

# A Consensus Operational Definition of Palliative Care In Action

A joint product of the Institute for Clinical Systems Improvement and the University of Minnesota  
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## Aim, Background, Problem— Why create an operational definition for palliative care?

**Aim:** To hasten the widespread implementation and consistent understanding of palliative care among the clinicians, purchasers, health plans and all the other people of Minnesota through the development and widespread use of a consensus-based operational definition of palliative care in practice.

**The larger ICSI Palliative Care Initiative aim:** To identify the elements of care delivery that will improve the quality of the patient's care while increasing its value. It will address care delivery redesign, payment methodologies, and elements of patient/family-centered care.

**Background:** Interest in palliative care is high and growing. Palliative care is a philosophy and structured system for delivering care that improves the quality of life of patients and their families facing problems associated with life-threatening illness—through prevention and relief of suffering by means of early identification, assessment and treatment of pain and other physical symptoms and problems: physical, psychosocial, and spiritual. Palliative care is not the same as hospice care and is not dependent on prognosis or particular disease. Adapted from WHO (2008-2012) and Palliative Care National Consensus project (2004-2012)

**Research evidence demonstrating the value of palliative care is significant and growing**—along with patient demand for improved chronic illness care (and patient / family experience) whether at the end of life or not. Hopes are high that palliative care will improve patient experience, patient-centeredness, and clinical quality, and quality of life when implemented on a meaningful scale.

**The problem: What counts as the genuine article?** Despite its long history (see appendix), palliative care can be considered an *emerging* field because 1) scope of application has gone far beyond its roots in hospice and cancer care, and 2) significant challenges remain for implementation on a meaningful scale in U.S. care systems. Implementation here in Minnesota was accompanied by these ambiguities typical of emerging fields:

### 1. The customary definitions emphasize values, principles, and goals much more than functional or operational specifics.

Our Minnesota health community was moving forward, but without a widespread and agreed-upon detailed functional definition to guide widespread implementation or performance measurement. Different, but compatible, short definitions created by leading researchers, practitioners, and advocates were in place, but there remained confusion or ambiguity as to just what palliative care needs to look like in practice.

- **For patients and families:** “What should I expect to encounter in palliative care? How would I recognize the genuine article if I saw it—the difference between the real thing and an advertising claim? How would I know whether the care my family received was up to standard? Is there a standard?”
- **For purchasers:** “What exactly am I buying if I add palliative care to the benefits? What do I tell my employees (or other constituents) they can expect to encounter in this benefit? How do I price it?”
- **For health plans:** “What specifically do I require clinical systems to provide to health plan members—and what will I specifically look at to see if they are providing it or not?”
- **For clinicians and medical groups:** “What exactly do I need to implement if it is to count as palliative care—and to advertise myself as doing palliative care rather than just providing a few treatments that have palliative effects? What are core functions, and what is up to me to decide?”
- **For policymakers and measurement experts:** “If I am being asked to change the rules or business models to support palliative care, exactly what functions need to be supported? What core functions will I measure?”

This ambiguity about what counts as the genuine article was particularly pronounced for patients and purchasers who felt that clinicians greatly over-estimated how much palliative care as a functional reality was consistently understood, let alone implemented around the community.

## 2. Implementation requires fidelity to a definition AND an acceptable range of local adaptation.

A generally understood operational definition was needed to enable our community to agree on what functions are to be in place in “the genuine article”—and how to assess and improve our own practices and compare notes using such a shared template.

***But such a definition could not become a cookie-cutter prescription.*** That is, a definition of palliative care in action must include a set of defining uniformities AND a set of permissible local adaptations. An operational definition would have to map both the uniformities and acceptable differences (“you can drop X or modify Y and it still counts as palliative care”). Otherwise, the definition would not be flexible enough across the many contexts for implementation of palliative care. This is the familiar challenge of balancing “fidelity and local adaptation” (Callahan, 2010; Johnson, 2007). None of the customary definitions of palliative care attempted this challenge.

**The project: create a “lexicon” or “operational definition.”** A consensus operational definition for palliative care was created among members of the Institute for Clinical Systems Improvement (ICSI) Palliative Care Steering Committee in 2010, which was composed of clinician implementers, employer purchasers, health plans, and patient representatives. ICSI convened and sponsored the project, bringing in a consultant from the University of Minnesota to facilitate the process and write the results.

### ***The product:***

1. Seven defining clauses that describe essential functionalities of palliative care in action (and point to acceptable differences or variation within those defining clauses).
2. Eleven parameters (an explicit vocabulary or typology for how one palliative care implementation might legitimately be different than another).
3. A number of derivative checklists, guideposts, and aids to self-assessment and implementation (not included here).

***The goal*** was to create a consensus operational definition useful to clinician and other implementers, policymakers, payers, patients, and researchers—and promise to deliver these particular specifics here among participants in Minnesota—knowing that the definition will evolve.

***The process:*** A core group from the ICSI Palliative Care Steering Committee created initial drafts while a larger second ring of contributors from the Steering Committee systematically broadened, deepened, and sharpened them. This product is sometimes also referred to as a “lexicon,” but goes beyond being a glossary to describing essential functions. A consultant from the University of Minnesota medical school (C.J.Peeck), who is familiar with definition and “lexicon” development, facilitated the process and wrote up the results.

Published methods for creating definitions in complex subject matters were employed (paradigm case formulation and parametric analysis; Ossorio, 2006). Other lexicons or operational definitions for emerging fields of health care have also been developed using this methodology: Health Care Home (Peek and Oftedahl, 2010), shared decision-making (in press), and the integration of behavioral health and primary care (Peek, 2011).

## Summary: Palliative Care Operational Definition?

(What the genuine article needs to look like in practice. Specifics are on pp. 6–8)

**What:** A philosophy and structured system for delivering care that improves the quality of life of patients and their families facing problems associated with life-threatening illness—through prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems: physical, psychosocial, and spiritual.

Adapted from WHO (2008–2012) and Palliative Care National Consensus project (2004–2012)

<b>How: Defining clauses or functions for palliative care</b> (What you must see in action—what defines the paradigm)	<b>Parameters</b> (Permissible differences in what you see in action)
<p><b>0. A population that is aware of palliative care</b>            Aware that you or your family members could at some point become engaged in palliative care as a part of healthcare            Often around the time of diagnosis or course of a life-limiting illness such as cancer, heart, pulmonary, liver, renal, neurological diseases or dementia.</p>	<p>1. Level of community / population awareness or demand            2. Level of clinician / staff awareness or demand</p>
<p><b>1. With multiple ways to quickly identify who may benefit from assessment for palliative care</b>            Many different people (with different tasks or roles) may flag the moment that assessment for palliative care is timely.            For example: in regard to the expected course or burden of a disease or with respect to whatever concerns arise in conversation.</p>	<p>3. Level of systematic patient identification</p>
<p><b>2. Initiating ongoing assessment dialogue—with patient / family readiness and needs at the center</b>            Asking, and then listening for “where people are at” with respect to problems and hopes, options, goals, preferences, support and resources at home—even if these are stressful conversations.</p>	<p>4. Target population            5. Scope of application (target venues)</p>
<p><b>3. Producing a plan of care from this assessment</b>            Informed or shared decision-making and advance care planning with respect to goals, options, and choices—recorded in an accessible care plan document—and maintained and updated according to current reality.</p>	<p>6. Level of shared decision-making</p>
<p><b>4. Employing interdisciplinary teamwork that carries out a plan of care across all seven palliative care domains.</b>            A patient and family connected with palliative care nurse, social worker, chaplain, physician or nurse practitioner with recognized expertise in curative and palliative care to write orders and supervise the plan of care.</p>	<p>7. Team functions / composition available</p>
<p><b>5. Coordinating or directing care across episodes and venues of care.</b>            A contact in the different venues (hospital, SNF, clinic, hospice, etc.) knows who the patient and family are—and has access to the plan of care (including advance care plans) at all times so there is no fragmentation or conflict about whether the person should be in hospital, home or other site of care.</p>	<p>8. Level of care coordination across time and space</p>
<b>Supported by</b>	
<p><b>6. Collection of practice-based data for decision-making to improve outcomes</b>            Routine practice data concerning quality, patient/family experience and affordability—including observations and concerns from patients and families—is used to make decisions that improve effectiveness of the program across all patients and care plans.</p>	<p>9. Ability to collect and use practice data</p>
<p><b>7. Consistent, reliable operational systems and business model</b>            Care and workflows occur consistently and reliably and are sustained by a business model that supports all elements of palliative care.</p>	<p>10. Level of operational reliability and consistency            11. Sustainability of business model</p>

## An Operational Definition of Palliative Care in Practice: Defining clauses with permissible transformations

Transformations (T) broaden what counts as palliative care practice by specifying what can be dropped or substituted and still be palliative care—along with what cannot be changed and remain genuine palliative care.

“Practice” simply means care delivery—what you would actually see on the ground in practice, rather than in theory—at any scale, from a very small group to a large organization to an entire community or region.

### 0. A population that is aware of palliative care.

Everyone recognizes that you or your family members could at some point across the lifespan become engaged in palliative care to relieve patient suffering and reduce illness burden—as a component of healthcare—often around the time of diagnosis or course of a chronic life-limiting illness.

For example: cancer, heart disease, pulmonary disease, dementia, liver disease, renal disease, neurological disease such as stroke, Parkinson’s, ALS, or MS, or multiple conditions with functional decline and failure to thrive (from ICSI guideline—see appendix).

T1	Change “everyone recognizes” to “most clinicians and many patients and family members recognize” (Such awareness will build up over time, but is not universal today)
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### 1. With multiple ways to quickly identify who may benefit from assessment for palliative care.

Many different people (with many different tasks or roles) may flag the moment that assessment for palliative care is timely. For example:

A. *In regard to the expected course of a disease or its burden*, anyone may flag the moment that assessment for palliative care is timely, e.g. primary care or specialty care providers, clinicians and staff of hospitals, nursing homes, and home care agencies, or family members and patients.

	No transformations. Clause 1A is necessary for a practice to claim it is a palliative care practice (Having only a minority of its clinicians ready and willing to flag the moment a palliative care assessment may be helpful does not qualify a practice (or its larger organization) to advertise itself as a “palliative care practice”)
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B. *With respect to whatever concerns arise in conversation*: Any clinician, patient, or family member involved is aware of palliative care and can at least initiate the conversation in context of what people are talking about or are concerned about.

T2	Change “any clinician or family member involved is aware” to “most clinicians and many patients or family members involved are aware”
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**2. Initiating ongoing assessment dialogue—with patient / family readiness and needs at the center.**

First asking, and then listening for “where people are at,” even if the conversations are stressful:

- A. What the patient and family perceives as their concerns and their hopes
- B. What the patient / family understands their options to be. Within each of the palliative care domains\*, a) what does the patient understand, b) what do they want to know, c) what are they hoping for, d) what are their goals and what are they ready for and e) what are their needs, preferences and concerns or fears.

\*Palliative care domains (from ICSI guideline): 1) Physical aspects of care; 2) Cultural aspects of care; 3) Psychological aspects of care; 4) Social aspects of care; 5) Spiritual, religious, and existential aspects of care; 6) Ethical and legal aspects of care; 7) Care of the imminently dying patient. (Similar to domains cited in the National Consensus Project)

- C. What kind of support and resources the patient can access at home—family ability and interest in participating, in what areas, and how actively

For example: financial, emotional, logistical, practical help, in addition to family/caregiver supports identified in the palliative care assessment across the seven domains

	<p>No transformations. Everything in Clause 2 is required for palliative care practice.</p> <p><b>Annotations:</b></p> <ol style="list-style-type: none"> <li>1. You can take a palliative care approach to a palliative care domain, but you aren't a palliative care practice unless you are <i>integrating the work in all seven palliative care domains</i>. If you drop a domain from your scope of practice, you are no longer a palliative care practice, because intrinsic to the concept of “palliative care practice” is working across all seven domains, as per the ICSI guideline.</li> <li>2. “Palliative” is an adjective that can be applied to many treatments, but “palliative care” represents a synthesis of palliative care treatments across the seven domains.</li> <li>3. A treatment not being “curative” doesn't automatically mean it is “palliative care.” Instead you can say it has a palliative effect, but the term “palliative care” is reserved for the synthesis across the seven domains, using the assessment principles expressed in Clause 2A and 2B.</li> </ol>
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**3. Producing a plan of care from this assessment**

- A. Includes informed or shared decision-making and advance care planning—where a) treatment options follow goals, and b) treatment choices are consistent with those goals—the assessment having gone into the benefits and burdens of each of the options.
- B. Recorded in a single accessible care plan document organized by a) goals of care, b) options, c) informed decision-making and d) plan of care—done across the palliative care domains.
- C. Maintained and updated according to current reality. Assessment (clause 2) and producing a plan of care (clause 3) are a continual reassessment circle, not just a one-time linear process

	<p>No transformations. Clauses 3A, 3B, 3C are necessary for “palliative care practice.”</p> <p>(Clause 3B does not specify how the single plan of care is made accessible, e.g., in an EMR or other way of keeping and accessing information).</p>
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**4. Employing interdisciplinary teamwork that carries out a plan of care across all seven palliative care domains.**

- A. A patient and family connected with a palliative care nurse, social worker, and chaplain.
- B. A willing physician or nurse practitioner with recognized expertise in both curative and palliative care joins the team in that spirit, writes orders and supervises the plan of care.
- C. Interdisciplinary means physician or nurse practitioner working with or as a team capable of addressing all seven palliative care domains in age-appropriate fashion and using an effective communication process to keep everyone (including patient & family) on the same page.

**Annotation:** The team carries out functions across the seven domains, but that does not mean seven different people (or any other specific number) is required to do that.

T3	Substitute “counselor or other figure who understands connections to social service resources” for “social worker”
T4	Substitute “pastoral counselor” or any other “spiritual” type guide for chaplain (There no deletion or substitution for “palliative care nurse”)
	There is no transformation for Clause 4B (Clause 4B requires a willing physician or nurse practitioner “with recognized expertise . . .” but does not specify what kind of physician or specialization in palliative care)
T5	Add “the team may be assembled ad-hoc for a particular occasion rather than a standing team, as long as the team can work together substantially in palliative care practice”

**5. Coordinating or directing care across episodes of care and venues for care.**

- A. A key contact person or palliative care coordinating figure in the different venues (hospital, SNF, clinic, hospice, home care, ambulance etc), readily accessible to the clinicians who knows who the patient and family is—and has access to the plan of care (and who can interact with the patient/family as needed)
- B. No fragmentation takes place—because of transition-management plans. There are no unresolved conflicts about whether the person should go to hospital or move between different kinds of facilities or services. If an episode in another facility is necessary, the attitude is “the care plan follows the patient—we help maintain and adjust your palliative care plan.”
- C. Palliative care plans are available to everyone involved—any time of day or night. The care plan follows the patient and family across all episodes and venues and is updated as needed all along the way.

T6	Add: “If key contacts and coordinating figures are not available and accessible in all the different venues, efforts underway to establish those contacts in frequently encountered venues”
T7	Add: “If fragmentation does take place, the fragmentation is debriefed and a plan formed to make it unlikely to repeat in the future”
T8	Add: “In the event that care plans are not available to everyone at any time of day or night, efforts to create practical ‘work-arounds’ or other methods to prevent fragmentation are in place for the most frequently encountered situations

**6. Collecting practice-based data for use in decision-making and improving outcomes**

- A. Routine practice data is collected using established tools and metrics as much as possible.  
Examples: In terms of Triple Aim (IHI)—quality, patient/family experience and affordability; NQF –reducing harm and disease burden, eliminating waste and inappropriate care, eradicating disparities.
- B. Patients and families know whom to contact with questions and concerns about quality of patient experience or effectiveness of current care plan or of specific members of the palliative care team in meeting patient/family needs. This is also practice-based data. Such questions & concerns may trigger reassessment of a care plan (outside regular reassessments or health event triggers).
- C. Routine practice data is actually used to make decisions to change what you are doing at the level of your system or individual cases and improve effectiveness as an ongoing part of the practice, across all patients and care plans

	No transformations. Clauses 6A, 6B, and 6C are all required in palliative care practices <small>(All practices must collect and use routine practice data for QI and provide some way for patients/families to provide feedback and ask questions)</small>
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**7. Supported by consistent and reliable operational systems and business model**

- A. Care and work processes required by points 1-6 above occur consistently and reliably because the care delivery model or system is made reliable with standard operational systems and policies—embedded in the system itself rather than relying on individuals merely remembering to do the right thing.
- B. A sustainable business model that supports all elements of palliative care 1-6 above

T9	Add: “When care or work processes are not consistently reliable, the breakdown is debriefed and a plan formed to make it more reliable in the future”
T10	Add: “Elements of palliative care not well supported by the business model are the focus of effort to create a better business model and short-range ‘work-arounds’ to support necessary activity in other ways.



## Parameters of Palliative Care Practice (how genuine practices may differ from one another)

Parameters are drawn from the acceptable transformations of the defining clauses

<i>Relevant defining clause(s) in the paradigm case</i>	
<b>Parameter</b>	Descriptive categories for that parameter

*A population that is aware of palliative care as a component or function of healthcare;  
With access to multiple ways to quickly identify who may benefit from assessment for palliative care*

<b>1. Level of community / population awareness of palliative care</b>	<b>Limited but sufficient</b> Sufficient reach of understanding and readiness or demand to enable palliative care programming to function in this community	<b>Partial</b> Wide but substantially incomplete understanding and readiness; need for continuing education, consciousness-raising, clarification	<b>Widely accepted and understood</b> Almost universal community understanding and readiness or demand for palliative care as a normal component or function in healthcare
<b>2. Level of clinician / staff awareness of palliative care</b>	<b>Limited but sufficient</b> Provider and staff understanding and readiness at a level that a patient can expect to encounter at least one care provider who can recognize the need, engage a patient in palliative care conversation, and initiate a palliative care assessment. A given patient has no assurance that any particular care provider is aware of palliative care.	<b>Partial but substantial</b> Wide but substantially incomplete provider / staff understanding and readiness to engage patients / families; need for continuing education, consciousness-raising, clarification	<b>Widely accepted and understood</b> Almost universal provider and staff understanding and readiness to engage patients and families for palliative care as a normal option in healthcare
<b>3. Level of systematic patient identification</b>	<b>Individual patient or clinician:</b> Non-systematic patient or clinician identification or flagging need for palliative care assessment	<b>System indicators:</b> Disease stage data, charts, claims, other system data suggesting need to find out if assessment is needed	<b>Standardized identification:</b> All or most patients in any likely risk group systematically identified / screened to reveal need for assessment

*Initiating ongoing assessment dialogue—with patient / family readiness and needs at the center  
Producing a plan of care from this assessment*

<b>4. Target population</b>	<b>Pediatrics / perinatal</b>	<b>Adult / young adult/ geriatric</b>	<b>Across the entire life span</b>
<b>5. Target venues (scope of application)</b>	<b>Single venue</b> (Hospital, SNF, assisted living, specialty clinic, PC clinic, hospice, home health etc—specify)	<b>More than one, but not all venues—specify</b>	<b>All venues</b>
<b>6. Level of shared decision-making</b>	<b>Informed consent</b> Provider-driven customs mostly based in conveying information and getting informed consent	<b>Informed consent plus limited shared decision-making</b> Disease stage data, charts, claims, other system data suggesting need to find out if assessment is needed	<b>Informed consent plus routine shared decision-making</b> Shared patient/family/clinician decision-making and decision aids built into routine clinical system

*Employing interdisciplinary teamwork to carry out a plan of care across all seven palliative care domains*

<b>7. Team composition</b>	<b>Minimum core team</b> At least one palliative care-trained or experienced health professional working in all the domains, working in partnership with a physician or nurse practitioner who writes orders	<b>Expanded team</b> Minimum core team plus one or more palliative care functions or disciplines, but less than a complete or extended team	<b>Complete / extended team</b> Minimum core team plus social service function, spiritual / chaplain function, palliative care specialist function, nursing function, or other
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**Annotation:** “Palliative care trained or experienced” means that the clinician is qualified to do it according to basic national palliative care standards or guidelines. This phrase does not necessarily mean “board-certified in palliative care” or “trained as a palliative care specialist.”

*Coordinating or directing care across episodes of care and venues for care.*

<b>8. Level of care coordination across time and space</b>	<b>Consultation / liaison only</b> Example: Palliative care consultation, leaving a note in the chart, with or without a team—with little or no expectation of follow-up care, coordination across venues or extended office hour availability	<b>Limited-scope treatment / coordination in a partially integrated system</b> Treatment and coordination— <ul style="list-style-type: none"> <li>• Limited to certain venues and/or</li> <li>• Limited to a given episode of care and/or</li> <li>• Intermittent coverage or office hours</li> </ul>	<b>Full scope treatment / coordination in a fully integrated system</b> Treatment and coordination— <ul style="list-style-type: none"> <li>• Integrated across all venues of care</li> <li>• Longitudinally across episodes of care</li> <li>• 24x7 coverage or office hours</li> </ul>
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*Collecting practice-based data for use in decision-making and improving outcomes*

<b>9. Ability to collect and use practice data</b>	<b>Commitment and embryonic system for collecting and using practice data for QI and effectiveness</b>	<b>Partially complete system for collecting and using practice-based data.</b>	<b>Mature data collection and use in decision making for quality and effectiveness, with integration of national standards where applicable</b>
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*Supported by consistent and reliable operational systems and business model*

<b>10. Level of operational reliability and consistency</b>	<b>Informal:</b> Referral, communication, charting, care coordination are non-standard processes that vary substantially by clinician, venue, clinical situation	<b>Partially routinized:</b> Some standards set for some processes but unwarranted variability and clinician preference still operate	<b>Standard work;</b> Whole team operates each part of the system in a standard expected way that quickly reveals lapses and system errors
<b>11. Sustainability of business model</b>	<b>Traditional fee-for-service</b> Traditional business model, e.g., FFS used to support palliative care functions with little or no benefits or payment methodologies tailored to other palliative care activities	<b>Hybrid</b> Some bundled or program fees or payments based on palliative care team model to augment traditional FFS healthcare payment model	<b>Payment for value and outcomes</b> A benefits and payment system specifically designed to sustainably support all key elements of palliative care team and function

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## Appendix 1

### Observations about clarity of palliative care in practice

**Introduction:** The historical roots of palliative care are well documented (see below). Furthermore, principles, values, and definitions of palliative care are plentiful (see appendix 4). The many definitions are compatible, but often emphasize somewhat different things or use different terms. And typically these definitions don't spell out in *operational detail* the core functions that must be in place for a given implementation to count as genuine palliative care.

This became a difficulty for the ICSI Palliative Care Steering Committee in its work to implement such programs as patients, or to use them. Despite the excellent historical and definitional work from many sources, there remained ambiguity about what functions actually have to be in place “in action” for a given program to qualify as a genuine implementation of palliative care. This ambiguity (see below) led to the need for the “operational definition” of this paper.

#### Historical roots of palliative care

“Palliative care began in the hospice movement and is now widely used outside of traditional hospice care. Hospices were originally places of rest for travelers in the 4th century. In the 19th century a religious order established hospices for the dying in Ireland and London. The modern hospice is a relatively recent concept that originated and gained momentum in the United Kingdom after the founding of St. Christopher's Hospice in 1967 by Dame Cicely Saunders, widely regarded the founder of the modern hospice movement. (Wikipedia, 2/12)

“Palliative care and hospices have developed rapidly since the late 1960s . . . Palliative care began to be defined as a subject of activity in the 1970s and came to be synonymous with the physical, social, psychological, and spiritual support of patients with life-limiting illness, delivered by a multidisciplinary team. Palliative care services have developed in many settings. . . . The worldwide need for this type of care remains much greater than the available provision, but there are encouraging signs of recognition by policymakers and influential bodies, and interest in palliative care has never been greater . . .” (from Clark 2007)

#### Observations about clarity of palliative care *in practice* (from Palliative Care Steering Committee (11/09))

*We are stumbling over* what palliative care needs to look like in action—the concrete applications—not in the abstract definitions.

- Others have defined it in general, e.g., WHO, international or national groups and think tanks. We should look at what has been defined in theory and then come to agreement on a more specific functional description of what we expect to see in practice, not just in theory.
- Palliative care is well understood by those doing it—but this understanding lacks consistency among other clinicians, and among administrators in clinics and hospitals. Clinician acceptance is inconsistent. I know of patients or families in the hospital who asked for a palliative care consult, but the physician wouldn't order it.
- The general healthcare professional and public doesn't know what it is. With other things medical, at least people know what they are—and usually what to expect when they encounter it. But the general public doesn't know what palliative care is or the difference from hospice.
- Is there a hard edge, a soft edge, or no edge to what should be considered palliative care—or is it “anything counts”? How could ICSI help define this and to which patients it is best suited: “Here is what it is, here are the key components you have to have, here is where it is found, and here is when you would use it.”

*What we all need is to share consistently understood functions and expectations for palliative care*—to recommend with the assurance of availability (and physician behavior) so it isn't dependent on a highly motivated family member to keep pressing everyone to get this explored.

- Patients do acquire the idea when the palliative care medicine team comes into the room, but there is often a disconnect between what patients understand right then and what they actually encounter later in a different part of the health system or with a different provider.

- Consistent availability is an issue. When the program is not available to you, the patient, 24x7, then it doesn't matter how good the program is.
- Patients and systems need a shared concept of when the specialist aspect of palliative care begins and generalist pain/suffering control leaves off. When do you refer to a palliative care specialist or program—especially given the limited availability of certified palliative care specialists and staff?
- Patients and clinicians need a shared understanding of how the “curative” and “palliative” interact in mindset and in goals. This may be easy to say, but how does “curative” and “palliative” combine in a way that isn't merely ambivalence and switching back and forth between them?
- It may be important to describe genuine palliative care practice separately for primary care, specialty care, hospital, hospice, or rural settings—picturing it in small towns, or ICU, NICU, OB or pulmonary or cancer center. This must be from a patient perspective as well as a provider perspective.

## Appendix 2

### About the need for consistent concepts, definitions, and lexicons in new fields

Paraphrased from Peek and Oftedahl (2010)

**Why include lexicon / conceptual / definitional work as part of forming practice development or research agendas in areas such as palliative care?** Questions about terms often come early in conversations intended to create research or practice-development agendas for emerging healthcare fields. For example:

“Do we have a good enough shared vocabulary (set of concepts and distinctions) for asking research questions together across many practices? Do we mean similar enough things by the words we use or how we distinguish one form of practice from another for purposes of implementing them or investigating their effects? Do we have a shared view of the edges of the concept we are investigating—the boundaries of the genuine article or the scope of our subject matter? If we don't share enough of that vocabulary, we will think we are asking the same research questions, using the same distinctions, doing the same interventions, or measuring the same things—but we won't be—and will confuse practices and funding organizations . . .” (from Peek, 2011)

#### Clearer and more consistent concepts and definition for a field are needed when:

1. Enough people are stumbling over language and what things mean—especially as encountered in practice, not only in theory or at the level of principles and values.
2. Enough people need clearer boundaries for an area X—what counts as “this is a genuine example of it” for describing to the public, setting expectations, assigning insurance benefits, certifications, or saying how something is different than “usual.”
3. People are asking, “What components are necessary for a given practice to really be X? What are the dimensions and milestones for practice improvement within these components?”
4. Researchers want to ask quality or research questions more consistently and clearly—especially in geographically distributed research or QI networks.

“...All mature scientific or technical fields have lexicons (systems of terms and concepts) developed well enough to allow collaborative and geographically distributed scientific, engineering, or applications work to take place. These lexicons are developed for practical reasons of communication among professionals doing the real work of science and practice.

Systematically related concepts have an esteemed place in the history of mature fields that we now take for granted, e.g., electrical engineering, physics, and software development. Conceptual development in these fields has enabled them to become mature sciences or technologies with associated empirical triumphs. In many cases the conceptual or pre-empirical development of these fields was done so long ago that we take it for granted and now see only the concrete empirical achievements.

But it takes a generally understood system of concepts and distinctions to do good science. . . .”

From Peek (2011) and inspired by Bergner, R. (2006) An Open Letter from Isaac Newton to the Field of Psychology. *Advances in Descriptive Psychology*, Vol. 8., Descriptive Psychology Press, Ann Arbor MI.

5. There is a felt need to improve the consistency or reputation of an area with “outsiders,” e.g., policy-shapers, legislators, funders and others who are not living the experience as “insiders.”
6. When your field is being distorted or misunderstood by the public or subset—when practitioners themselves are inconsistent in the way they present the field to the outside world.

## Appendix 3

### About the method for creating a consensus operational definition: Paradigm case formulation and parametric analysis

**Consensus.** An operational definition to serve practical purposes for a broad range of people interested in palliative care could not be created by one person or perspective alone. Doing so would increase the sense of ambiguity or multiplying compatible but different definitions (usually without much functional specificity) that implementers and patients had noticed.

**Definition.** Fortunately methods for defining complex subject matters that meet the requirements exist in the published literature (Ossorio, 2006). A “paradigm case formulation” is a vehicle for creating a definition that maps both similarities and differences. A “parametric analysis” builds on the paradigm case to create a specific vocabulary for how one instance of palliative home care might differ from another instance across town.

The paradigm case and parameters amount to a set of interrelated concepts (like an extended definition) that can be used in comparing practices, setting standards, or asking research questions using a common vocabulary.

**The consensus process is facilitated in two stages:** 1) A core group draft done in this case by seven people, followed by 2) a “second ring” review / contributor group, in this case of two-dozen people.

In each stage, the product contains parts A-C—progressively refined until good enough to use:

- A. ***Create a paradigm case of palliative care in practice.*** “Here’s a case of palliative care in action if ever there was one.” One indisputable example of palliative care—that is deliberately aspirational—not necessarily representative of what you find out there—but would like to find. This step maps out the uniformities in what we mean by palliative care.
- B. ***Introduce transformations of this paradigm case.*** The purpose of transformations is to identify additional cases that we as a group also believe qualify as palliative care—“You could change X or delete Y and it would still be palliative care.” This step maps the differences in what we mean by palliative care. The paradigm case and transformations, when taken together is our “definition” of palliative care practice.
- C. ***Parameters: Dimensions for legitimate differences between practices.*** These dimensions create a vocabulary for how one palliative care practice might be different from the one next door.

The facilitation details for this group consensus process were devised by Peek, and are beyond the scope of this report. For more information, contact [cjpeek@umn.edu](mailto:cjpeek@umn.edu)

#### Requirements: A method for creating an operational definition with standing in the field would. . .

- Be consensual but analytic (a disciplined transparent process—not a political campaign)
- Involve actual implementers and users (“native speakers” of the palliative care language)
- Focus on what functionalities look like in practice (not just on principles, values, or visible ‘anatomical features’)
- Specify acceptable variations around the required pattern—so it is not a rigid prescription.
- Be amenable to gathering around it an expanding circle of “owners” and contributors (not just an elite group coming up with a declaration)

Peek, 2011, Peek & Oftedahl, 2010

**Other applications** of this methodology include collaborative care practice (Peek, 2011), health care home in action (Peek and Oftedahl, 2010) and shared patient-clinician decision-making.

## Appendix 4

### Palliative Care: A sample of common definitions and descriptions

#### Definitions:

##### *From ICSI Palliative Care Survey Report (2009):*

Palliative care focuses on improving quality of life for patients with serious illness (and for their families) through expert pain and symptom management, care coordination and informed decision making with the support of an interdisciplinary team. Palliative care is not the same as hospice care and is not dependent on prognosis.

##### *From Palliative Care National Consensus Project* ( <http://www.nationalconsensusproject.org/DisplayPage.aspx?Title=What%20Is%20Palliative%20Care?> )

Palliative care is both a philosophy of care and an organized, highly structured system for delivering care:

- The goal is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies.
- Expands traditional disease-model medical treatments to include goals of enhancing quality of life for patients and family members, helping with decision-making, and providing opportunities for personal growth.
- Palliative care can be rendered along with life-prolonging treatment or as the main focus of care. Such care is appropriate to those suffering with cancer, heart conditions, liver failure, renal failure, Alzheimer's disease, spinal cord injuries, and a number of other conditions.
- Palliative care is appropriate for all patients from the time of diagnosis with a life-threatening or debilitating condition, regardless of the patient's age.

Palliative care is medical care provided by an interdisciplinary team, including:

- The professions of medicine, nursing, social work, chaplaincy, counseling, nutrition, rehabilitation, pharmacy, therapists, and other health care professions.
- It further aims to identify and address the physical, psychological, spiritual, and practical burdens of illness.

Palliative care is integral to all health care delivery system settings:

- Hospital, emergency department, nursing home, home care, assisted living facilities, outpatient and non-traditional settings.
- The palliative care team collaborates with professional and informal caregivers in each of these settings to ensure coordination, communication and continuity of care across institutional and home care settings.

Palliative care affirms life by supporting:

- The patient and family's goals for the future, including their hopes for cure or life-prolongation.
- Their hopes for peace and dignity throughout the course of illness, the dying process and death.
- The patient and family in making decisions that enable them to work toward their goals in the course of one's illness, condition or injury.

The need for palliative care in the U.S. can be met through:

- Ongoing health professional education in palliative care principles and practice.
- Increasing access to palliative care specialists in hospitals, nursing homes and home care.
- Promoting timely access to hospice services to all eligible patients.
- Creatively integrating hospice and palliative care programs across treatment settings.
- Defining appropriate accountability and performance measures for palliative care services.

### **WHO definition of palliative care (2008):**

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms.
- Affirms life and regards dying as a normal process.
- Intends neither to hasten or postpone death.
- Integrates the psychological and spiritual aspects of patient care.
- Offers a support system to help patients live as actively as possible until death.
- Offers a support system to help the family cope during the patient's illness and in their own bereavement.
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated.
- Will enhance quality of life, and may also positively influence the course of illness.
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

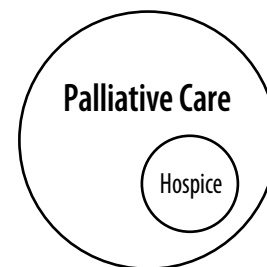
### **From ICSI Palliative Care Guideline (2009, 2011)**

Palliative care: The patient has either:

- A limited life expectancy (regardless of symptom burden or goals for care), or
- A significant symptom burden (regardless of prognosis or goals for care) or goals for care exclusively to achieve and maintain comfort (regardless of prognosis or symptom burden) .

Hospice: The patient has both:

- A limited life expectancy (specifically six months or less), and
- The goals for care are exclusively to achieve and maintain comfort, regardless of the symptom burden.



### **Key elements of palliative care**

#### **From National Consensus Project: Key elements of palliative care**

1. Patient population: Patients of all ages experiencing a debilitating chronic or life-threatening illness, condition, or injury.
2. Patient and family-centered care: The uniqueness of each patient and family is respected and the patient and family constitute the unit of care. The family is defined by the patient . . . and may be related or unrelated to the patient . . . individuals who provide support and with whom the patient has a significant relationship. The care plan is determined by the goals and preferences of the patient and family, with support and guidance in decision-making from the healthcare team.
3. Timing of palliative care: Ideally begins at the time of diagnosis of a life-threatening or debilitating condition and continues through cure or until death and into the family's bereavement period.
4. Comprehensive care: Employs a multidimensional assessment to identify and relieve suffering through the prevention or alleviation of physical, psychological, social, and spiritual distress . . .



5. Interdisciplinary team: Presupposes provision of interdisciplinary team evaluation and treatment . . . skilled in care of the patient population to be served . . . can be expanded to include range of professionals needed . . . core group from medicine, nursing and social work . . . may include combination of volunteer coordinators, bereavement coordinators, chaplains, psychologists, pharmacists, nursing assistants, home attendants, dieticians, and language pathologist, physical occupational, art, play, music and child-life therapists case managers . . .
6. Attention to relief of suffering: Prevent and relieve the many and various burdens . . .
7. Communication skills (with all individuals involved in the care of patients and their families): Sharing of information, active listening, determining goals and preferences, assistance with medical decision-making . . .
8. Skill in care of the dying and the bereaved: Prognostication, signs and symptoms of imminent death, and the associated care and support needs of patients and families before and after death.
9. Continuity across settings: . . . proactive management to prevent crises and unnecessary transfer.
10. Equitable access: Across all ages and patient populations, diagnostic categories, healthcare settings, including rural and regardless of race, ethnicity, sexual preference or ability to pay.
11. Quality assessment and performance improvement: . . . Development, implementation, and maintenance of an effective quality assessment and performance improvement program . . . regular and systematic assessment and evaluation of the processes of care and measurement of outcomes using validated instruments: IOM six aims: Timely, patient-centered, effective/beneficial, accessible/equitable, knowledge/evidence-based, efficient/not wasteful.

***From ICSI Palliative Care Guideline (2009, 2011)***

Nearly all physicians and health care providers offer palliative care to their patients, much the same way they offer varying degrees of many different medical specialties.

- Primary: Indeed, there is a presumption that providers will all be able to provide *a primary level of palliation* for symptoms commonly encountered in their respective practices.
- Secondary: Depending on individual interest and prevalence of specific symptoms or situations in a given practice, many providers develop additional skills and provide a *secondary level of palliative care*.
- Tertiary: More challenging cases of distressing symptoms or complicated communication systems would be appropriate for referral to *tertiary palliative care* to a multidisciplinary team that includes board-certified specialists when available. These specialists are also responsible for teaching other providers and building systems to guarantee the highest possible level of palliative care expertise for a population of patients.

**In actual practice: venues for palliative care** (highest to lowest—from ICSI Palliative Care Survey):

- In-patient consultation
- Hospice
- In-patient palliative care
- Ambulatory palliative care services
- Palliative home care
- Palliative care consultation in long-term care
- Structured palliative care services in long-term care.

## **From palliative care guidelines**

### ***Guideline Sections:*** From National Consensus Project

1. Structure and Processes of Care
2. Physical Aspects of Care
3. Psychological and Psychiatric Aspects of Care
4. Social Aspects of Care
5. Spiritual, Religious and Existential Aspects of Care
6. Cultural Aspects of Care
7. Care of the Imminently Dying Patient
8. Ethical and Legal Aspects of Care

### ***From ICSI Palliative Care Guideline (2009)***

#### Aims

1. Increase the identification of patients who are in the early stages of a progressive, debilitating disease who would benefit from palliative care services.
2. Improve the effectiveness and comfort level of the primary care provider in communicating the necessity and benefits of palliative care with those patients with a progressive, debilitating illness.
3. Improve the assessment of the identified patient's palliative care needs utilizing the seven domains of palliative care.
4. Increase palliative care planning with patients who have been identified in the early stages of a progressive debilitating disease.
5. Improve the continual reassessment and adjustment of the patient's palliative care plan as conditions warrant, utilizing the seven domains of care.
6. Increase the completion, documentation and ongoing utilization of advance directives for patients with a progressive, debilitating illness.

#### Implementation Recommendation Highlights

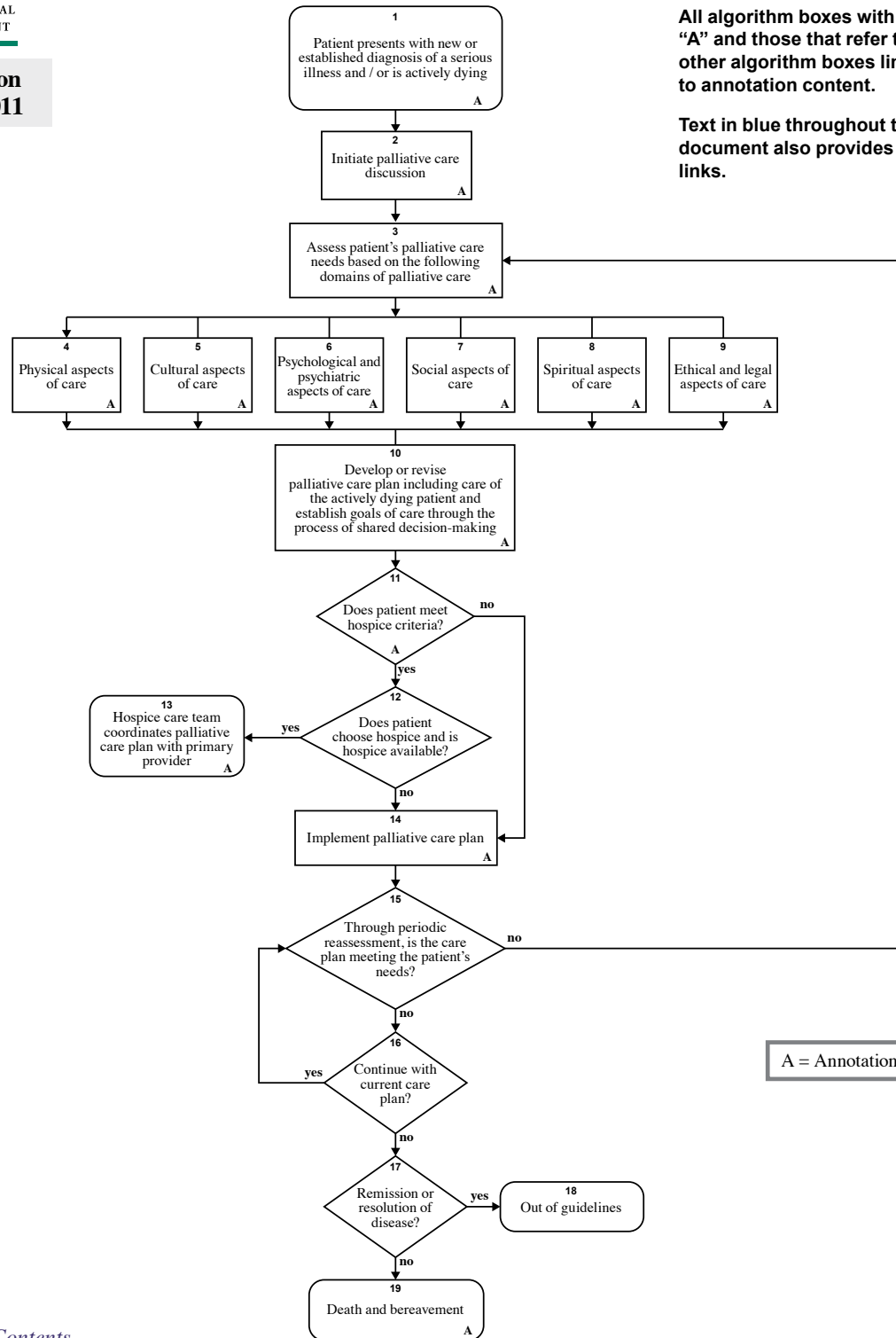
1. Develop a process to provide education to clinicians, patients and families regarding the elements and appropriateness of palliative care. It is important to address the difference between palliative care and hospice.
2. Develop a process that will allow providers to identify and assess patients who would benefit from palliative care services. This process should include the use of a screening tool that utilizes the seven domains.
3. Develop scripts for health care providers that will assist them in initiating and discussing palliative care services.
4. Develop a process for timely referral to palliative care consultation for patients with a progressive, debilitating disease.



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## Health Care Guideline: Palliative Care for Adults



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