

**NH PALLIATIVE CARE SURVEY  
FOR  
THE PALLIATION WORKGROUP OF THE NEW HAMPSHIRE  
COMPREHENSIVE CANCER COLLABORATION (NH CCC)**

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**The University of New Hampshire  
Survey Center**

The UNH Survey Center is an independent, non-partisan academic survey research organization and a division of the UNH College of Liberal Arts.

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## Executive Summary

The University of New Hampshire Survey Center conducted a survey for The Palliation Workgroup of the New Hampshire Comprehensive Cancer Collaboration (NH CCC) in conjunction with NH Hospice and Palliative Care Organization. The specific area of interest is how patients are informed about palliative care in New Hampshire. One hundred twenty-nine (129) surveys were emailed to various NH healthcare provider organizations including in-patient, out-patient, nursing, skilled, and long term health care facilities. On June 16, 2010 those with unique email addresses (105) were sent an email inviting them to participate in an internet survey, those without an email address were mailed a paper survey (24). A reminder was sent on June 21, 2010. Telephone interviews were conducted between June 16, 2010 and July 9, 2010 for respondents who did not respond by email or mail. Ultimately, eighty-two surveys were completed (38 by mail or email and 44 by telephone) yielding a response rate of 64 percent which is high for a survey of this type.

The following bulleted points summarize the major findings of the survey. Figures at the end of this section depict these findings. Section A contains the open-ended responses, detailed tabular results can be found in Appendix B, and Appendix C includes the survey instrument.

*\* In cases where there are fewer than 20 respondents, caution should be used when looking at differences since one organization's response may have a large impact on percentages.*

### **Organizations**

- Over two-thirds of the organizations (69%) that responded are nursing, skilled or long-term care facilities, 22 percent are in-patient care facilities and 9 percent were out-patient care facilities.
- Each of the types of facilities had high response rates within their type;
  - In-patient care (hospitals) had a 72 percent response rate, 18 out of 25 hospitals responded.
  - Out-patient care facilities had a 47 percent response rate, 7 out of 15 cancer centers and oncology practices responded.
  - Nursing, skilled or long-term care facilities had a 90 percent response rate, 57 out of 63 facilities responded.
- The majority of organizations (88%) responding to the survey report identifying patients in need of Palliative care.
- The majority of organizations (56%) reported either 100 or less beds available or patients in the practice, 32 percent reported between 100 and 200 beds or patients, and 12 percent report organizations larger than 200 beds or patients.

## **Palliative Care Services**

- The majority of organizations (85%) report having staff responsible for coordinating palliative care for cancer patients; 9% have dedicated staff and 76% have staff that coordinate in addition to other duties. **Figure 1**
  - Three-quarters of in-patient/out-patient organizations (76%) report having staff responsible for coordinating palliative care for cancer patients; 24% have dedicated staff and 52% have staff that coordinate in addition to other duties.
  - Nearly 9 out of 10 nursing, skilled or long-term facilities (88%) report having staff responsible for coordinating palliative care for cancer patients; 2% have dedicated staff and 86% have staff that coordinate in addition to other duties.
  
- More than a quarter (27%) of organizations provide palliative care services after a cancer patient is referred for palliative care through their own staff, 10 percent use a contracted agency to provide services, more than half (60%) use a combination of staff and contracted agency services, and 4 percent report some other means of providing services. **Figure 2**
  - More than half (52%) of in-patient or out-patient organizations provide palliative care services through their own staff, 8 percent use a contracted agency to provide services, one third (32%) use a combination of staff and contracted agency services, and 8 percent report some other means of providing services.
  - Less than one-fifth (16%) of nursing, skilled or long-term care facilities provide palliative care services after a cancer patient is referred for palliative care through their own staff, 11 percent use a contracted agency to provide services, nearly three-quarters (71%) use a combination of staff and contracted agency services, and 2 percent report some other means of providing services.
  
- Over half (54%) of organizations have a physician provide initial assessment of cancer patients who are referred for palliative care, followed by registered nurses (19%), nurse practitioners (12%), social workers (9%), or some other provider (8%). **Figure 3**
  - Nearly half (46%) of in-patient/out-patient organizations have a physician provide initial assessment of cancer patients who are referred for palliative care, followed by registered nurses (33%), nurse practitioners (16%), social workers (1%), or some other provider (4%).
  - Over half (58%) of nursing, skilled or long-term care facilities have a physician provide initial assessment of cancer patients who are referred for palliative care, followed by registered nurses (13%), social workers (13%), nurse practitioners (9%), or some other provider (9%).
  
- Most palliative care teams include social workers (85%), registered nurses (80%), physicians (75%), pastoral/spiritual care providers (64%), nurse practitioners (49%). Fewer organizations report having board certified palliative care physicians (28%), complementary/alternative medicine practitioners (25%), and board certified nurse practitioners (11%). **Figure 4**
  - Within in-patient or out-patient organizations, most palliative care teams include social workers (71%), registered nurses (63%), pastoral/spiritual care providers (58%), and physicians (46%). Fewer organizations report having board certified palliative care physicians (42%), complementary/alternative medicine practitioners (29%), nurse practitioners (17%), and board certified nurse practitioners (13%).
  - Within nursing, skilled or long-term care facilities, most palliative care teams include social workers (91%), registered nurses (88%), physicians (88%), pastoral/spiritual care providers (66%), and nurse practitioners (63%). Fewer organizations report having complementary/alternative medicine practitioners (23%), board certified palliative care physicians (21%), and board certified nurse practitioners (11%).

### **Informative Practices**

- The majority of organizations provide palliative care information when curative care is no longer available (66%), at hospice referral (56%), or when there is a change in condition (52%). Fewer organizations provide information at the time of terminal diagnosis (45%), when there are uncontrollable symptoms (39%), at first contact (29%), at the beginning of treatment (22%), or at time of first cancer diagnosis (21%). Two percent say no information is given. **Figure 5.**
  - The majority of in-patient or out-patient organizations provide palliative care information when curative care is no longer available (68%). Fewer organizations provide information when there is a change in condition (48%), at hospice referral (44%), when there are uncontrollable symptoms (44%), at the time of terminal diagnosis (40%), at first contact (16%), at the beginning of treatment (8%), or at time of first cancer diagnosis (4%). Four percent say no information is given.
  - The majority of nursing, skilled or long-term care facilities provide palliative care information when curative care is no longer available (65%), at hospice referral (61%), or when there is a change in condition (54%). Fewer organizations provide information at the time of terminal diagnosis (47%), when there are uncontrollable symptoms (37%), at first contact (35%), at the beginning of treatment (28%), or at time of first cancer diagnosis (28%). Two percent say no information is given.
- Palliative care information is directed toward the following groups at the following rates: cancer patients (84%) non-cancer patients (74%), family members (69%), children (5%), clinical staff (83%), and non-clinical staff (58%). **Figure 6**
  - Palliative care information is directed toward the following groups at the following rates at in-patient or out-patient organizations: cancer patients (72%) non-cancer patients (52%), family members (64%), children (13%), clinical staff (84%), and non-clinical staff (44%).
  - Palliative care information is directed toward the following groups at the following rates at nursing, skilled or long-term care facilities: cancer patients (89%) non-cancer patients (84%), family members (71%), children (0%), clinical staff (82%), and non-clinical staff (64%).
- Patients are most often provided information verbally for all topics on palliative care followed by printed information, internet links, audio/visual methods, or some other method. For more detailed descriptions see figures: **Figures 7 to 11.**
  - This pattern holds for both in-patient/out-patient organizations as well as nursing, skilled or long-term care facilities.

### **Organizational Awareness**

- Thirty-four percent (34%) of surveyed organizations had heard of the National Consensus Project, Clinical Practice Guidelines for Quality Palliative care, also known as the 8 domains of palliative care, while 45 percent had not and 21 percent did not know if they had or had not heard of the project. **Figure 1**
  - Nearly half (48%) of in-patient or out-patient organizations had heard of the National Consensus Project, Clinical Practice Guidelines for Quality Palliative care, also known as the 8 domains of palliative care, while 36 percent had not and 16 percent did not know if they had or had not heard of the project.
  - Over one quarter (28%) of nursing, skilled, or long-term care facilities had heard of the National Consensus Project, Clinical Practice Guidelines for Quality Palliative care, also known as the 8 domains of palliative care, while 49 percent had not and 23 percent did not know if they had or had not heard of the project.

- Thirty-two percent (32%) of surveyed organizations offered in-service programs to increase staff education about palliative care at least twice a year, 44 percent offered programs at least once a year, 9 percent offered programs at least once every other year, and 14 percent offered programs less than every two years. **Figure 13**
  - One-quarter (26%) of in-patient or out-patient organizations offered in-service programs to increase staff education about palliative care at least twice a year, 35 percent offered programs at least once a year, 9 percent offered programs at least once every other year, and 30 percent offered programs less than every two years.
  - One-third (35%) of nursing, skilled, or long-term care facilities offered in-service programs to increase staff education about palliative care at least twice a year, 48 percent offered programs at least once a year, 9 percent offered programs at least once every other year, and 7 percent offered programs less than every two years.

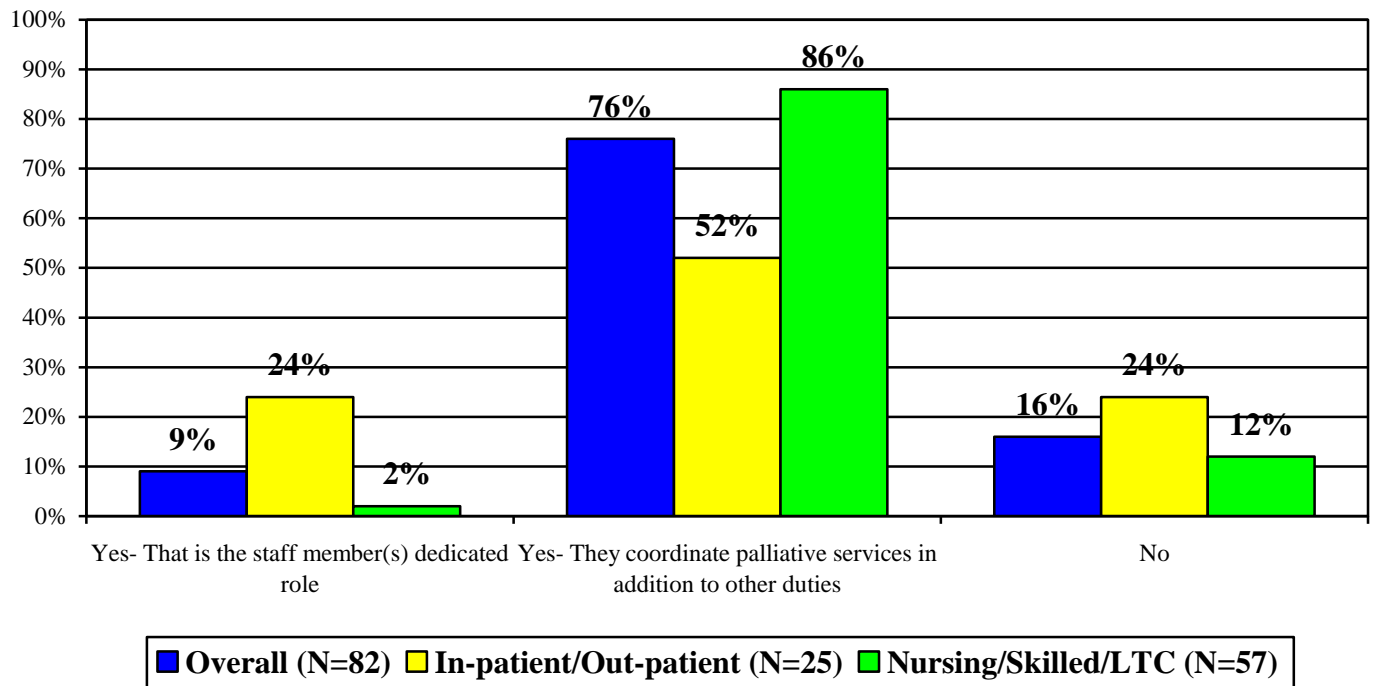
### **Cancer and Palliative Care**

- A plurality of organizations (46%) report that a tenth of their patients have cancer, a quarter of organizations (24%) report that 11 to 30 percent of their patients have cancer, 13 percent of organizations report that a third to half of their patients have cancer, one in ten (11%) organizations report that half or more of their patients have cancer. Four percent of organizations (4%) reported to have no cancer patients annually. **Figure 14**
  - Less than one-quarter (21%) of in-patient or out-patient organizations report that a tenth of their patients have cancer, one-fifth (16%) report that 11 to 30 percent of their patients have cancer, a third (31%) report that a third to half of their patients have cancer, while another third (31%) report that half or more of their patients have cancer.
  - A majority (56%) of nursing, skilled, or long-term care facilities report that a tenth of their patients have cancer, a quarter (28%) report that 11 to 30 percent of their patients have cancer, 6 percent report that a third to half of their patients have cancer, and 4 percent report that half or more of their patients have cancer. Six percent (6%) reported to have no cancer patients annually.
- A third of organizations (34%) report that 1 to 10 percent of those referred to palliative care have cancer, another third report (30%) report that 11 to 50 percent of those referred to palliative care for are cancer patients. A third (32%) report that over 50 percent of those referred to palliative care have cancer and 5 percent report that none of the patients referred for palliative care have cancer. **Figure 15**
  - Over one-quarter (28%) of in-patient or out-patient organizations report that 11 to 50 percent of those referred to palliative care have cancer, while nearly three-quarters (72%) report that over 50 percent of those referred to palliative care have cancer.
  - Nearly half (47%) of nursing, skilled, or long-term care facilities report that 1 to 10 percent of those referred to palliative care have cancer, another third report (32%) report that 11 to 50 percent of those referred to palliative care for are cancer patients. Nearly one-fifth (15%) report that over 50 percent of those referred to palliative care have cancer and 7 percent report that none of the patients referred for palliative care have cancer.

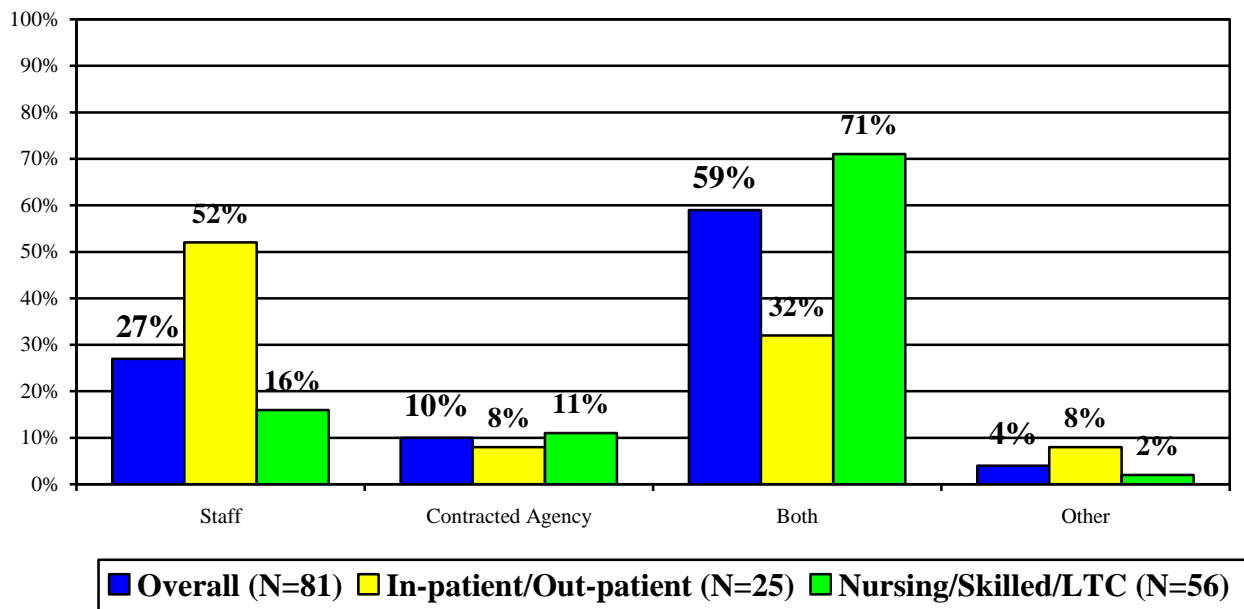
### **Communication**

- Over half of respondents selected email brochures (57%) as the best way to inform them of the best practices of palliative care, followed by mailed brochures (45%), newsletters (31%), meetings/conferences (24%), a website (21%), and/or some other method (2%). **Figure 16**
  - This pattern holds for both in-patient/out-patient organizations as well as nursing, skilled or long-term care facilities.

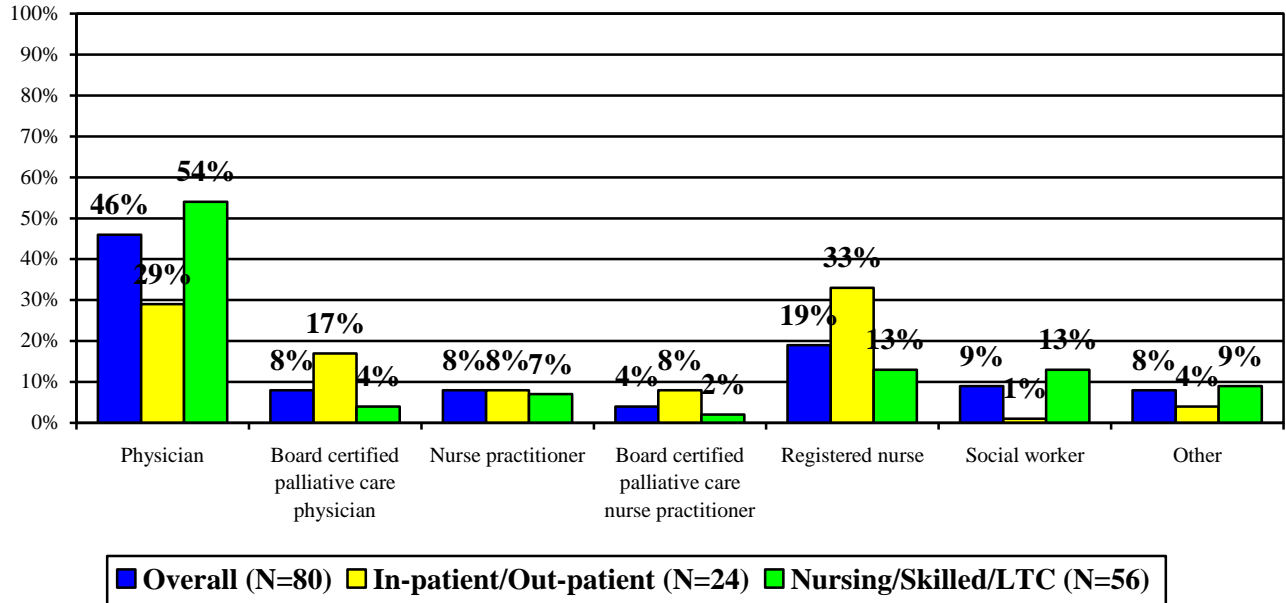
**Figure 1 - Q6:** Does your organization have staff that is responsible for coordinating palliative care for your cancer patients?



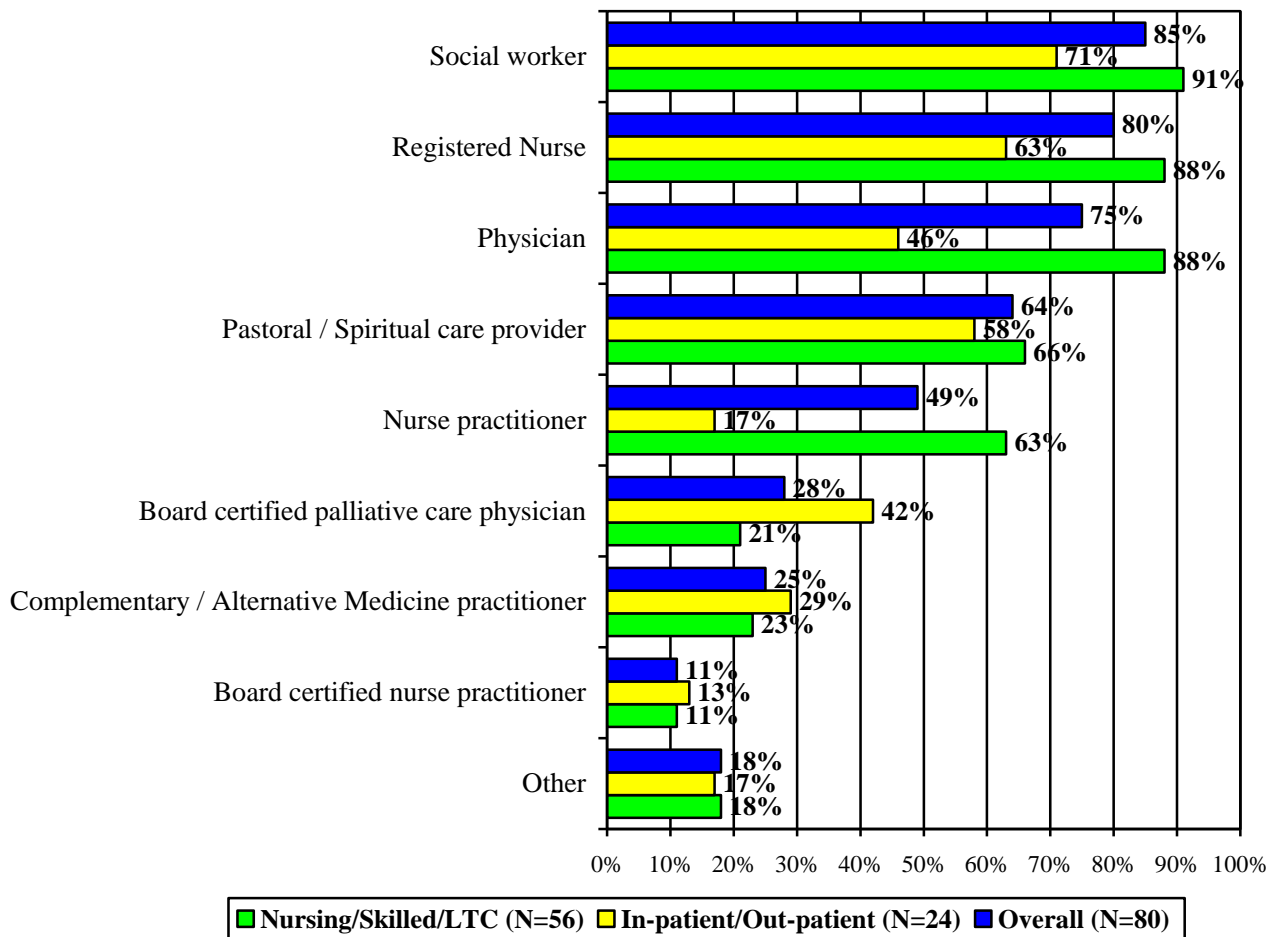
**Figure 2 - Q7:** Who provides palliative care services after a cancer patient is referred for palliative care?



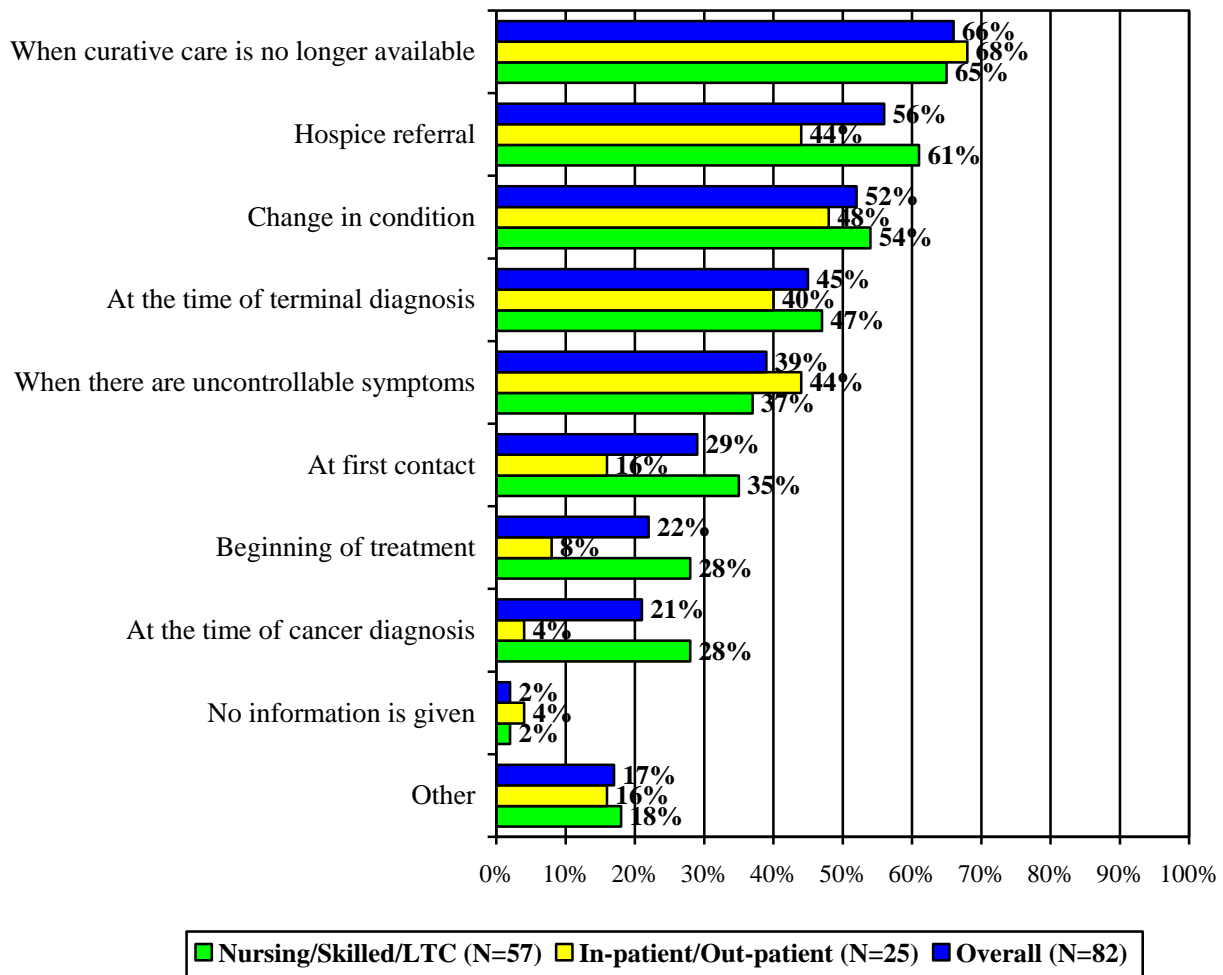
**Figure 3 - Q8: Who provides the initial assessment of cancer patients referred for palliative care?**



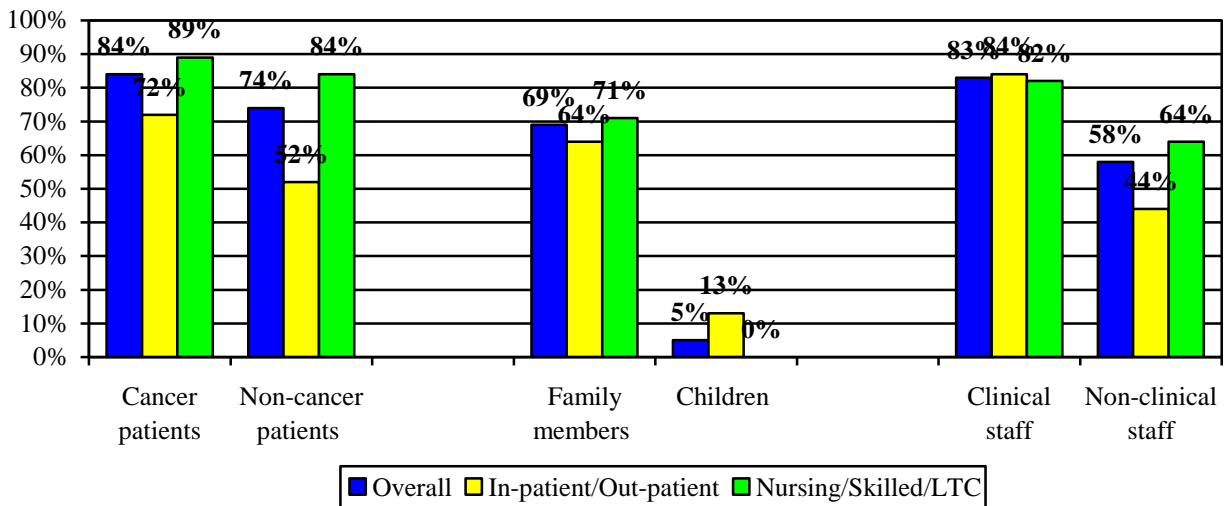
**Figure 4 - Q9: Who makes up the palliative care team / program available to your cancer patients?**  
(Check all that apply. Percentages may add to more than 100 percent.)



**Figure 5 - Q10: When is palliative care information given to cancer patients?**  
(Check all that apply. Percentages may add to more than 100 percent.)



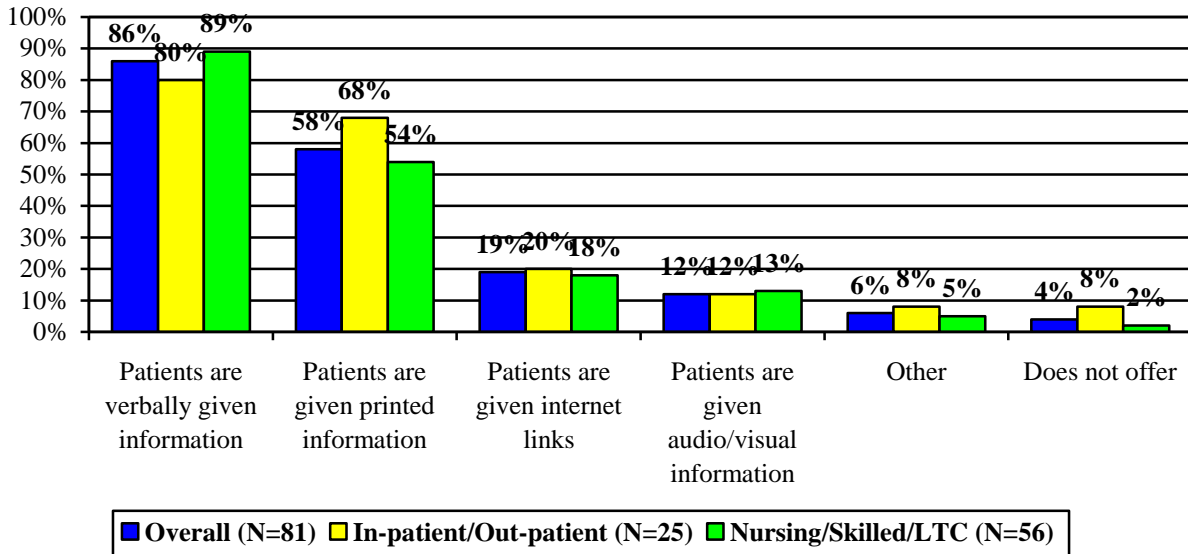
**Figure 6 - Q11: Does your organization provide information about palliative care services directed toward educating each of the following groups: % YES** (See detailed tables for N's of individual questions)



**Figures 7 to 12 - Q12: How does your organization offer information to cancer patients on the following issues?**

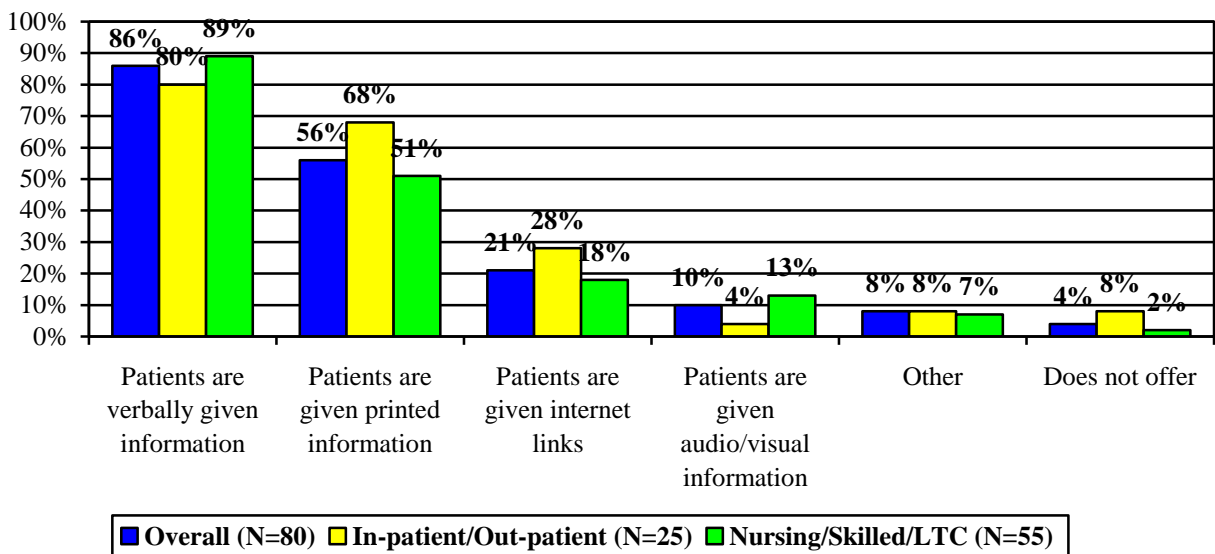
**Figure 7 - Pain and symptom management.**

*(Check all that apply. Percentages may add to more than 100 percent.)*



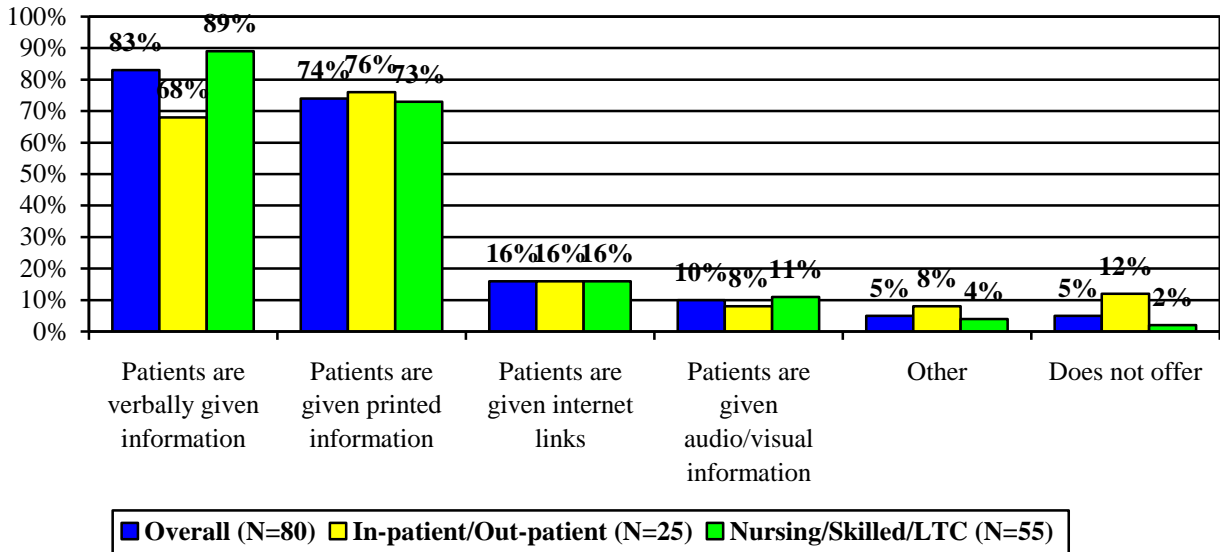
**Figure 8 - Psychosocial and emotional aspects of cancer.**

*(Check all that apply. Percentages may add to more than 100 percent.)*



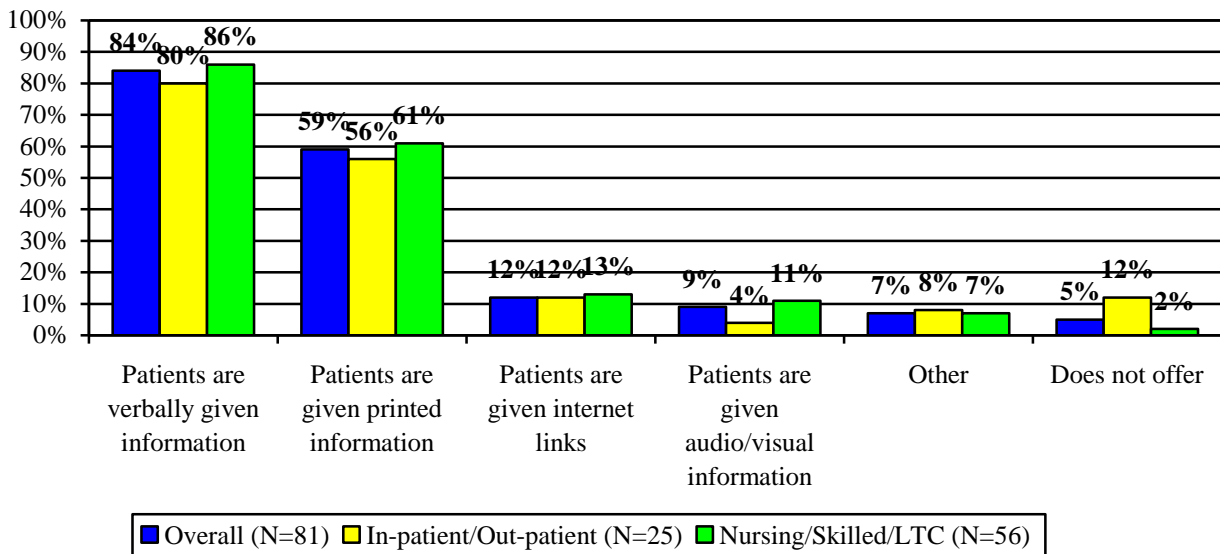
**Figure 9 - Advance care planning.**

(Check all that apply. Percentages may add to more than 100 percent.)



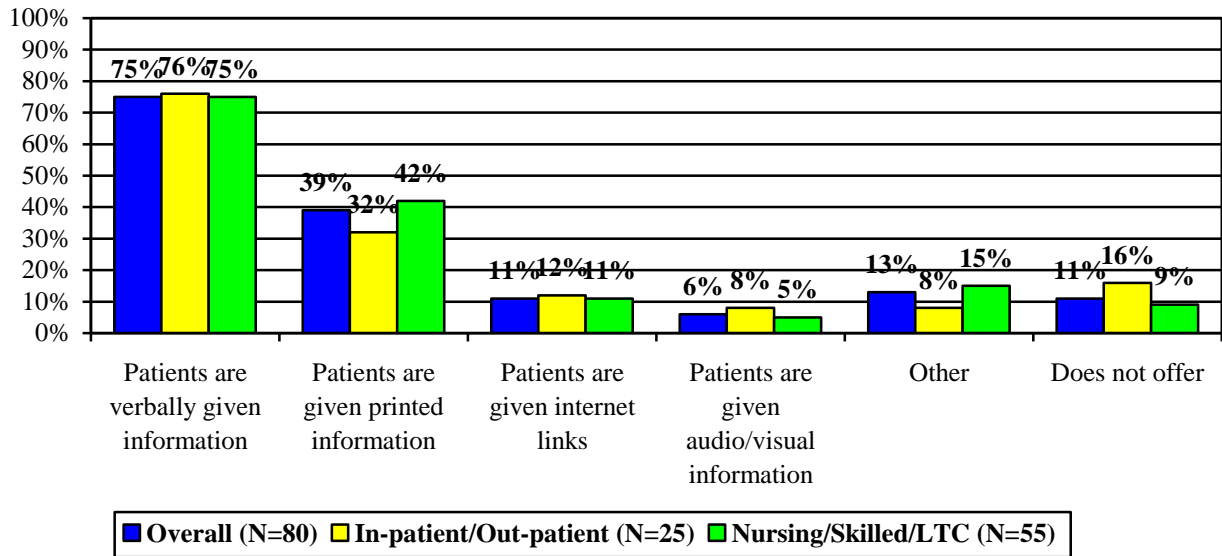
**Figure 10 - General information about palliative care (as described in introduction).**

(Check all that apply. Percentages may add to more than 100 percent.)

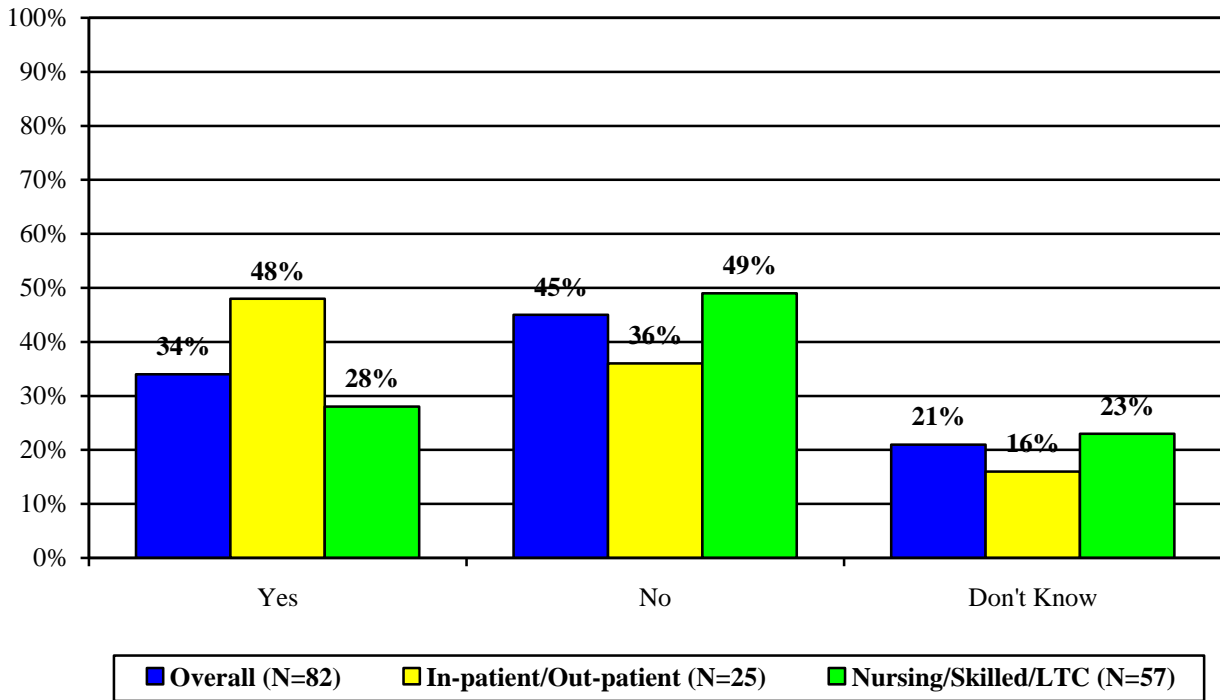


**Figure 11 - Spiritual aspects of cancer.**

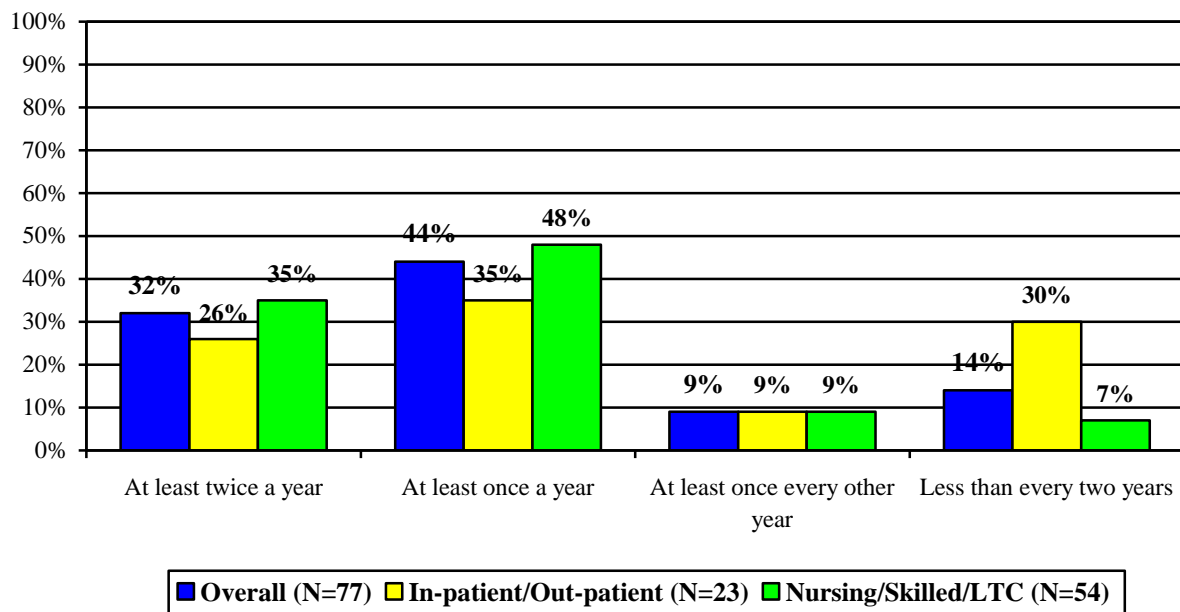
(Check all that apply. Percentages may add to more than 100 percent.)



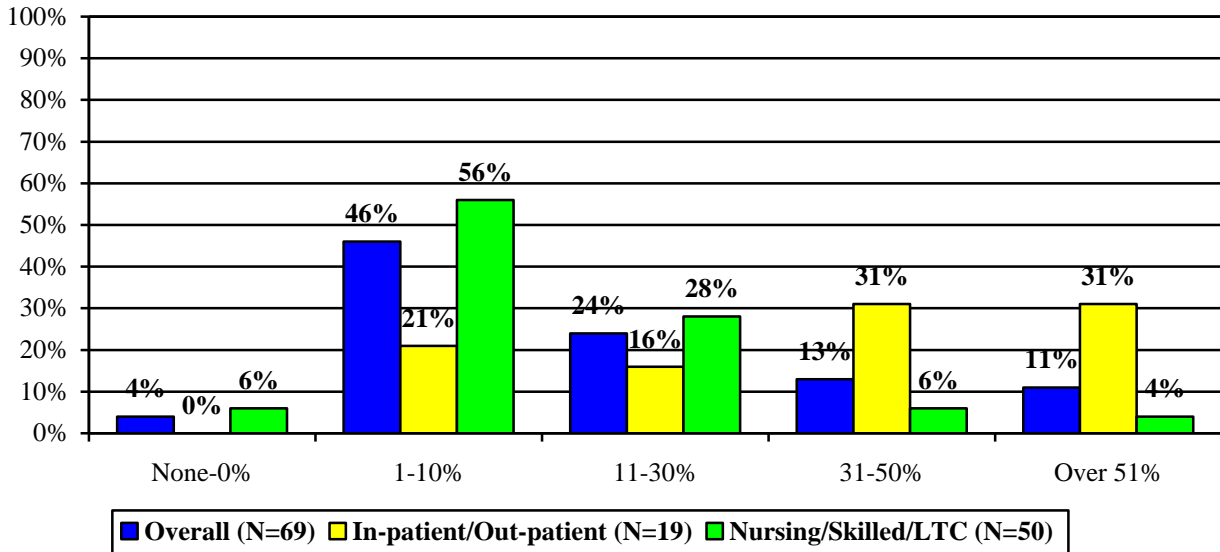
**Figure 12 - Q13:** Is your organization aware of the National Consensus Project, Clinical Practice Guidelines for Quality Palliative care, also known as the 8 domains of palliative care?



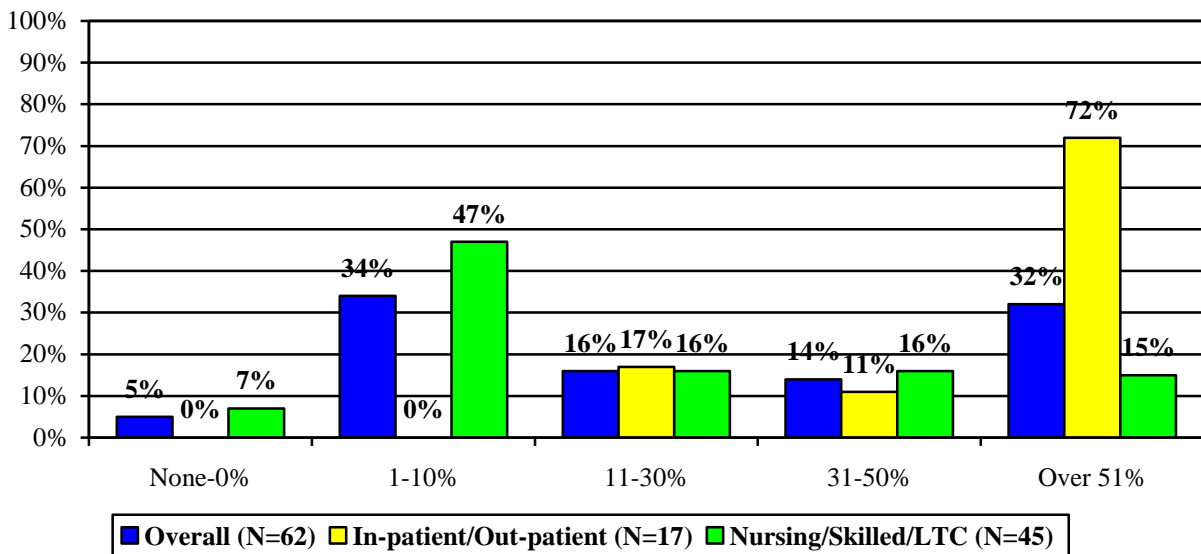
**Figure 13 - Q14:** How often does your organization offer in-service programs to increase staff awareness or education about palliative care?



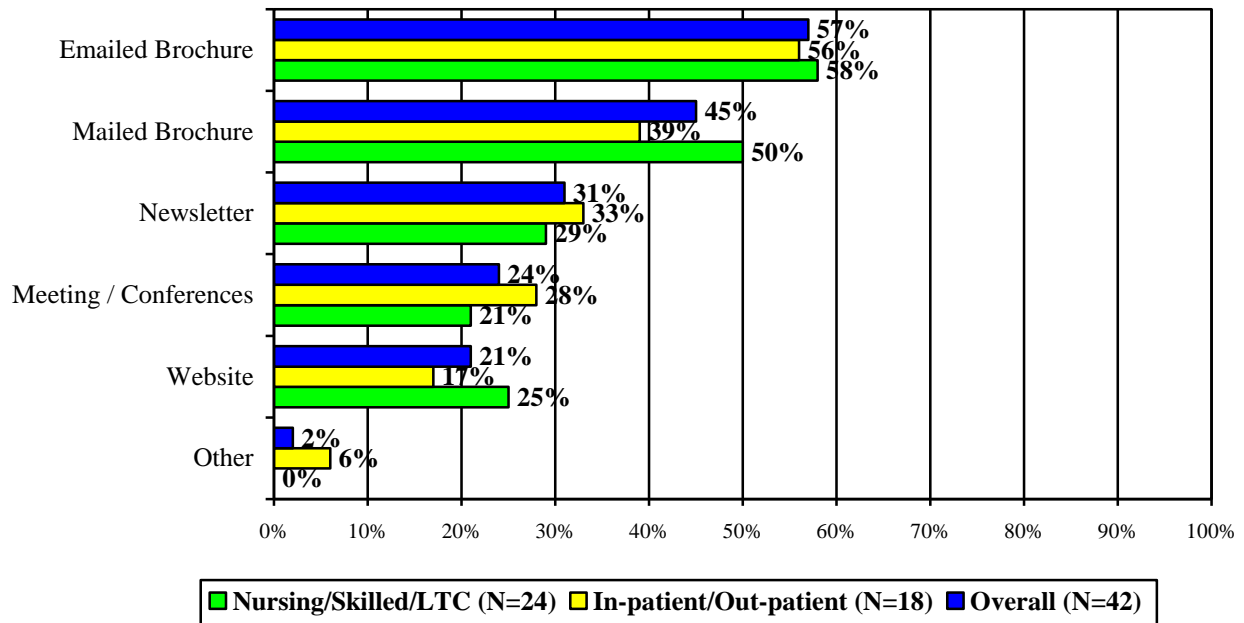
**Figure 14 - Q15:** Approximately what percentage of patients admitted to your organization annually, have cancer?



**Figure 15 - Q16:** Approximately what percentage of patients who are referred to palliative care have cancer?



**Figure 16 - Q17:** What is the best way to inform you of updates for best practices of palliative care?  
(Check all that apply. Percentages may add to more than 100 percent.)



**APPENDIX A**

**OPEN ENDED RESPONSES**

Q2: Which of the following best describes your organization?

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- Continuing Care Retirement Community
- we provide services in all 3 locations
- Inpatient hospital, outpatient physicians/services, VNA homecare/hospice services
- Outpatient Radiation Oncology
- critical access hospital
- all 3
- Both In-patient and Out-patient ambulatory care
- retirement facility
- long term and rehab
- rural hospital
- homecare
- nursing home and skilled

Q6: Does your organization have staff that is responsible for coordinating palliative care for your cancer patients?

---

- We work with Home Health and Hospice
- We have a hospice care unit that can hold 13 residents, and others live throughout the building
- TRYING TO BUILD PALLIATIVE CARE PROGRAM,,, ONLY MYSELF RN, CHPN AND CLERGY
- I make the referral through a contract with the vna.

Q7: Who provides palliative care services after a cancer patient is referred for palliative care?

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- Staff and sometimes hospice staff
- Our staff and we have contracts with 3 area hospice agencies.
- Palliative Care staff
- home health or hospice
- does not apply
- I think its an outpatient service, we are in the process of setting up our palliative care services.
- we dont have a palliative group here we do work with them. we have one dr. who has worked with palliative care.

Q8: Who provides the initial assessment of cancer patients referred for palliative care?

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- Physician, NP , & RN
- Physician and NP
- IDT
- Nursing staff
- A nurse practitioner assists the board certified palliative care physician in the initial assessment.
- Team approach; Nurse practitioner, social worker, physician (at times)
- Usually it is either our Nurse Navigator, RN or our Board Certified Palliative Care Physician
- All staff working with the particular resident
- Physician and or Nurse Practitioner
- team effort nurses and social workers

- attending physician or nurse practitioner
- we dont really deal with that too much and when they get here they already have it thru hospice.
- no formal referral.
- social worker, rn, or the dr
- physician, nurse practitioner, social worker, or registered nurse, could be any or all of these.

Q9: Who makes up the palliative care team / program available to your cancer patients? (Check all that apply)

---

- Hospice
- Hospice services
- Social Worker
- Resp Therapist, Nutritionist
- IDT
- on-site hospice evaluations are done at MCNH upon request
- Nursing staff
- HOSPICE
- LNA, activities
- Program Manager, is also the Social Worker.
- Dieticien
- we do not have an established palliative care program
- palliative care team has been disbanded due to lack of interest
- All staff
- In process of development
- Team of specially trained In-patient Palliative Care Volunteers; Music, Art and Expressive therapist
- dietition
- and rehab
- hospice, dietition
- we have a angle care program here for extra support.
- clinical nurse specialist for palliative care.
- we are in the process of forming the services right now.

Q10: When is palliative care information given to cancer patients? (Check all that apply)

---

- Depends on resident and situation
- Individualized
- Varies widely
- Depends on each physician, and stage of illness. Goal is to referrals much earlier.
- Every new NCCC pt receives an Orientation Booklet with info re PC services offered.
- they would know about before they get here
- they already know about it before they get here
- they are already diagnosed when they get here.
- they already have palliative care when they get here.
- I not sure since they are referred to us
- no formal referral
- the info would be given to them before they get here
- we do care and comfort

Q17: What is the best way to inform you of updates for best practices of palliative care?

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- postings for meetings and conferences and mail
- through palliative care member or email.
- mail and email
- any and all of the above
- all of the above

**APPENDIX B**  
**TABULAR RESULTS**

Q6: Does your organization have staff that is responsible for coordinating palliative care for your cancer patients?

	Yes - That is the staff member(s) dedicated role	Yes - They coordinate palliative services in addition to other duties	No	Number Responding
<b>NH Health Providers</b>	9%	76%	16%	82
<b>Organization Type</b>				
In-patient/Outpatient	24%	52%	24%	25
Nursing / Skilled / Long Term	2%	86%	12%	57
<b>Organization Size</b>				
100 or less	9%	79%	12%	43
101 or more	3%	79%	18%	33
<b>Identify Pts Needing PC</b>				
Yes	8%	78%	14%	72
No	10%	60%	30%	10

Q7: Who provides palliative care services after a cancer patient is referred for palliative care?

	Staff	Contracted agency	Both	Other - specify	Number Responding
<b>NH Health Providers</b>	27%	10%	59%	4%	81
<b>Organization Type</b>					
In-patient/Outpatient	52%	8%	32%	8%	25
Nursing / Skilled / Long Term	16%	11%	71%	2%	56
<b>Organization Size</b>					
100 or less	30%	12%	53%	5%	43
101 or more	16%	9%	72%	3%	32
<b>Identify Pts Needing PC</b>					
Yes	28%	10%	61%	1%	72
No	22%	11%	44%	22%	9

Q8: Who provides the initial assessment of cancer patients referred for palliative care?

	Physician	Board Certified Palliative Care Physician	Nurse Practitioner	Board Certified Palliative Care Nurse Practitioner	Social Worker	Registered Nurse (RN)	Other Specify	Number Responding
<b>NH Health Providers</b>	46%	8%	8%	4%	9%	19%	8%	80
<b>Organization Type</b>								
In-patient/Outpatient	29%	17%	8%	8%	0%	33%	4%	24
Nursing / Skilled / Long Term	54%	4%	7%	2%	13%	13%	9%	56
<b>Organization Size</b>								
100 or less	40%	7%	12%	5%	16%	19%	2%	43
101 or more	59%	6%	3%	0%	0%	16%	16%	32
<b>Identify Pts Needing PC</b>								
Yes	49%	8%	7%	3%	10%	17%	6%	71
No	22%	0%	11%	11%	0%	33%	22%	9

Q9: Who makes up the palliative care team / program available to your cancer patients? (Check all that apply. Percentages may add to more than 100 percent.)

	Physician	Board Certified Palliative Care Physician	Nurse Practitioner	Board Certified Palliative Care Nurse Practitioner	Social Worker	Pastoral/Spiritual Care Provider	Complementary/Alternative Medicine (CAM)	Registered Nurse (RN)	Other - Specify	Number Responding
<b>NH Health Providers</b>	75%	28%	49%	11%	85%	64%	25%	80%	18%	80
<b>Organization Type</b>										
In-patient/Outpatient	46%	42%	17%	13%	71%	58%	29%	63%	17%	24
Nursing / Skilled / Long Term	88%	21%	63%	11%	91%	66%	23%	88%	18%	56
<b>Organization Size</b>										
100 or less	77%	28%	53%	14%	81%	70%	28%	77%	12%	43
101 or more	78%	22%	50%	6%	91%	56%	25%	88%	25%	32
<b>Identify Pts Needing PC</b>										
Yes	76%	30%	52%	11%	89%	66%	25%	85%	14%	71
No	67%	11%	22%	11%	56%	44%	22%	44%	44%	9

Q10: When is palliative care information given to cancer patients? (Check all that apply. Percentages may add to more than 100 percent.)

	At first contact	At the time of cancer diagnosis	At the time of a terminal diagnosis	Beginning of treatment	When curative care is no longer indicated	Hospice referral
<b>NH Health Providers</b>	29%	21%	45%	22%	66%	56%
<b>Organization Type</b>						
In-patient/Outpatient	16%	4%	40%	8%	68%	44%
Nursing / Skilled / Long Term	35%	28%	47%	28%	65%	61%
<b>Organization Size</b>						
100 or less	40%	26%	49%	28%	60%	63%
101 or more	21%	18%	45%	18%	73%	58%
<b>Identify Pts Needing PC</b>						
Yes	32%	22%	49%	24%	71%	58%
No	10%	10%	20%	10%	30%	40%

	Change in condition	When there are uncontrollable symptoms	No information is given	Other - Specify	Number Responding
<b>NH Health Providers</b>	52%	39%	2%	17%	82
<b>Organization Type</b>					
In-patient/Outpatient	48%	44%	4%	16%	25
Nursing / Skilled / Long Term	54%	37%	2%	18%	57
<b>Organization Size</b>					
100 or less	51%	47%	2%	16%	43
101 or more	55%	33%	3%	15%	33
<b>Identify Pts Needing PC</b>					
Yes	58%	44%	1%	13%	72
No	10%	0%	10%	50%	10

Q11.a: Does your organization provide information about palliative care services directed toward educating each of the following groups: Cancer patients.

	Yes	No	Don't Know	Number Responding
<b>NH Health Providers</b>	<b>84%</b>	<b>13%</b>	<b>2%</b>	<b>82</b>
<b>Organization Type</b>				
In-patient/Outpatient	72%	20%	8%	25
Nursing / Skilled / Long Term	89%	11%	0%	57
<b>Organization Size</b>				
100 or less	84%	14%	2%	43
101 or more	85%	15%	0%	33
<b>Identify Pts Needing PC</b>				
Yes	88%	11%	1%	72
No	60%	30%	10%	10

Q11.b: Does your organization provide information about palliative care services directed toward educating each of the following groups: Non-cancer patients in need of palliative care services.

	Yes	No	Don't Know	Number Responding
<b>NH Health Providers</b>	<b>74%</b>	<b>23%</b>	<b>2%</b>	<b>82</b>
<b>Organization Type</b>				
In-patient/Outpatient	52%	40%	8%	25
Nursing / Skilled / Long Term	84%	16%	0%	57
<b>Organization Size</b>				
100 or less	74%	26%	0%	43
101 or more	79%	18%	3%	33
<b>Identify Pts Needing PC</b>				
Yes	76%	22%	1%	72
No	60%	30%	10%	10

Q11.c: Does your organization provide information about palliative care services directed toward educating each of the following groups: Children in need of palliative care service.

	Yes	No	Don't Know	Number Responding
<b>NH Health Providers</b>	5%	90%	5%	62
<b>Organization Type</b>				
In-patient/Outpatient	13%	78%	9%	23
Nursing / Skilled / Long Term	0%	97%	3%	39
<b>Organization Size</b>				
100 or less	3%	97%	0%	30
101 or more	4%	85%	12%	26
<b>Identify Pts Needing PC</b>				
Yes	6%	92%	2%	52
No	0%	80%	20%	10

Q11.d: Does your organization provide information about palliative care services directed toward educating each of the following groups: Family members in need of palliative care services.

	Yes	No	Don't Know	Number Responding
<b>NH Health Providers</b>	69%	28%	2%	81
<b>Organization Type</b>				
In-patient/Outpatient	64%	28%	8%	25
Nursing / Skilled / Long Term	71%	29%	0%	56
<b>Organization Size</b>				
100 or less	70%	30%	0%	43
101 or more	72%	28%	0%	32
<b>Identify Pts Needing PC</b>				
Yes	72%	27%	1%	71
No	50%	40%	10%	10

Q11.e: Does your organization provide information about palliative care services directed toward educating each of the following groups: Non-clinical staff.

	Yes	No	Don't Know	Number Responding
<b>NH Health Providers</b>	<b>58%</b>	<b>33%</b>	<b>9%</b>	<b>81</b>
<b>Organization Type</b>				
In-patient/Outpatient	44%	44%	12%	25
Nursing / Skilled / Long Term	64%	29%	7%	56
<b>Organization Size</b>				
100 or less	63%	33%	5%	43
101 or more	53%	34%	13%	32
<b>Identify Pts Needing PC</b>				
Yes	59%	31%	10%	71
No	50%	50%	0%	10

Q11.f: Does your organization provide information about palliative care services directed toward educating each of the following groups: Clinical staff.

	Yes	No	Don't Know	Number Responding
<b>NH Health Providers</b>	<b>83%</b>	<b>15%</b>	<b>2%</b>	<b>82</b>
<b>Organization Type</b>				
In-patient/Outpatient	84%	16%	0%	25
Nursing / Skilled / Long Term	82%	14%	4%	57
<b>Organization Size</b>				
100 or less	81%	16%	2%	43
101 or more	85%	12%	3%	33
<b>Identify Pts Needing PC</b>				
Yes	83%	14%	3%	72
No	80%	20%	0%	10

Q12.a: How does your organization offer information to cancer patients on the following issues? - Pain and symptom management.  
(Check all that apply. Percentages may add to more than 100 percent.)

	Does not offer	Patients are given printed Information	Patients are verbally given information	Patients are given internet links	Patients are given audio/visual information	Other	Number Responding
<b>NH Health Providers</b>	<b>4%</b>	<b>58%</b>	<b>86%</b>	<b>19%</b>	<b>12%</b>	<b>6%</b>	<b>81</b>
<b>Organization Type</b>							
In-patient/Outpatient	8%	68%	80%	20%	12%	8%	25
Nursing / Skilled / Long Term	2%	54%	89%	18%	13%	5%	56
<b>Organization Size</b>							
100 or less	5%	56%	81%	16%	9%	7%	43
101 or more	3%	56%	91%	19%	16%	6%	32
<b>Identify Pts Needing PC</b>							
Yes	1%	59%	87%	20%	13%	7%	71
No	20%	50%	80%	10%	10%	0%	10

Q12.b: How does your organization offer information to cancer patients on the following issues? - Psychosocial and emotional aspects of cancer.  
(Check all that apply. Percentages may add to more than 100 percent.)

	Does not offer	Patients are given printed Information	Patients are verbally given information	Patients are given internet links	Patients are given audio/visual information	Other	Number Responding
<b>NH Health Providers</b>	<b>4%</b>	<b>56%</b>	<b>86%</b>	<b>21%</b>	<b>10%</b>	<b>8%</b>	<b>80</b>
<b>Organization Type</b>							
In-patient/Outpatient	8%	68%	80%	28%	4%	8%	25
Nursing / Skilled / Long Term	2%	51%	89%	18%	13%	7%	55
<b>Organization Size</b>							
100 or less	5%	51%	84%	16%	12%	9%	43
101 or more	3%	58%	90%	23%	10%	6%	31
<b>Identify Pts Needing PC</b>							
Yes	1%	57%	87%	23%	11%	9%	70
No	20%	50%	80%	10%	0%	0%	10

Q12.c: How does your organization offer information to cancer patients on the following issues? - Advance care planning.  
(Check all that apply. Percentages may add to more than 100 percent.)

	Does not offer	Patients are given printed Information	Patients are verbally given information	Patients are given internet links	Patients are given audio/visual information	Other	Number Responding
<b>NH Health Providers</b>	5%	74%	83%	16%	10%	5%	80
<b>Organization Type</b>							
In-patient/Outpatient	12%	76%	68%	16%	8%	8%	25
Nursing / Skilled / Long Term	2%	73%	89%	16%	11%	4%	55
<b>Organization Size</b>							
100 or less	7%	63%	79%	12%	9%	5%	43
101 or more	3%	84%	87%	19%	10%	6%	31
<b>Identify Pts Needing PC</b>							
Yes	3%	76%	83%	17%	10%	6%	70
No	20%	60%	80%	10%	10%	0%	10

Q12.d: How does your organization offer information to cancer patients on the following issues? - General information about palliative care (as described in introduction).  
(Check all that apply. Percentages may add to more than 100 percent.)

	Does not offer	Patients are given printed Information	Patients are verbally given information	Patients are given internet links	Patients are given audio/visual information	Other	Number Responding
<b>NH Health Providers</b>	5%	59%	84%	12%	9%	7%	81
<b>Organization Type</b>							
In-patient/Outpatient	12%	56%	80%	12%	4%	8%	25
Nursing / Skilled / Long Term	2%	61%	86%	13%	11%	7%	56
<b>Organization Size</b>							
100 or less	5%	60%	81%	12%	9%	7%	43
101 or more	6%	59%	84%	16%	9%	9%	32
<b>Identify Pts Needing PC</b>							
Yes	1%	62%	86%	14%	10%	8%	71
No	30%	40%	70%	0%	0%	0%	10

Q12.e: How does your organization offer information to cancer patients on the following issues? Spiritual aspects of cancer.  
(Check all that apply. Percentages may add to more than 100 percent.)

	Does not offer	Patients are given printed Information	Patients are verbally given information	Patients are given internet links	Patients are given audio/visual information	Other	Number Responding
<b>NH Health Providers</b>	11%	39%	75%	11%	6%	13%	80
<b>Organization Type</b>							
In-patient/Outpatient	16%	32%	76%	12%	8%	8%	25
Nursing / Skilled / Long Term	9%	42%	75%	11%	5%	15%	55
<b>Organization Size</b>							
100 or less	9%	37%	74%	12%	7%	16%	43
101 or more	16%	42%	74%	10%	3%	10%	31
<b>Identify Pts Needing PC</b>							
Yes	9%	40%	76%	11%	6%	14%	70
No	30%	30%	70%	10%	10%	0%	10

Q13: Is your organization aware of the National Consensus Project, Clinical Practice Guidelines for Quality Palliative care, also known as the 8 domains of palliative care?

	Yes	No	Don't know / Not sure	Number Responding
<b>NH Health Providers</b>	34%	45%	21%	82
<b>Organization Type</b>				
In-patient/Outpatient	48%	36%	16%	25
Nursing / Skilled / Long Term	28%	49%	23%	57
<b>Organization Size</b>				
100 or less	30%	58%	12%	43
101 or more	36%	33%	30%	33
<b>Identify Pts Needing PC</b>				
Yes	33%	44%	22%	72
No	40%	50%	10%	10

Q14: How often does your organization offer in-service programs to increase staff awareness / education about palliative care?

	Less than every two years	At least once every other year	At least once a year	At least twice a year	Number Responding
<b>NH Health Providers</b>	<b>14%</b>	<b>9%</b>	<b>44%</b>	<b>32%</b>	<b>77</b>
<b>Organization Type</b>					
In-patient/Outpatient	30%	9%	35%	26%	23
Nursing / Skilled / Long Term	7%	9%	48%	35%	54
<b>Organization Size</b>					
100 or less	17%	10%	46%	27%	41
101 or more	7%	10%	40%	43%	30
<b>Identify Pts Needing PC</b>					
Yes	16%	10%	42%	32%	69
No	0%	0%	63%	38%	8

Q15: Approximately what percentage of patients admitted to your organization annually have cancer?

	None - 0%	1% - 10%	11% - 20%	21% - 30%	31% - 40%	41% - 50%	51% - 60%
<b>NH Health Providers</b>	<b>4%</b>	<b>46%</b>	<b>14%</b>	<b>10%</b>	<b>9%</b>	<b>4%</b>	<b>1%</b>
<b>Organization Type</b>							
In-patient/Outpatient	0%	21%	11%	5%	26%	5%	5%
Nursing / Skilled / Long Term	6%	56%	16%	12%	2%	4%	0%
<b>Organization Size</b>							
100 or less	9%	69%	3%	3%	6%	6%	0%
101 or more	0%	23%	30%	20%	10%	3%	3%
<b>Identify Pts Needing PC</b>							
Yes	3%	46%	16%	10%	10%	5%	2%
No	17%	50%	0%	17%	0%	0%	0%

	61% - 70%	81% - 90%	91% - 99%	All - 100%	Number Responding
<b>NH Health Providers</b>	<b>3%</b>	<b>3%</b>	<b>1%</b>	<b>3%</b>	<b>69</b>
<b>Organization Type</b>					
In-patient/Outpatient	5%	11%	5%	5%	19
Nursing / Skilled / Long Term	2%	0%	0%	2%	50
<b>Organization Size</b>					
100 or less	0%	0%	3%	3%	35
101 or more	7%	3%	0%	0%	30
<b>Identify Pts Needing PC</b>					
Yes	3%	2%	2%	3%	63
No	0%	17%	0%	0%	6

Q16: Approximately what percentage of patients who are referred to palliative care have cancer?

	None - 0%	1% - 10%	11% - 20%	21% - 30%	31% - 40%	41% - 50%	51% - 60%
<b>NH Health Providers</b>	5%	34%	10%	6%	6%	8%	10%
<b>Organization Type</b>							
In-patient/Outpatient	0%	0%	12%	6%	6%	6%	18%
Nursing / Skilled / Long Term	7%	47%	9%	7%	7%	9%	7%
<b>Organization Size</b>							
100 or less	10%	45%	7%	7%	7%	3%	7%
101 or more	0%	28%	10%	7%	7%	14%	10%
<b>Identify Pts Needing PC</b>							
Yes	5%	32%	11%	7%	7%	9%	11%
No	0%	60%	0%	0%	0%	0%	0%

	61% - 70%	71% - 80%	81% - 90%	91% - 99%	All - 100%	Number Responding
<b>NH Health Providers</b>	5%	2%	5%	2%	8%	62
<b>Organization Type</b>						
In-patient/Outpatient	18%	0%	12%	0%	24%	17
Nursing / Skilled / Long Term	0%	2%	2%	2%	2%	45
<b>Organization Size</b>						
100 or less	3%	3%	0%	0%	7%	29
101 or more	3%	0%	7%	3%	10%	29
<b>Identify Pts Needing PC</b>						
Yes	4%	2%	5%	2%	7%	57
No	20%	0%	0%	0%	20%	5

Q17: What is the best way to inform you of updates for best practices of palliative care?

	Mailed Brochure	Emailed Brochure	Newsletter	Meeting / Conference	Website	Other-Specify	Number Responding
<b>NH Health Providers</b>	45%	57%	31%	24%	21%	2%	42
<b>Organization Type</b>							
In-patient/Outpatient	39%	56%	33%	28%	17%	6%	18
Nursing / Skilled / Long Term	50%	58%	29%	21%	25%	0%	24
<b>Organization Size</b>							
100 or less	47%	47%	0%	20%	13%	7%	15
101 or more	41%	64%	50%	27%	32%	0%	22
<b>Identify Pts Needing PC</b>							
Yes	44%	53%	33%	25%	22%	3%	36
No	50%	83%	17%	17%	17%	0%	6

**APPENDIX C**  
**QUESTIONNAIRE**



# Access to Information on Palliative Care Survey



The Palliation Workgroup of the New Hampshire Comprehensive Cancer Collaboration (NH CCC) in conjunction with NH Hospice and Palliative Care Organization invite you to participate in this brief survey about information related to palliative care in New Hampshire. This survey should take between 5 - 10 minutes to complete. The Palliation Workgroup is working toward the following objective: Establish a baseline of how cancer survivors access information about palliative care.

The National Consensus Project for Quality Palliative Care states: "The goal of palliative care 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. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for the patient and family, optimizing function, helping with decision making, and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care."

Responses to this survey will be kept confidential within the Palliation Workgroup of the New Hampshire Comprehensive Cancer Collaboration (NH CCC) and all results will be reported in the aggregate. Thank you for taking the time to complete this important survey. Our work could not be done without the continued support of institutions like yours.

## About your Organization

1. Who is the best person to contact within your organization with information about palliative care for patients and staff?

Contact Name \_\_\_\_\_

Organization Name \_\_\_\_\_

Mailing Address 1 \_\_\_\_\_

Mailing Address 2 \_\_\_\_\_

City / Town \_\_\_\_\_

Zip Code \_\_\_\_\_

Email Address \_\_\_\_\_

Phone Number \_\_\_\_\_

2. Which of the following best describes your organization?

- In-patient care*
- Out-patient ambulatory care*
- Nursing / Skilled / Long Term Care Facility*
- Other - Specify \_\_\_\_\_*

3. How many beds do you have at your organization? \_\_\_\_\_  
*(In-Patient or Nursing/Skilled/LTC)*

4. How many patients do you currently have in your practice? \_\_\_\_\_  
*(Outpatient ambulatory or other)*

## About your Organization's Palliative Care Services

5. Does your organization identify cancer patients in need of palliative care?

- Yes
- No

6. Does your organization have staff that is responsible for coordinating palliative care for your cancer patients?

- Yes - That is the staff member(s) dedicated role
- Yes - They coordinate palliative services in addition to other duties
- No
- Other – specify \_\_\_\_\_

7.

Who provides palliative care services after a cancer patient is referred for palliative care?

- Staff
- Contracted agency
- Both
- Other - specify \_\_\_\_\_

8.

Who provides the initial assessment of cancer patients referred for palliative care?

- Physician
- Board certified palliative care physician
- Nurse practitioner
- Board certified palliative care nurse practitioner
- Social worker
- Pastoral / Spiritual care provider
- Complementary / Alternative Medicine (CAM) practitioner
- Registered nurse (RN)
- Other - Specify \_\_\_\_\_

9.

Who makes up the palliative care team / program available to your cancer patients? (Check all that apply)

- Physician
- Board certified palliative care physician
- Nurse practitioner
- Board certified palliative care nurse practitioner
- Social worker
- Pastoral / Spiritual care provider
- Complementary / Alternative Medicine (CAM) practitioner
- Registered nurse (RN)
- Other - Specify \_\_\_\_\_

# Palliative Care Information

10. When is palliative care information given to cancer patients? (Check all that apply)

- At first contact
- At the time of a cancer diagnosis
- At the time of a terminal diagnosis
- Beginning of treatment
- When curative care is no longer indicated
- Hospice referral
- Change in condition
- When there are uncontrollable symptoms
- No information is given
- Other - Specify \_\_\_\_\_

11. Does your organization provide information about palliative care services directed toward educating each of the following groups:

	Yes	No	Don't Know
Cancer patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Non-cancer patients in need of palliative care services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Children in need of palliative care services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family members in need of palliative care services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Non-clinical staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clinical staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12. How does your organization offer information to cancer patients on the following issues? (Check all that apply)

	Does Not offer	Patients are given printed Information (brochures, handouts, info sheets, etc.)	Patients are verbally given information	Patients are given internet links	Patients are given audio/visual information (video/DVD/CD-Rom)	Other
Pain and symptom management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychosocial and emotional aspects of cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Advance care planning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General information about palliative care (as described in introduction)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spiritual aspects of cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

13. Is your organization aware of the National Consensus Project, Clinical Practice Guidelines for Quality Palliative care, also known as the 8 domains of palliative care?

- Yes
- No
- Don't know / Not sure

14. How often does your organization offer in-service programs to increase staff awareness / education about palliative care?

- Less than every two years
- At least once every other year
- At least once a year
- At least twice a year

- 15.** Approximately what percentage of patients admitted to your organization annually have cancer?
- |                                    |                                     |
|------------------------------------|-------------------------------------|
| <input type="checkbox"/> None - 0% | <input type="checkbox"/> 51% - 60%  |
| <input type="checkbox"/> 1% - 10%  | <input type="checkbox"/> 61% - 70%  |
| <input type="checkbox"/> 11% - 20% | <input type="checkbox"/> 71% - 80%  |
| <input type="checkbox"/> 21% - 30% | <input type="checkbox"/> 81% - 90%  |
| <input type="checkbox"/> 31% - 40% | <input type="checkbox"/> 91% - 99%  |
| <input type="checkbox"/> 41% - 50% | <input type="checkbox"/> All - 100% |

- 16.** Approximately what percentage of patients who are referred to palliative care have cancer?
- |                                    |                                     |
|------------------------------------|-------------------------------------|
| <input type="checkbox"/> None - 0% | <input type="checkbox"/> 51% - 60%  |
| <input type="checkbox"/> 1% - 10%  | <input type="checkbox"/> 61% - 70%  |
| <input type="checkbox"/> 11% - 20% | <input type="checkbox"/> 71% - 80%  |
| <input type="checkbox"/> 21% - 30% | <input type="checkbox"/> 81% - 90%  |
| <input type="checkbox"/> 31% - 40% | <input type="checkbox"/> 91% - 99%  |
| <input type="checkbox"/> 41% - 50% | <input type="checkbox"/> All - 100% |

- 17.** What is the best way to inform you of updates for best practices of palliative care?
- Mailed brochure
  - Emailed brochure
  - Newsletter
  - Meeting / Conference
  - Website
  - Other - Specify \_\_\_\_\_

- 18.** Do you have any additional comments for the Palliation Workgroup of the New Hampshire Comprehensive Cancer Collaboration (NH CCC) about your palliative care information needs?
- 
- 

Thank you for taking the time to complete the survey.

If you would like information about palliative care for your patients:

[www.getpalliativecare.org](http://www.getpalliativecare.org) or [www.ninr.nih.gov](http://www.ninr.nih.gov)

If you would like information about setting up a palliative care program at your institution: [www.capc.org](http://www.capc.org)

If you would like general information about palliative care:

[www.NHCancerPlan.org](http://www.NHCancerPlan.org) or [www.NHHPCO.org](http://www.NHHPCO.org)