National Quality Forum	MHCC pilot hospital alignment	
Preferred Practice		recommendation
Provide palliative and hospice care by an interdisciplinary team of	All pilots have access to interdisciplinary teams of professionals at the hospital. Report will include details on the staffing structure and specific credentials, as reported in CAPC survey and to staff in interviews.	Recommended for inclusion in
skilled palliative care professionals, including, for example, physicians, nurses, social workers, pharmacists, spiritual care counselors and others	Collaboration with primary health care providers is essential in the inpatient hospital care setting.	best practices and also as a requirement
who collaborate with primary health care professional(s).	Next II all standards investigation of the second state of the second state in the second state of the sec	Not
Provide access to palliative and hospice care that is responsive to the	Not all pilots provide immediate access to care 24/7. Report will include details on the availability, as	recommended
patient and family 24 hours a day, seven days a week.	reported in CAPC survey and to staff in interviews. Report will also include opinions of the pilots regarding why immediate access at any time of day or night may not be necessary.	recommended
Provide continuing education to	All pilots report providing continuing education, training, and clinical support for staff. Providing this	Recommended
all health professionals on the	should be a best practice. Pilots reported the use of the following resources, in order of frequency:	for inclusion in
domains of palliative care and	 9 use each of the following: Medical Order for Life-Sustaining Treatment (MOLST), attend 	best practices and
4. Provide adequate training and	conferences, use specialized in-house training coordinated by program staff and palliative care team meetings	also as a requirement
clinical support to assure that professional staff are confident in	 8 use Center to Advance Palliative Care (CAPC) Resources and End-of-Life Nursing Education Consortium (ELNEC) Training 	requirement
their ability to provide palliative	 7 use End-of-Life/Palliative Education Resource Center (EPERC) Materials 	
care for patients.	 6 use Schwartz Rounds and team meetings with non-palliative care staff members 	
	 5 use Grand Rounds, participate in local networking events, and listed AAPHPM meetings as helpful 	
	 4 use UNIPACs 3 offer fellowships and use Virginia Commonwealth University (VCU) Resources 	
5. Hospice care and specialized	All pilots have certified staff members. Report will include details on the staffing structure and specific	Recommended
palliative care professionals should	credentials, as reported in CAPC survey and to staff in interviews.	for inclusion in
be appropriately trained,	r i i i i i i i i i i i i i i i i i i i	best practices and
credentialed and/or certified in their		also as a
area of expertise.		requirement

6. Formulate, utilize and regularly review a timely care plan based on a comprehensive interdisciplinary assessment of the values, preferences, goals and needs of the patient and family and, to the extent that existing privacy laws permit, ensure that the plan is broadly disseminated, both internally and externally, to all professionals involved in the patient's care.	 All pilots report assessing the need of the patient and family. Details are below and will be assessed for similarities and differences to determine common practices. Certified Nurses meet with patient/family after an order by the Attending Physician. Use template to assess the ability of the patient to participate and how much and what everyone understands, patient history, family status, spiritual values, life review, cultural and ethnic beliefs. Meetings may occur over several days or multiple admissions. The physician is involved in the evaluation, we do not use any standard model. Meeting usually consist of some combination of palliative clinician (MD or NP), palliative SW, ACE RN, attending MD, and sometimes hospital care manager. Standard history and exam that includes AMDs, Code status, MSAS-C, spiritual assessment Family meeting includes PC consultant, chaplain, and social worker/case manager Use Dr. Steve Levinson's Key Steps to Ethical Decision making Initial face to face consult conducted by palliative MD or NP usually with social worker when goals are established. Hospital care coordinator notified. Follow up planning in weekly team meeting with pastoral counselors, dietician, pharmacist. The consult team uses informal, internal tracking tool not part of the patient medical record. Family meeting insolve physician or extender, dictated as a consult note. Social worker involved if there are discharge issues. Specialty services (speech, floor RN, PT) depending on case. For high risk cancer patients, we use a checklist (pain, adv directives, etc) Goals, preferences, and values are explored at sit-down family meeting, often in more than one visit. SPIKES protocol is informally used. When possible and needed, the primary attending, PC SW and/or Chaplain joins. When available, we will review a patient's living will. Each member of the interdisciplinary team meets with the patient/family a family meeting is	Recommended fo inclusion in best practices and also as a requirement
7. Ensure that on transfer between health care settings, there is timely and thorough communication of the patient's goals, preferences, values and clinical information so that continuity of care and seamless follow-up are assured.	 All pilots report communication of some information. Details are below and will be assessed for similarities and differences to determine common practices. Direct communication by phone, in person or with discharge care plans in the EMR. Direct communication with providers during the hospital stay. No outpatient follow up, however communicate with the various hospices for patients that do accept hospice at discharge. The team members call before the consultation and after the consultation. (2) Fax back or EPIC-send a note the same day. Include PCP and involved MDs in DC summary. The PC consultant contacts the referring physician and primary attending with recommendations and outcome of goals of care and documents in the patient's electronic health record. Phone calls and in person verbal discussions within the hospital, consultation and progress notes. Occasional phone calls to primary care in community if patient is managed by hospitalists. 	Recommended fo inclusion in best practices and also as a requirement

8. Health care professionals should present hospice as an option to all patients and families when death within a year would not be surprising, and reintroduce the hospice option as the patient declines.	 When there are notable changes, primary provider is paged and given a verbal update. All consult notes are transcribed and copied to the attending physician, community physician if known, and to facilities. Written notes in the chart, EMR notes generated by SW, and a secure text paging system (amion.com). For outside providers, fax and phone calls to get the info back to providers. MD to MD phone calls, Faxing consult/follow up notes via EMR to PMD, Hospital dc summaries include PC input Within the hospital: formal written communication via the EMR through a dictated consultation, a formal interdisciplinary team assessment note, expanded palliative social work and chaplain assessment. Ongoing progress notes indicating updates, plan of care and goals. Meet with the bedside nurse before seeing patient, invite the nurse and treating team to family meetings and follow up via verbal communication. Outside providers receive a phone call the time of consult and a discharge phone call and written information. Outside the hospital: telehealth program for patients with heart failure to receive an electronic tablet and videochat with the team after leaving the hospital. 4/11 report that they follow-up with patient care after discharge in some way (some receive outpatient services at the pilot program). While most pilots reported doing this, pilots also stressed the importance of understanding when this was appropriate. Factors that might contribute to the munot doing this: 1. If they have access to hospice staff trained to do this, and an interest in differentiating palliative care from hospice; 2. If the primary physician is not supportive of that plan; 3. If they know the patient or family would not be receptive; 4. If the practice in the program is to wait until the attending physician suggests hospice as an option. 	Not recommend but recommend requirement that program be able respond to patient/family needs of this nat	a it e to
9. Patients and caregivers should be asked by palliative and hospice programs to assess physicians'/health care professionals' ability to discuss hospice as an option.	l pilot reported using an assessments tool to measure patient satisfaction of this aspect of care. While it should be a best practice, programs likely would need both technical assistance and additional resources for this to transpire successfully.	Recommended f inclusion in best practices	
10. Enable patients to make informed decisions about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.	 All pilots report this. Details are below and will be assessed for similarities and differences to determine common practices. Discussions held in person. Conversations patient centered, focused and goals of care drive most discussions. Additional resources added for disease knowledge or interventions. Instructional handouts available for options. Families can be teleconferenced or called independently when appropriate. Information regarding the patient is gathered from the attending, consultants, family and the pt. During family meetings 	Recommended f inclusion in best practices and als as a requirement	t so

 One on one with the patient or family: usually requires multiple follow up. Social worker support essential. Truthfully after asking permission Discussed with the patient and/or family. Interventions and goals reviewed in the patient/ family meeting Verbal explanations at the bedside (teaching tools may be used including Fast Facts and Dr. Joann Lynn's Handbook for Mortals). Speakerphone/conference call when indicated. In person during family meetings generally with more than one team member Family meetings and goals of care meetings (1-2 hours long). Includes specialist if indicated and coordinate recommendations before presenting to the family and patient. At sit down family meetings with follow up as needed. SW and chaplain may join MD when case is complex or emotional Patients informed using a standardized approach to family meeting with formal meeting, to sit down and discuss in detail their disease process, prognosis, and options for decision making informed consent. This is done in partnership with the treating medical team, all consultants and our team. Patients are informed using an approach well documented in the paliative literature; using key phrases and pearls. For example, always asking the patient what they know/what they have been told, sitting down at the bedside, taking time for pause, firing a "warning shot" before providing bad news, asking open ended questions such as what are your fears, wories, hopes. All pilots report this. Details are below and will be assessed for similarities and differences to determine common practices. Education provided with verbal instruction, disease specific pieces of literature for families and patients. Caregivers must be able to verbalize understanding. Education atlored toward the patient and family's level of understanding including but not limited to pamphlets, literature etc. Social worker provides support to families in follow up meeting, providin	Recommended for inclusion in best practices and also as a requirement

	 We use the Caregiver tool kit (derived by state). We also use materials like Gone from my sight and materials from different agencies. Regular communication in language they understand. Occasionally use handouts/pamphlets. By meeting one on one with individuals and appropriate team members. Use a folder specific to the patient/family individual needs (ex. disease education, grief and bereavement, Medicare benefits, living will and advance directive information) 	
12. Measure and document pain, dyspnea, constipation and other symptoms using available standardized scales.	Commission staff will analyze CAPC survey responses	Recommended for inclusion in best practices and also as a requirement
13. Assess and manage symptoms and side effects in a timely, safe and effective manner to a level acceptable to the patient and family	No pilots reported using an assessment tool to measure patient satisfaction of this aspect of care. While it should be a best practice, programs likely would need both technical assistance and additional resources for this to transpire successfully.	Recommended for inclusion in best practices
 Measure and document anxiety, depression, delirium, behavioral disturbances and other common psychological symptoms using available standardized scales. 	5 pilots report this. 2 list MSAS; 2 list ESAS, 1 lists NQM guidelines	Recommended for inclusion in best practices
15. Manage anxiety, depression, delirium, behavioral disturbances and other common psychological symptoms in a timely, safe and effective manner to a level acceptable to the patient and family	No pilots reported using an assessment tool to measure patient satisfaction of this aspect of care. While it should be a best practice, programs likely would need both technical assistance and additional resources for this to transpire successfully.	Recommended for inclusion in best practices
16. Assess and manage psychological reactions of patients and families to address emotional and functional impairment and loss, including stress, anticipatory grief and coping-in a regular ongoing fashion.	 10 of 11 pilots reported this. Details are below and will be assessed for similarities and differences to determine common practices. Assessment done in EMR and additional resources such as social work, psychiatry, child life, bereavement and chaplaincy brought in as needed Physician and social worker perform initial assessment. For the patients who accept hospice, we communicate our findings to the hospices and they follow up with the patient and families. Social work note documentation, and meetings, clinician documentation and meetings (2) Chaplain Assessed by the consultant and documented in the consult note in the EHR. Ongoing with daily rounds and phone calls. Social workers and chaplains have nearly daily contact. Bedside nurses provide consistent support. This is not a formal process, but is part of routine care. Multiple meetings and follow up but no standardized assessment Issues are listed as a "problem" in the "assessment and plan" part of the patient's chart. Assessment is made via discussion w/o a formal set of questions. The management process may include daily 	Recommended for inclusion in best practices and also as a requirement

	 reassessment, SW or chaplain for psychosocial or spiritual support. The SW and chaplain may document issues too. Assessment by the clinical team, using formal interviewing and assessment techniques. Ongoing supportive counseling strategies are implemented accordingly. From a service perspective, we use our satisfaction survey surrounding family meetings to inform how we are doing in supporting patients and families' level of stress and coping based on their responses. 	
17. Develop and offer a grief and bereavement care plan to provide services to patients and families prior to, and for at least 13 months after, the patient's death.	Pilots report that it would be appropriate to refer patients to a separate hospice for this service. Documenting the process for referrals would be a best practice.	Not recommended, but recommend a requirement that program be able to respond to patient/family needs of this nature
18. Conduct regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information, discuss goals of care, disease prognosis and advance care planning, and offer support.	All pilots report this and this should be an expected practice of hospital specialty palliative care teams.	Recommended for inclusion in best practices and also as a requirement
19. Develop and implement a comprehensive social care plan <u>that</u> includes, at a minimum, communication, caregiver availability, and decisionmaking, that addresses the social, practical and legal needs of the patient and earegivers, including but not limited to: relationships, communication, existing social and cultural networks, decision making, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, access to medicines and equipment.	 All pilots report that they address certain aspects of the needs listed, though not all pilots address all of the specific needs listed in the preferred practices. It is likely in this case that the hospital has additional resources to provide services to patients. 100% of pilots report addressing communication, caregiver availability, and decisionmaking 10/11 pilot address relationships, existing social and cultural networks, and access to medicine and equipment 8 address financial needs 7 address caregiver stress, and work and school 2 address sexuality 	Recommended for inclusion in best practices and also as a requirement to include general assessment

20. Develop and document a plan based on assessment of religious, spiritual and existential concerns using a structured instrument and integrate the information obtained from the assessment into the palliative care plan.	 5/11 pilots reported the use of a structured tool to assess these concerns. In each case, concerns were also integrated into the palliative care plan. 3 use FICA 1 (Holy Cross) uses a Palliative Care Spiritual Care Power Form developed by the Trinity Palliative Care Collaborative 1 (Palliative Care Collaborative 1 reported the use of EMR Two more gave details on their non-structured tools including a checklist describing interventions provided and a "problem list" in the doctor's assessment and plan and social worker and chaplain notes Tools to be shared and included in Appendix. 	Recommended for inclusion in best practices
21. Provide information about the availability of spiritual care services, and make spiritual care available either through organizational spiritual care counseling or through the patient's own clergy relationships.	Most pilots have access to hospital chaplain services. One pilot reported not having spiritual care services.	Recommended for inclusion in best practices and also as a requirement
22. Specialized palliative and hospice care teams should include spiritual care professionals appropriately trained and certified in palliative care	All pilots have access to hospital chaplains. 2 reported that some spiritual care professionals have training in palliative care, though most do not or do not know if available spiritual care professionals have this training.	Recommended for inclusion in best practices and also as a requirement to have ongoing/regular relationship with spiritual care professionals
23. Specialized palliative and hospice spiritual care professionals should build partnerships with community clergy and provide education and counseling related to end-of-life care.	4 pilots report that they provide education and counseling to community clergy. This is likely very dependent on having the time and resources.	Recommended for inclusion in best practices
24. Incorporate cultural assessment as a component of comprehensive palliative and hospice care assessment, including, but not limited to: locus of decision making, preferences regarding disclosure of information, truth telling and	 All pilots report that they incorporate a cultural assessment. 10 provided details on specific elements: All respondents report that family communication is part of this assessment 9/10 reported including language 8 reported including: preferences regarding disclosure of information, suffering and grieving, perspectives on death, and funeral/burial rituals 7 include dietary preferences 6 include runt telling and decision making 	Recommended for inclusion in best practices and also as a requirement to include general assessment

decision making, dietary preferences, language, family communication, desire for support measures such as palliative therapies and complementary and alternative medicine, perspectives on death, suffering and grieving and funeral/burial rituals.	 5 include locus of decision making, and desire for support measures such as palliative therapies and complementary and alternative medicine 	
25. Provide professional interpreter services and culturally sensitive materials in the patient's and family's preferred language.	5/11 pilots have materials available in Spanish, one of those have advance directives in other languages. All have interpreter services available; one reports that these interpreter services are trained in palliative care issues.	Recommended for inclusion in best practices and also as a requirement to have interpreter services available; Include communal advocacy for developing Spanish-language materials for use in hospitals
26. Recognize and document the transition to the active dying phase and communicate to the patient, family and staff the expectation of imminent death.	 All pilots recognize and communicate the transition, at minimum. Additional details that were provided: 4 reported discussion/verbal communication with patient and family, without additional specifics 1 reported: Multiple family meetings and this change in status is a time point that triggers another conversation with the patient and family to discuss expectations and strategies for management. We follow our patients every day so there is ongoing dialogue with patients and families, but when this transition is evident, it requires a more formal conversation with all stakeholders. 2 reported use of the pamphlet, "Gone from my sight" 2 pilots reported that they do, but it is rarely necessary due to close proximity of inpatient hospice unit. Most patients are transferred to inpatient hospice unless too unstable to travel or family preference. 2 pilots described documentation in hospital records: Patient's status if actively dying is documented in the daily progress notes in the EHR which are accessible to all providers; Discussion with physicians, nursing and interdisciplinary team; patient's condition and expected prognosis discussed with family members as appropriate; Chaplain provides spiritual support to family Document in chart and initiate a comfort care order set (which we created in our EMR) 	Recommended for inclusion in best practices and also as a requirement
27. Educate the family on a timely	All pilots report this, though one reports that its team could use training in more age-appropriate,	Recommended
basis regarding the signs and	developmentally appropriate, and culturally appropriate approaches.	for inclusion in

symptoms of imminent death in an age-appropriate, developmentally appropriate and culturally appropriate manner.		best practices and also as a requirement
28. As part of the ongoing care planning process, routinely ascertain and document patient and family wishes about the care setting for site of death, and fulfill patient and family preferences when possible.	All pilots report this. Additionally, 8 pilots reported reviewing circumstances in cases when preferences are not met.	Recommended for inclusion in best practices and also as a requirement
29. Provide adequate dosage of analgesics and sedatives as appropriate to achieve patient comfort during the active phase and address concerns and fears about using narcotics and analgesics hastening death.	 Pilots described how they ensure appropriate dosages and address concerns about using narcotics and analgesics. Responses will be assessed for similarities and differences to determine common practices. Palliative Care algorithms and standard hospice admission orders. Attendings write the orders for all meds. Continuous assessment and titration to comfort. Order writing, monitoring and follow up with bedside clinical and nursing team (2) Daily assessment Clinical assessment of patient and adjusting dosage appropriately for adequate symptom management This is individualized based on history (is the patient opioid naïve or opioid tolerant?) and titrated based on patient response and assessment. The palliative physicians and nurse practitioner are certified in hospice and palliative care. They make recommendations to the patient's primary team and or hospice as appropriate. Protocols on comfort care order set and input from pharmacy. Direct patient observation and feedback from nursing/other team members Use of two standardized protocols for supporting medical staff and ensuring safety for this phase of care. Palliative care order set and protocol for withdrawal of mechanical ventilation. In addition, dedicated clinical pharmacist is residency trained in palliative care involved in all of our patients to ensure that appropriate doses are used to keep patients comfortable and safe. Regarding addressing concerns and fears, pilots use: Education families that the goal is comfort and a dignified death, however if the patient or family's symptoms are not controlled we will discuss the option of escalating medications even if it leads to death. Educating families that the goal is comfort and a dignified death, however if the patient or family's symptoms are not controlled we will discuss the option of escalating medications even if it leads to death. Educating tamilies that the goal is c	Recommended for inclusion in best practices and also as a requirement

30. Treat the body after death with respect according to the cultural and religious practices of the family and in accordance with local law.	 Individualized. I have found that this is a rare concern expressed by some family members and we educate on goals of care and ensuring comfort and that the disease process and medical status cause death, not the therapeutic interventions we use. By providing verbal education to patient, family and providers, and when appropriate there is a CAPC Fast Fact #8 on the topic of double effect. Open conversations with patient, family and staff Anticipatory guidance and ongoing education via discussion The clinical pharmacist is actively involved in educating patients, families and other clinicians about the fears involved with using medications. The clinical pharmacist helps to train the palliative care team to have similar language in educating patients and families, and they are also present during family meetings to directly address these issues. Pilots described how they treat and document preferences. At some pilots, palliative care teams are not involved and/or hospitals have protocols that are followed. Discussion with patient and/or family at the appropriate time. Cultural and Religious views are taken into consideration and followed. Depends on place of death and religious/cultural preferences Ask families, most often when dealing with a religion/culture less familiar to us. Generally not involved. This is not usually a part of our consult service. If religious rituals are known, they will be communicated to the primary team and staff of the unit. Hospital policy and documented preferences from EMR (2) we ask about it beforehand, especially for Muslim or Jewish patients The hospital has standard post mortem policies. We respect cultural traditions and family can view in the patient has a protocol to follow after death but the team has worked with the hospital to allow the body to remain in place of several hours if needed for family visitation or rituals. Preparations are made in advan	Recommended for inclusion in best practices and also as a requirement to have policies/protocols and staff training, though probably also required by hospital
31. Facilitate effective grieving by implementing in a timely manner a bereavement care plan after the patient's death when family remains the focus of care.	CMS Conditions of Participation require that hospice care providers offer this service to all community members, regardless of whether their family member was a hospice patient. Commission staff assessment of pilot program responses is that palliative care programs do not need to include this component, as long as they have a plan or policy in place to address family needs for this service, via another provider if necessary.	Recommended for inclusion in best practices and also as a requirement to have a policy to

		address patient and family needs for bereavement services
32. Document the designated surrogate/decision maker in accordance with state law for every patient in primary, acute and long- term care and in palliative and hospice care.	9/11 hospitals report documenting a surrogate decision maker. Commission staff recommends this as a best practice.	Recommended for inclusion in best practices and also as a requirement
33. Document the patient/surrogate preferences for goals of care, treatment options and setting of care at first assessment and at frequent intervals as conditions change.	All pilots report this documentation. Commission staff recommends this as a best practice.	Recommended for inclusion in best practices and also as a requirement
34. Convert the patient treatment goals into medical orders and ensure that the information is transferable and applicable across care settings, including long-term care, emergency medical services and hospital care, through a program such as the Physician Orders for Life-Sustaining Treatment (POLST) program.	All pilots report this documentation. 10/11 respondents report using MOLST. Commission staff recommends this as a best practice.	Recommended for inclusion in best practices and also as a requirement to fully use MOLST or similar program
35. Make advance directives and surrogacy designations available across care settings while protecting patient privacy and adherence to HIPAA regulations, e.g., by Internet-based registries or electronic personal health records.	All pilots report making this available in EMR. Commission staff recommends this as a best practice.	Recommended for inclusion in best practices and also as a requirement
36. In conjunction with hospital staff, dDevelop healthcare and community collaborations to promote advance care planning and the completion of advance directives for all individuals, for example, the Respecting Choices and Community Conversations on Compassionate Care programs.	 All pilots report this engaging in this activity. 3 pilots reported familiarity with Respecting Choices (1 uses it as a tool); 4 report familiarity with Community Conversations on Compassionate Care (1 uses it as a tool and 1 would like to see it used more). Other efforts reported include: Present every year at National Decision Making Day. Present to church groups and senior centers. Included this year as a wellness educational opportunity. Presentations planned for our Long Term Care Community as well. Hospitalist and Nursing Home doctors. Family/patient meetings for goals of care, advanced care planning and MOLST completion. Lots of community work/lectures 	Recommended for inclusion in best practices and also as a requirement

	 The Palliative Care physicians, Spiritual Care and Ethics Committee members participated in "Consider the Conversation" - a panel discussion at the Montgomery County Medical Society encouraging end of life care discussions (April 2014). The Palliative Care Physicians have given multiple presentations at hospital Grand Rounds, Hospitalist Noon Lecture and Department of Medicine meetings. The team will conduct activities to engage providers and the general population on Advance Directive Day (April 16) to increase awareness of advance care planning Public education at various venues in Washington County including senior citizen groups, health fairs, community health education programs, within the health system for National Health Care Decisions Day, health system publications, local radio show on topics like MOLST and advance directives, etc. Coastal Hospice and Peninsula Regional Medical Center are partners in the Palliative Team, and together along with the Area Agency on Aging, we brought in 2 guest speakers to present an educational offering to professionals and the community on Advance Directives. We had over 80 attendees, and we are currently planning additional community education, utilizing a local television station, and planning education to hospital staff and the hospice speakers bureau. Additionally all stage III and IV cancer patients are to receive a palliative consultation in the outpatient clinic to introduce them to palliative care and begin education on advance directives. Community education, joint efforts with the cancer center, employee advanced directives as part of our Wellness Works employee program Regular meetings with rehab centers/nursing homes whose patients are often admitted to Suburban. We serve on state advisory committees to promote the formation and use of these forms. We also speak at local events and promote decision making in the community as well as teach in the University setting to educate		
37. Establish or have access to ethics committees or ethics consultation across care settings to address	their educational initiatives as well to advocate for community partnerships 10/11 pilots reported what they consider their access to ethics committees appropriate. 3 reported using it monthly, 7 reported using in less than once per month. Commission staff recommends this as a best practice.	Recommended for inclusion in best practices and also	
ethical conflicts at the end of life. 38. For minors with decision- making capacity, document the child's views and preferences for medical care, including assent for	One pilot program treats minors. 2 reported that they do not see minors at the pilot site. 2 reported that they do not have a process or good options; 2 reported they would refer them to a children's hospital or specialist; 3 reported in-system referral options	as a requirement Recommended for inclusion in best practices and also as a requirement to	Formatted: Highlight
weight in decision making. Make appropriate professional staff members available to both the child and the adult decision maker for consultation and intervention when		develop relationship with provider who specializes in pediatric palliative care	Commented [LC1]: Still keep as requirement?

the child's wishes differ from those of the adult decision maker.