset, before the development of strategies to improve care.

Define the Problem. An ICU palliative care initiative is often prompted by concerns about one or more of the following: 1) high rates of death or other unfavorable outcomes in the ICU or the same hospitalization; 2) high utilization of critical care resources for patients who are unlikely to benefit, constricting availability for other patients in need; 3) distress or dissatisfaction reported by patients and/or families; 4) delayed and/or inconsistent performance of evidence-based palliative care processes; 5) distress or burnout experienced by ICU staff; and 6) underutilization of palliative care specialists in care of ICU patients. **Table 2** below sets forth examples of data that may help to define such concerns more specifically. In determining which types of data and how much to collect, feasibility is a crucial consideration, since resources for the data collection effort are often limited.

Data relating to mortality and other outcomes can help to identify patient groups to which interventions might be appropriately targeted. Hospital administrative databases routinely contain fields for status at ICU and hospital discharge and for discharge destination of survivors. Basic information about source of admission (e.g., Emergency Department, hospital ward, inter-

institutional transfer), demographics, diagnoses, procedures, also found in such databases, can then be used to define groups expected to derive greatest benefit from an ICU palliative care intervention, such as those at highest risk for mortality or dependence on institutional care.

Table 2. Data Defining Problems to be Addressed by an ICU Palliative Care Initiative

Mortality / Other Outcomes	Proportion /profile of patients dying in ICU or in same hospitalization
	Proportion/ profile of patients requiring institutional care after hospital discharge
Utilization	Length of stay in ICU and hospital
	Proportion /profile of patients with long length of stay
	Frequency of Emergency Department diversion and or surgical scheduling delays due to lack of ICU bed availability
Patient/Family Distress	Patients' symptom ratings
	Scores on family satisfaction surveys
Care Processes	Proportion of patients with documentation of interdisciplinary family meeting addressing goals of care
	Proportion of patients receiving pastoral care visit
Staff Distress	Surveys or focus groups of physician and nursing staff
Specialty Input	Proportion/profile of patients receiving palliative care consultation

Utilization data are helpful for targeting (as well as subsequent evaluation) of improvement efforts. Given the high cost of care in the ICU relative to other hospital units, and the importance of efficient throughput from the Emergency Department, operating rooms, and other units to the ICU, long length of stay in the ICU is typically a major concern for hospital and ICU administrators, particularly if patient outcomes after prolonged stays are poor. Data on ICU length of stay are usually easy to obtain from hospital databases and often routinely evaluated at the hospital and ICU level. Within the length of stay dataset, sorting of patients with long stays (e.g., >7, 10 or 14 days) according to characteristics (e.g., advanced age), diagnoses (DRG number), and vital status at discharge can help to identify groups for whom proactive palliative care intervention might be especially important. In addition, length of stay is generally a responsive measure of the effectiveness of such an intervention, as shown in studies evaluating the impact of palliative care consultation for ICU patients meeting certain criteria,¹⁻³ and of scheduled family meetings by the ICU team in specified circumstances.⁴ Data on the frequency of Emergency Department diversion or of surgical scheduling delays resulting from lack of ICU

bed availability can provide another perspective on the need for and potential favorable impact of an ICU palliative care initiative.

Data from patients and families may highlight a need for ICU palliative care improvement. Surveys of patient/family satisfaction, which most hospitals conduct periodically, are potential data sources. Within the Department of Veterans Affairs Health System, all in-patient deaths are followed by surveys of bereaved families, and data from these surveys have catalyzed palliative care initiatives in ICUs as well as other hospital venues. All ICUs are required to maintain documentation of compliance with Joint Commission mandates for routine assessment and control of pain. Review of a representative sample of medical records can help to identify a need for systematic improvement of symptom control.

Care process data. As we have reviewed in an earlier monograph, in the [IPAL-ICU Portfolio](#), patients and families have identified certain care processes as important for high-quality palliative care in critical care settings.⁵⁻⁷ These processes, which map to domains and processes of care endorsed by the National Consensus Project for Quality Palliative Care⁸ and the National Quality Forum Framework of Preferred Palliative Care Practices,⁹ include:

- identification of the patient’s surrogate decision-maker,
- investigation of advance directive status,
- discussion of resuscitation preference, and
- proactive communication about prognosis and care goals between the interdisciplinary ICU team and the patient’s family.

Data on (documentation of) performance are available through review of medical records, which might be conducted for patients meeting particular criteria or for all patients admitted to the ICU during a specific interval. Such data may focus attention on timeliness or reliability of care process performance as a goal for palliative care improvement, and serve as a baseline for subsequent measurement of the success of an improvement effort.

Staff Attitudes and Experiences. Few hospitals or ICUs formally evaluate staff for job-related distress. Recent research studies document that burnout, moral distress, and job dissatisfaction are prevalent among critical care physicians and nurses, attributed in part to the clinicians’ concerns that some care they provide is more burdensome than beneficial or is inconsistent with the patient’s preferences.¹⁰ High rates of staff turnover or conflict may be other correlates of such concerns. Evaluation of staff well-being using standardized instruments or via informal surveys in individual staff interviews or group sessions in the ICU may elicit important information and perspectives, which can then be addressed as part of an improvement effort. In addition, meetings on other relevant topics with a wide range of professionals and staff contributing to care of ICU patients and families (physician, nurse, social worker, chaplain, housestaff, respiratory therapist, unit clerk, patient care associate) will provide a fuller understanding of issues needing attention, while building a “culture” of collaboration and support for the effort, as discussed more fully below.

Referral for Palliative Care Consultation. More patients die in ICUs than in any other hospital setting.¹¹ For survivors, ICU treatment is often accompanied by a significant burden of symptoms both for the patient and for the family, and may result in long-term cognitive and physical impairments with an unacceptable quality of life.¹² Although many ICU clinicians have knowledge and skills to meet palliative care needs of critically ill patients and their families without specialist input, data indicate that palliative care consultants contribute positively to ICU care.^{1-3, 13} A review of rates and timing of palliative care referral for ICU patients (which might focus on patients dying in the ICU, and those at highest risk for hospital death, incomplete recovery, prolonged stay, or other unfavorable outcomes) may identify earlier and/or more frequent involvement of palliative care specialists as a target for improvement efforts in the ICU.

Table 3. Inventory of Resources for an ICU Palliative Care Improvement Effort	
<i>Type of Resource</i>	<i>Specific Example</i>
<i>Clinical</i>	Palliative care consultation service (both availability [e.g., M-F or 24/7] and current staffing level are relevant)
	Critical care clinician(s) with formal palliative care training (e.g., ELNEC-Critical Care-trained nurses)
	Social worker
	Chaplain
<i>Educational</i>	Palliative care experts in relevant disciplines (nursing, medicine, social work, pastoral care) for education on symptom management, communication skills, family support, bereavement care)
	Nurse educator (with or without ELNEC-Critical Care “Trainer Training”)
	Staff from hospital counsel’s office or ethics committee for education on legal and regulatory frameworks for decision-making
<i>Organization/Utilization</i>	In-patient palliative care unit or hospice beds; accommodation of ventilator-dependent patients on regular medical unit(s)
	Community-based facilities that will accept ICU patients receiving care focused exclusively or

	primarily on comfort
	Discharge planner
<i>Data Collection/Management</i>	Case manager conducting periodic chart reviews
	Quality specialist conducting periodic chart reviews
	Information Systems personnel analyzing hospital databases

Take an Inventory of Available Resources. Although additional resources may be sought to support an ICU palliative care initiative, initial planning should be based on existing resources to enhance feasibility. **Table 3** above lists resources that are potentially helpful, which can be grouped in four major categories: Clinical Care, Education, Organization/Utilization, and Data Collection/Management.

Clinical Resources. As discussed in our article on “Models for Structuring a Clinical Initiative to Improve ICU Palliative Care,”¹⁴ such an initiative may rely primarily on consultants to provide palliative care for selected ICU patients (“Consultative Model”) or may integrate palliative care principles and practices in routine ICU care for all patients (“Integrative Model”), or both. Availability of an adequately-staffed palliative care consultation service is essential for implementation of the Consultative Model, but is also an important resource for any ICU palliative care improvement effort. A social worker, mental health professional, or chaplain can also assist with implementation of clinical practice changes, such as a new program of proactive meetings by an interdisciplinary team with ICU families. In our experience, even busy clinicians in these disciplines are usually enthusiastic about participating in a well-designed palliative care initiative.

Educational Resources. Education to support an improvement initiative involves three main components. First, clinicians may need to strengthen knowledge and skills in relevant areas of palliative care, such as management of multiple symptoms in the context of organ failure and adverse effects from first-line analgesic therapy; legal, regulatory, ethical and empirical frameworks for surrogate decision-making and limitation of intensive care therapies; and approaches to prognostic uncertainty, strong emotions, and conflict in ICU family meetings. Second, clinicians responsible for implementing new work processes need education on the scientific evidence supporting these changes so that they understand their rationale and importance. Third, timely and reliable performance of processes requires in-service training on use of the systems that are designed to facilitate such performance. Educational resources for these purposes may already exist within the ICU and/or palliative care services, but planning should consider other potential resources, such as the general counsel’s office, chaplaincy, and other departments in the hospital, as well as a range of high-quality web-based materials. Examples of web-based resources are listed in **Table 4**, below.

Organization/Utilization. By increasing the frequency and quality of communication between clinicians, patients and families, an effective ICU palliative care initiative can shorten the time to implementation of an appropriate and realistic care plan, which will likely also shorten length of stay in the ICU. These benefits are maximized by the availability of alternative venues of care for patients who no longer need or cannot benefit from continued intensive care therapy. Thus, the needs assessment should consider what venues are or might be available to accept ICU patients in these circumstances, and their capacities. An increasing number of hospitals have created in-patient palliative care units that can accept ICU patients for whom comfort has become the paramount goal of care; some of these units will care for patients receiving mechanical ventilation. In other hospitals, ventilated patients whose care is focused on comfort can be transferred to a regular ward. Step-down units may also be available.

Table 4. Web-Based Educational Resources for an ICU Palliative Care Initiative: Some Examples.

Educational Resource	Description
Communicating About Critical Care (C-3)	7 curriculum modules used in communication skills training program for intensive care fellows (free)
Initiative for Pediatric Palliative Care (IPPC)	5 curriculum modules on pediatric palliative care (free)
ELNEC Pediatric Palliative Care Training Course	9 modules are lectures by expert ELNEC faculty (on-line subscription access for unlimited viewing from any computer with internet-access)
Integrating Palliative and Critical Care Video	Educational video about improving palliative care in the ICU (free access on website of National Institute of Nursing Research)
Education in Palliative and End-of-Life Care Project (EPEC)	17 modules for on-line learning, available for purchase (CME credit available)
End of Life/Palliative Education Resource Center (EPERC) Fast Facts and Concepts	concise, practical, peer-reviewed, and evidence-based summaries on key topics (free)

Data Collection/Management. The success of the initiative will depend on the ability to track results and ultimately to demonstrate positive impact. However, both ICUs and palliative care teams often lack staff and other resources for collection, management or analysis of such data. It is important, therefore, that measurement be carefully planned, limited and simplified to

make it feasible in relation to the capabilities. In addition, a variety of potential resources for support should be considered. In some institutions, review of medical records for data relevant to the initiative can be assigned to a quality monitor, compliance officer, or case manager who is also reviewing these records for other purposes. The hospital may be willing to assign Information Systems staff to assist in accessing and analyzing certain elements in administrative databases. Contacts to departments and individuals with responsibility for patient/family satisfaction surveys should be pursued.

Anticipate Barriers. A variety of barriers to implementation of an ICU palliative care initiative can be anticipated. For one thing, many ICUs are already involved in initiatives to improve quality in multiple other areas, such as prevention of catheter-related bloodstream infection, sepsis care, hand-offs between care venues, and antibiotic stewardship, and they may be reluctant to add a palliative care project to existing activities. Some ICUs may lack a physician leader to help coordinate the effort, or the senior physician may lack interest in or commitment to the integration of palliative care. If hospital leadership is not involved in planning or fails to see an alignment between the goals of the initiative and the overall goals of the institution, it may not be possible to allocate the resources needed for implementation. Economic pressures on hospitals may constrict resources in general, although there is increasing evidence that palliative care improvement contributes to cost reduction. In addition, some clinicians, mainly physicians, still see palliative care and intensive care as mutually exclusive rather than synergistic approaches, and resist efforts to integrate palliative care more fully in the ICU. Each ICU will also confront some specific barriers, such as lack of a room that is appropriate for family meetings, or of a social worker or chaplain who is assigned to support the ICU; and systems for care and/or documentation that are poorly designed to facilitate care processes associated with high-quality palliative care. To identify these barriers, it is often helpful to “walk the process,” that is, to shadow clinicians to see what barriers they encounter in seeking to deliver components of palliative care in the ICU.¹⁵ These observations can then guide design of more effective systems for care delivery. In conducting the initial needs assessment, general and specific barriers should be listed so that strategies to address them are incorporated in the action plan for the initiative.

3. Develop an Action Plan. There are five key steps in developing an action plan for a successful and sustainable ICU palliative care initiative: 1) Establish overall goals that address unmet needs using available resources, and that are aligned with institutional priorities; 2) Set initial targets that are clear and feasible within a specified time frame; 3) Identify the changes in clinical practice and systems that are needed to achieve the targets; 4) Address the need for new documentation formats to reflect clinical changes; 5) Plan for evaluation of progress toward specific targets and overall goals.

Table 5 briefly illustrates the application of this method in an action plan for a hypothetical initiative that seeks as a single overall goal to improve communication between clinicians and ICU families. This goal is well-aligned with a high institutional priority to reduce ICU length of stay in order to lower costs and improve throughput to the ICU from the Emergency Department. As one specific target, the initiative will focus on ensuring that each

patient's family has an opportunity before Day 4 in the ICU to discuss the patient's condition, treatments, prognosis, and goals of care in an interdisciplinary meeting with the attending physician and the bedside nurse, social worker, and/or chaplain. The aim is to achieve this target by the end of Month 6 of the initiative for at least half of the patients in ICU for at least 5 days. The planning workgroup identifies a number of clinical practice and system changes that will help to promote more timely performance of effective family meetings. The workgroup also recognizes that a new family meeting documentation template is needed to ensure that clinicians who do not attend the meeting are informed of what was discussed and to permit subsequent review of medical records for measurement and feedback of family meeting performance. A subcommittee of the Workgroup is tasked to develop specifications for the numerator and denominator of a measure of such performance, with results to be evaluated at 2-month intervals for the first 6 months. A second subcommittee will identify educational needs for the initiative and resources to assist in meeting these needs. The ICU's quality monitor, a nurse who reviews medical records to track compliance with protocols for reducing medication errors and catheter-related bloodstream infections, will collect data on family meeting performance.

Table 5. Example of an Abbreviated Action Plan.*

Overall Goal	Improve communication between the clinical team and families of critically ill patients	
Specific Target	By Month 6, at least half of families of patients in ICU for ≥ 5 days will have opportunity to meet with interdisciplinary ICU team for goal setting	
Clinical Practice / System Change Actions	ICU social worker will track admissions and arrange meetings by scheduled day; new plan for coverage will free bedside RN to attend; meeting reminder to be included in Daily Goals Sheet; families to be given Meeting Guide on patient's admission.	
Documentation Actions	New family meeting documentation template to be placed in chart.	
Measurement Actions	Numerator and denominator for family meeting measure, including specifications defining participants to attend meetings and topics for discussion; measure will be collected by review of medical records by Quality RN.	
Assignments	Develop plan for nurse coverage: ICU Nursing Director	
	Develop new document templates: Dr. A and Nurse B	
	Develop Family Meeting Guide: Dr. C, Nurse D, Social Worker	
	Plan program of educational support: Nurse Educator with Palliative Care Team members in workgroup; review of plan by ICU Director	
	Specify family meeting measure: ICU MD and RN Directors	

*Each component of this sample action plan including the assignments of responsibility for clinical practice/system changes, measurement, and other tasks, should be adjusted as appropriate for each specific initiative and setting.

4. Engage the Entire Interdisciplinary Team to Create a Supportive ICU Culture. The Johns Hopkins Quality and Safety Research Group, which has led the field of ICU safety and quality improvement, emphasizes the need for a supportive “culture” in the unit where change is to be implemented.¹⁵⁻¹⁶ Without it, an improvement effort cannot endure, even if it initially succeeds. The culture supporting improvement is fostered in a variety of ways. One is to invite the entire interdisciplinary team to regular meetings in which the rationale and plan for the initiative are explained, barriers and strategies are identified, and progress is reported. Discussion can also include specific examples of patients or families with unmet palliative care needs and others who benefited from high-quality palliative care. This is a key forum for ICU leaders and, if possible, hospital leaders, to communicate a strong commitment to the initiative and their appreciation of the participation of all staff. Among the most essential elements of an ICU culture supporting high-quality care is active involvement and empowerment of nursing staff, who actually deliver the largest share of patient care, spend the most time with patients and families, and carry significant responsibility for implementing new practices and work systems. In reducing catheter-related bloodstream infections, simply mandating hand hygiene and proper antiseptic procedures in catheter placement by physicians was less effective than empowering nursing staff to postpone performance of the procedure until these prerequisites, specified on a checklist, were completed. Furthermore, the new system including the checklist could not succeed unless the nurse felt sufficiently respected, confident, and comfortable to enforce it. Success and sustainability of ICU palliative care improvement are equally dependent on the creation of a strong, collaborative culture in which nurses are given a central role along with a high level of respect as well as responsibility.

Summary. Several key steps should be taken in organizing an ICU palliative care initiative, as summarized in **Table 6**. Each ICU is different – even within a single institution, one ICU may be vastly different from another in a variety of important ways. Thus, implementation of the steps we outline will need adaptation for an initiative to succeed and endure in a specific ICU setting. When beginning an initiative involving organizational change, it is helpful to review some available resources on leading a change management project and/or engage someone from your institution with experience in this area to assist you. Methods for planning and implementation of a multi-ICU collaborative to improve other aspects of ICU care, such as prevention of catheter-related bloodstream infection, have been described by the Johns Hopkins Quality and Safety Research Group.¹⁵ Application of these methods to ICU palliative care improvement was piloted by the Voluntary Hospital Association’s Transformation of the ICU Program,⁷ and is being explored in an ongoing initiative by multiple ICUs in Veterans Integrated Service Network 3, but this broader approach is beyond the scope of the present monograph.

Table 6: Key Steps for Organizing an ICU Palliative Care Initiative
▶ Convene a project workgroup
▶ Conduct a needs assessment

▶ Prepare an action plan

▶ Foster a supportive culture in the ICU

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