



**KŌKUA MAU**  
“Continuous Care”

Hawai‘i Hospice and Palliative Care Organization

## **Palliative Care: An Underutilized Resource in Cancer Survivorship and Improving Quality of Life for People with Cancer**

### **SUMMARY**

Kokua Mau, Hawaii’s Hospice and Palliative Care organization has collaborated successfully with the Hawaii Comprehensive Cancer Control Program (CCCCP) since 2005. To learn if and how other states have collaborated with organizations providing hospice and palliative care, Kokua Mau conducted a survey in September 2009. The survey focused on five areas: public education; patient, family and care giver education; research, epidemiology and prevention; professional education; as well as policy and planning.

The survey was sent to 66 State, U.S. Associated Pacific Islands/Territories, and Tribal Organization CCCC Programs. Of 33 respondents, 29 reported that they already collaborate with hospice and palliative care organizations. Although 44% (29/66) of the CCCC Programs are already collaborating on palliative care in some capacity, there is much potential for further collaboration in most states. Concrete examples of potential areas of collaboration are found in the comments section of the survey report. We hope this will encourage others to begin or increase collaboration between CCCC and the hospice and palliative care community.

### ***The Issues:***

Hospice and palliative care professionals and programs are an often under-utilized resource for Comprehensive Cancer Control Programs (CCCCPs), as CCCC Programs and coalitions increase their goals and emphasis on cancer survivorship and quality of life. With palliative care being one of the fastest growing multidisciplinary fields in medical services, there is great potential for strengthening and increasing collaborations that can greatly improve the quality of life of people living with cancer and their loved ones.

### ***Palliative Care***

Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis.

The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any

stage in a serious illness, and can be provided together with curative treatment. *Center to Advance Palliative Care (CAPC, 2011.)*

## ***Defining Palliative Care***

A number of national and international organizations have created consensus statements on palliative care showing a convergence of agreement of its increased importance.

**National Consensus Project for Quality Palliative Care:** The goal of palliative care is to prevent and relieve suffering and support the best quality of life for patients ...and their families. ...both a philosophy of care and an organized program for delivering care to persons...with life threatening conditions. This care focuses on enhancing quality of life...optimizing function, helping with decision making, and providing opportunities for personal growth can be delivered concurrently with life-prolonging care or as the main focus of care. (Source: [nationalconsensusproject.org/](http://nationalconsensusproject.org/))

**National Quality Forum:** ...patient and family centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care, throughout the continuum of illness, involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice. (Source: [qualityforum.org](http://qualityforum.org))

**World Health Organization:** an approach that improves quality of life of patients and their families facing 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. (Source: [who.int/cancer/palliative/definition/en/](http://who.int/cancer/palliative/definition/en/))

The potential of palliative care is often untapped both for people with cancer and their loved ones. People mistakenly believe that palliative care is the same as hospice care, and like hospice care, they often wait too long when they could be benefitting from the holistic palliative services available. Involving palliative care professionals from the time of diagnosis means that people can have emotional, social and spiritual support from the beginning, as they form a relationship with the palliative care team. As treatment progresses, people may need more pain and symptom management. Keeping a relationship with the palliative care team means that cancer survivors can also get support once cancer treatment ends, helping them to monitor side effects and impacts of the treatment and receive support as needed.

## ***Hospice Care***

Hospice care is a subset of palliative care and is for those patients with a prognosis of six months or less to live and who have decided to stop curative treatments. The hospice team, primarily a doctor, nurse, social worker, chaplain and volunteers, work with the person and his or her family

as well the person's doctors and other existing healthcare professionals, to relieve suffering. Hospices are known as the experts in pain management but also help with the management of other symptoms including emotional, social and spiritual suffering, to improve the quality of life of people through to the end of their lives. Hospice is currently an underutilized resource in the United States. Nationally, individuals stay an average of 71 days in hospice care (2009, CMS Data). In Hawaii, that average is 56 days and approximately 30% of people who die from cancer in this state access hospice services..

### ***Areas of Collaboration***

In addition to offering excellent care to people with cancer and their families, palliative and hospice professionals can be good partners for CCCPs and CCC Coalitions. Every state has a Hospice and Palliative Care Organization and individual hospices can serve as resources for education and training, legislation and policies, and in research, evaluation and epidemiology. They can help CCCPs to achieve their goals and objectives of improving the quality of life.

### ***CCCP Comprehensive Cancer Control Collaboration Survey***

Kokua Mau, Hawaii's Hospice and Palliative Care organization has collaborated with the Hawaii CCCP since 2005, helping to create the first state cancer plan. Building on the existing partnership, Kokua Mau and the Hawaii CCCP have been exploring ways to work together to improve the quality of life of people living with cancer in Hawaii.

To learn how other states have collaborated, Kokua Mau conducted a survey to assess activity in five areas: public education; patient, family and care giver education; research, epidemiology and prevention; professional education; as well as policy and planning. These five categories were identified based on a scientific literature review and guided by the results of Prof. Jaya Rao's research on public health and palliative care. Two of her articles are in the resource section.

The survey was conducted from June to September of 2009 and was sent to 66 State, U.S. Territory, and Tribal Organization CCCP Programs. There was a significant favorable response rate to the survey, with 33 respondents providing information. Not all respondents reported their state but 24 respondents who did were from the following states and jurisdictions: Arizona, Arkansas, Colorado, Delaware, Georgia, Hawaii, Idaho, Iowa, Kentucky, Michigan, Minnesota, Ohio, Oregon, Nebraska, New Hampshire, New York, North Carolina, South Dakota, West Virginia, Washington, Wisconsin, as well as the state of Chuuk in the Federated States of Micronesia and the Territory of Guam.

Of those who responded, 29 report that they already had some form of collaboration with hospice and palliative care organizations and one indicated no plans for collaboration. Although 29/66 (44%) of the CCCPs are already collaborating on palliative care in some capacity, in most states there is much potential for expanding joint efforts focusing on mutual goals.

## OVERVIEW OF RESULTS

The survey questions about collaboration with hospice and palliative care organizations were divided into the five subset areas of collaboration. A summary of the questions and responses are presented here; detailed responses and comment from the CCCPs are found in the next section.

**Area 1. Collaboration on Policy and Planning:** *How have you or do you plan to collaborate with hospice and/or palliative care organizations?*

28 individuals responded to this question

1. *Incorporate end-of-life into state comprehensive cancer plans:* 27
2. *Identify a state palliative care liaison to coordinate activities:* 22
3. *Identify and work on legislative barriers to care:* 17

**Area 2. Collaboration on Public Education:** *How have you or do you plan to collaborate with hospice and/or palliative care organizations?*

24 individuals responded to this question

1. *Facilitate dissemination of end-of-life materials:* 22
2. *Educate the public on the importance of Advance Directives and advance care planning:* 19
3. *Establish an information clearinghouse on EOL (end-of-life) for caregivers and providers:* 5

**Area 3. Collaboration on Patient, Family, and Caregiver Education:** *How have you or do you plan to collaborate with hospice and/or palliative care organization*

18 individuals responded to this question

1. *Provide informational materials to clinics and hospital:* 18
2. *Provide culturally appropriate materials to families:* 16
3. *Provide training across chronic disease programs for families:* 10

**Area 4. Collaboration on Research, Epidemiology, and Evaluation:** *How have you or do you plan to collaborate with hospice and/or palliative care organizations?*

24 individuals responded to this question

1. *Study barriers to end-of-life care:* 19
2. *Assist in the collection of relevant end-of-life data for surveys, such as BRFSS:* 15
3. *Assess work force capability to provide end-of-life care:* 11

**Area 5. Collaboration on Professional Education:** *How have you or do you plan to collaborate with hospice and/or palliative care organizations?*

25 individuals responded to this question

1. *Include end-of-life topics in conferences:* 22
2. *Provide end-of-life training to cancer professionals and state workers:* 17
3. *Integrate palliative and hospice into chronic disease programs:* 15

The quantitative results give a quick overview of existing collaborative efforts, or the lack thereof. The comments section provides insights into how these collaborations could take shape in light of different approaches, depending on each CCCP's make up and structure. These comments are featured extensively in this report in the hope they might inspire other CCCP to replicate some of the approaches taken. States are identified alphabetically, so they may be contacted directly. Kokua Mau can facilitate any exchange of information or assist with identifying contact persons. Existing collaborations are diverse and a few selected overall comments are presented here:

### ***Overall comments***

AK: "International Palliative Care symposium ... ([www.palliativeak.org](http://www.palliativeak.org)) was the fifth in a series of annual educational conferences. Hospice presented on grief and bereavement.... CCC is assisting in offering ELNEC (End of Life Nursing Education Consortium) classes that were video recorded and will be shared with hospice organizations throughout Alaska... We are co-sponsoring test-preparation classes to help RN's become certified in Hospice and Palliative Care... The CCC also sponsors the Living with Grief annual series from the Hospice Foundation of America, and a community wide grief ceremony held at the Alaska Native Heritage Center".

GUAM: "... Hospice staff is a member of our Coalition; They coordinate workshops to educate community about hospice/palliative care available through various organizations"

WV: "Members of Hospice organizations sit on our state's cancer coalition and have held offices as well. Additionally, the coalition:

- conducted 4 pain management/palliative care public education classes in the underserved areas of the state in the fall of 2009 & early winter
- works closely with the End-of-Life Center in our state
- has included goals/objectives addressing this topic in the state's cancer plan, and
- awarded at least 6 mini-grants to organizations for cancer support groups.
- Our tentative plans are to continue the existing partnership while being flexible in exploring way to expand it.

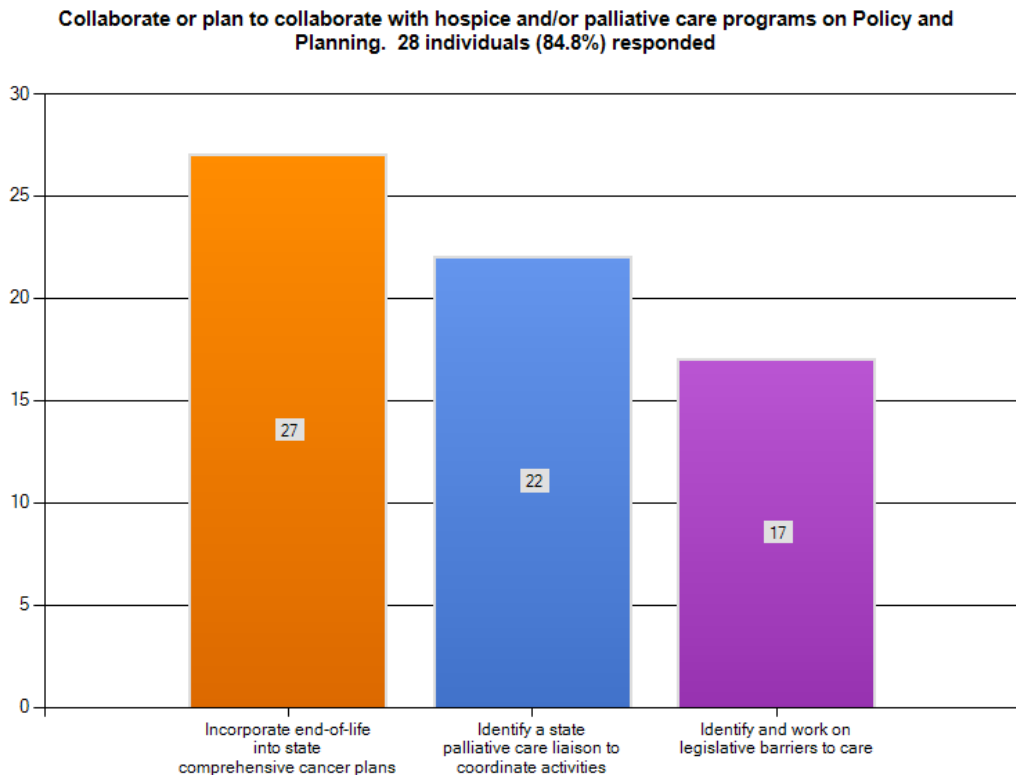
## Detailed Results Areas 1-5

### Area 1. Collaboration on Policy and Planning

**Survey Question: How have you or do you plan to collaborate with hospice and/or Palliative Care organizations? (Check all that apply)**

1. Incorporate end-of-life into state comprehensive cancer plans
2. Identify a state palliative care liaison to coordinate activities
3. Identify and work on legislative barriers to care
4. Other (open ended comments)

Twenty-eight individuals responded to this question; of these 27 responded favorably to collaborating to incorporate end-of-life into state comprehensive cancer plans, 22 support identifying a state palliative care liaison to coordinate activities, and 17 favor identifying and working on legislative barriers to care.



Comments included:

AK: “Our next policy issues will be around pain initiatives.”

Chuuk, FSM: “Like mentioned on the first page (of this survey), Chuuk has no hospice. As soon as there is one, the Chuuk CCCP will recruit members to be on the CCC Coalition and start collaboration at the same time.”

DC “Our cancer consortium funds both the Greater Washington Palliative Care and the Pediatric Palliative Care organizations as a sole source grantee. These groups provide palliative care to underserved communities in DC.”

GA: “We have a Georgia Pain Initiative ([www.georgiapaininitiative.org](http://www.georgiapaininitiative.org)) that addresses the 1st and 3rd question above. Our Comprehensive Cancer Control plan also addresses hospice and palliative care “Support training and education on pain management.”

ID: “End-of-life issues weren't included in our first strategic plan. Now an End of Life task group has been formed and planning has started. I'm not sure yet about working legislative barriers as planning is just beginning on identifying end-of-life issues.”

IA “We have worked with the state palliative care liaison in the past. When the position changed hands, the new individual has not been active in our state partnership.”

MI: “In Michigan, we used our Special Cancer Behavioral Risk Factor Survey data on end-of-life care, and our 2004 study on End-of-Life Care in Michigan (based on CDC question: Is End of Life a Public Health Issue?), to create a state program - - Pain Management and Palliative Care Program - - to directly address pain, palliative care, and end-of-life care. The program was launched in 2008. The director of the Michigan Hospice and Palliative Care Organization is closely tied with both the CCC as well as the new pain program.”

NE: “Support relationship building and project implementation with the Veteran's Administration facilities in our state.”

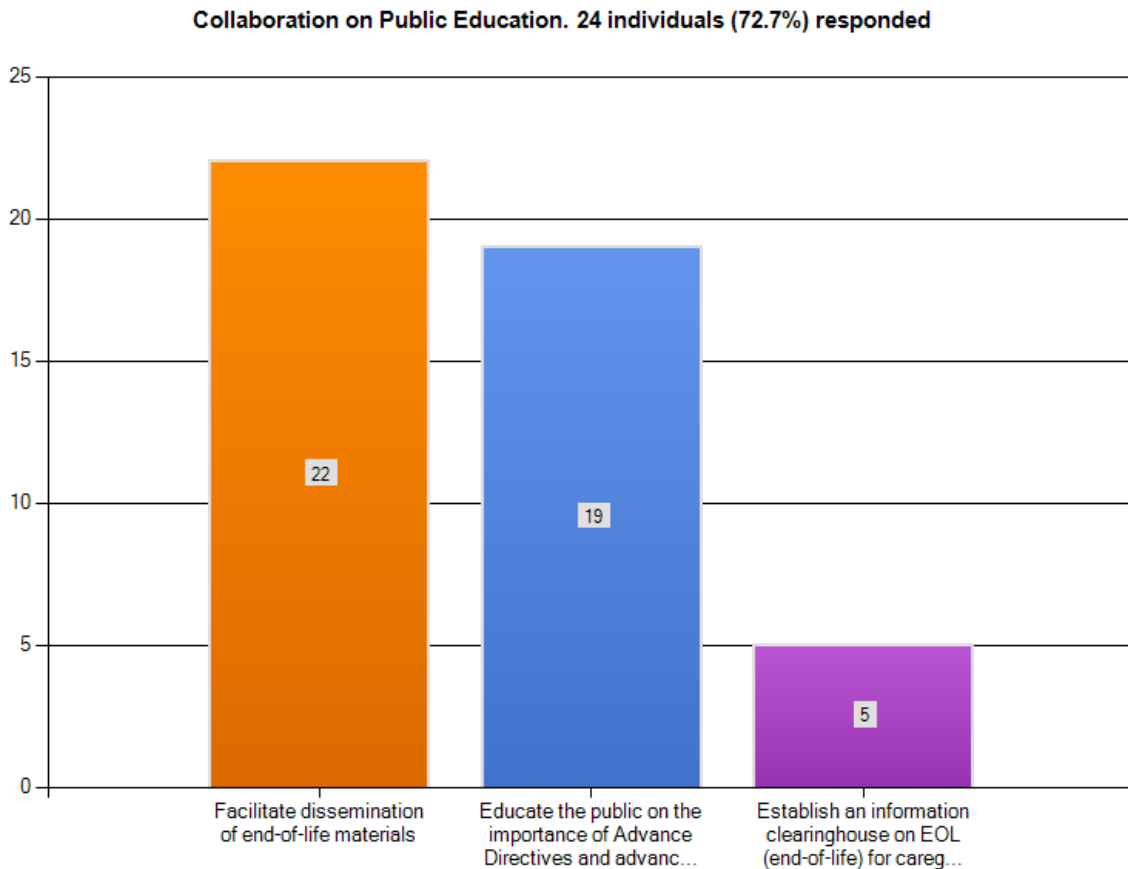
NY: “The E.D. of our state's Hospice and Palliative Care Association sits on the Steering Committee of our CCC Consortium. The Steering Committee has identified palliative care as one of four specific areas of focus for policy, advocacy, education for the coming years and this individual is also the liaison to the committee which will focus on addressing those issues. She has been involved with us for several years and has been great about reaching out to her colleagues statewide to encourage their involvement in our activities and has provided a great insight to our policy workgroup as well.”

## Area 2. Collaboration on Public Education

**Survey item: How have you or do you plan to collaborate with hospice and/or palliative Care organizations? (Check all that apply)**

1. Facilitate dissemination of end-of-life materials
2. Educate the public on the importance of Advance Directives and advance care planning
3. Establish an information clearinghouse on EOL (end-of-life) for caregivers and providers

Twenty four individuals responded regarding how they currently collaborate or plan to collaborate with hospice and/or palliative care programs on Public Education. Of those, 22 responded favorably to facilitating dissemination of end-of-life materials; 19 favor educating the public on the importance of Advance Directives and advance care planning; and five support establishing an information clearinghouse on end-of-life for caregivers and providers.



Comments include:

AK: “Our State is working on the POLST paradigm (started in Oregon) we call MOST (Medical Orders for Scope of Treatment). This task force has been meeting for about 3 years and now has had the form adopted by skilled nursing facilities and hospitals. The goal of this form is to increase the quality of care



between facilities, and so the wishes are followed. I would be happy to share more about this program in Alaska.”

ID: “There is an End of Life Organization which just formed by merging a palliative care organization and a hospice care organization. They put together a book with all this type of information and distributed to libraries, hospitals and others for free. Now they make it available at a charge. I'm not sure about a clearinghouse.”

KY “Just as clarification on the answers above, here is how the related portion of the Cancer Action Plan:

Objective 12.2: Increase quality of life resources available to patients & their families, with special attention to end of life resources.

Strategies:

- Increase availability of support groups/systems, information & counseling services.
- Develop & support multidisciplinary palliative care teams specifically committed to symptom management that begins at diagnosis (inpatient & outpatient).
- Encourage the development and/or use of cancer resource centers as a clearinghouse for cancer information. Educate health care providers in the use of these facilities.”

MI: “MHPCO continues to work with the state CCC, the new pain program, and attends meetings of the Michigan Advisory Committee on Pain and Symptom Management. It would be accurate to say that we each strive to advance / promote the work of the other.”

“In the past, the CCC has provided funding to MHPCO to develop materials, to help them revamp their website, etc. The CCC also was instrumental in 1999 in getting a RWJ grant to help develop the Michigan Partnership for the Advancement of EOL Care. Unfortunately, no new funding sources were identified after the initial three year period.”

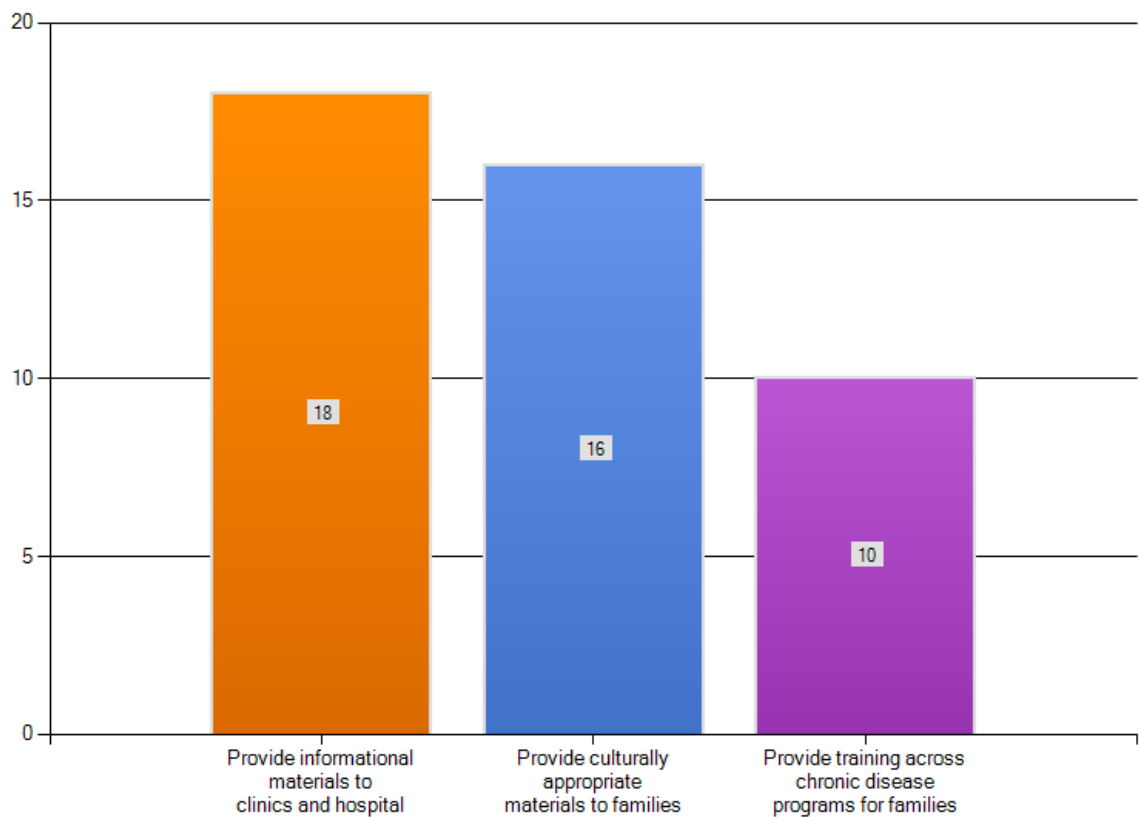
### Area 3. Collaboration on Patient, Family, and Caregiver Education

**Survey item: How have you or do you plan to collaborate with hospice and/or Palliative Care organizations? (Check all that apply)**

1. Provide informational materials to clinics and hospital
2. Provide culturally appropriate materials to families
3. Provide training across chronic disease programs for families
4. Other

Twenty individuals responded regarding how they currently collaborate or plan to collaborate with hospice and/or palliative care programs on Patient, Family, and Caregiver Education. Of those, 18 responded favorably to collaboration that provides informational materials to clinics and hospitals, 16 favor collaboration to provide culturally appropriate materials to families, and 10 support collaboration to provide training across chronic disease programs for families.

**Collaboration on Patient, Family, and Caregiver Education. 20 Individuals (60.6%) responded**



Comments include:

AK: “Care of the caregiver is similar across chronic disease programs. Good caregiver information about self care and respite is a priority.”

MI: “In the past, the CCC provided funding to translate materials into Spanish and Arabic.”

NE: “Provide caregiver education and facilitate development of caregiver support groups.”

KY “Here is how the related portions of our Cancer Action Plan is worded:

Objective 12.3: Increase utilization of available services that enhance quality of life for cancer patients from diagnosis onward. Strategies:

- Increase awareness of available services that enhance quality of life for cancer patients from diagnosis onward.
- Work at the community level to increase access to cancer support services, through low cost transportation & placement of services in rural medical facilities.
- Develop patient navigation or case management programs that improve quality of life.
- Ensure adequate services & equitable quality of life for culture specific groups by focusing outreach efforts where people are, with an emphasis on utilizing outreach in faith based groups, community centers, workplaces, etc.

Objective 12.5: Increase awareness of concept of cancer as a chronic disease.

Strategies:

- Include updated definitions of survivorship in cancer treatment messages.
- Conduct trainings for health professionals, community health workers & patient navigators on evolving concept of cancer survivorship.
- Promote & disseminate printed survivorship information, for both providers & patients, to medical facilities across Kentucky
- Promote & disseminate information on effective pain management, from diagnosis onward.”

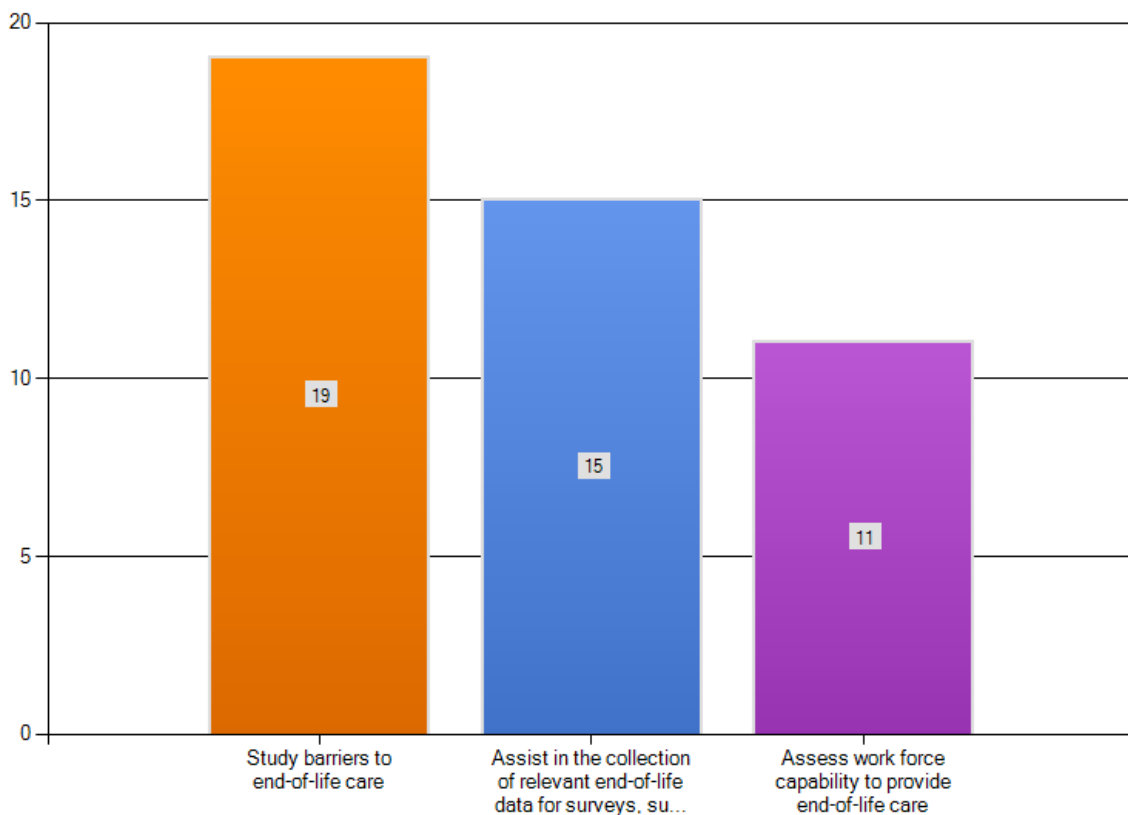
## Area 4. Collaboration on Research, Epidemiology, and Evaluation

Survey item: How have you or do you plan to collaborate with hospice and/or Palliative Care organizations? (Check all that apply)

1. Study barriers to end-of-life care
2. Assist in the collection of relevant end-of-life data for surveys, such as BRFSS
3. Assess work force capability to provide end-of-life care
4. Other

Twenty four individuals responded regarding how they currently collaborate or plan to collaborate with hospice and/or palliative care programs on Research, Epidemiology, and Evaluation. Of those, 19 favor collaboration to study barriers to end-of-life care, 15 favor collaboration to assist in the collection of relevant end-of-life data for surveys, such as BRFSS, and 11 favor collaboration to assess work force capability to provide end-of-life care.

Collaboration on Research, Epidemiology, and Evaluation. 24 individuals (72.7%) responded



Comments include:

AK: “The pain initiative is an attempt to address barriers. Diversity in understanding what hospice and palliative care means.”

Chuuk, FSM: “There has not been much, if any, research in Chuuk or the Federated States of Micronesia lately to establish baseline data and health barriers and disparities. Studying end-of-life barriers will be a good project to start with.”

KY: “We have an excellent relationship with the Kentucky cancer registry, who provides us with a wealth of data. Our Cancer Action looks to collect baseline data about programs:

Objective 12.1: Identify quality of life programs proven to be effective (i.e. best practices).

Strategies:

- Establish quantifiable criteria to determine which programs are among the best practices for addressing cancer survivor needs.
- Identify best practices based on agreed upon criteria & rank order programs accordingly.
- Identify gaps in survivorship research & provide funding to test new models & approaches.”

“Our workforce objective/strategies are not research oriented, but programmatic:

Objective 12.3: Increase utilization of available services that enhance quality of life for cancer patients from diagnosis onward.

Strategies:

- Increase human resources/workplace education regarding patient rights.
- Advocate for more appropriate reimbursement of medically necessary psychosocial & palliative care.
- Ensure adequate services & equitable quality of life for culture specific groups by focusing outreach efforts where people are, with an emphasis on utilizing outreach in faith based groups, community centers, workplaces, etc.”

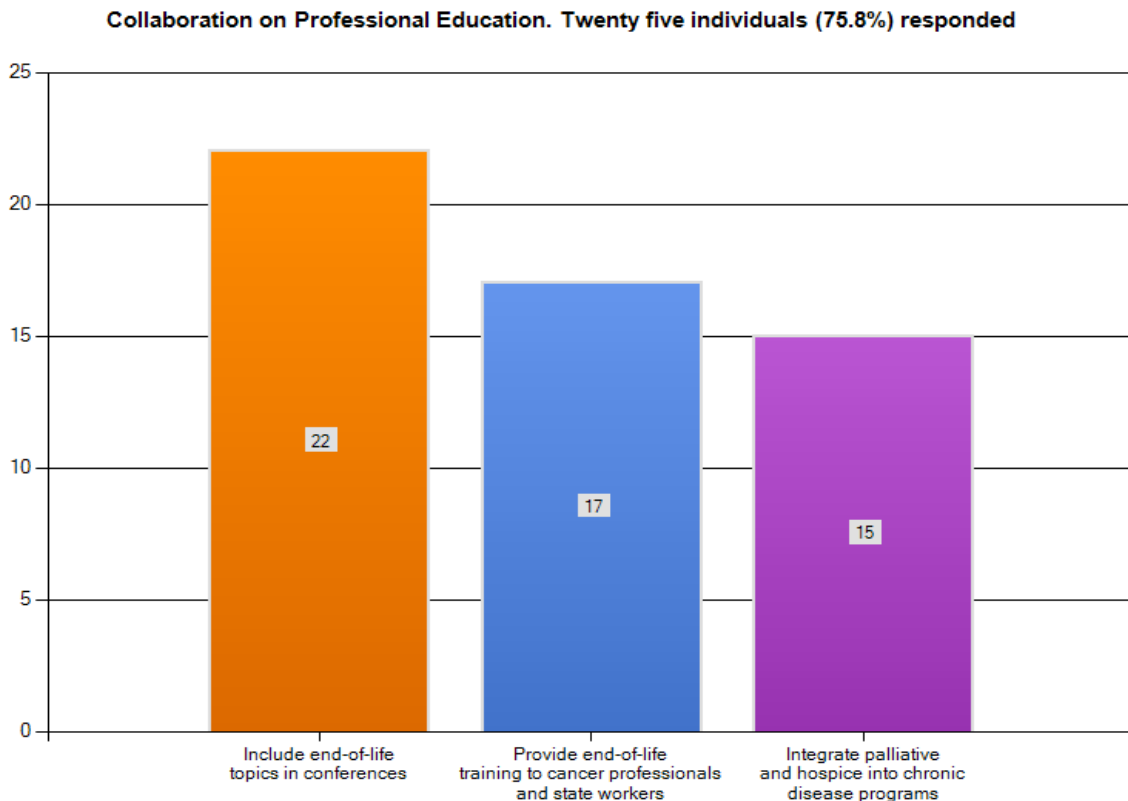
MI: “The new pain program conducts studies of health care professionals related to pain management and EOL care. These surveys are added on to current work force surveys (shortages, etc.)”

## Area 5. Collaboration on Professional Education

**Survey item: How have you or do you plan to collaborate with hospice and/or Palliative Care organizations? (Check all that apply)**

- 1. Include end-of-life topics in conferences**
- 2. Provide end-of-life training to cancer professionals and state workers**
- 3. Integrate palliative and hospice into chronic disease programs**

Twenty-five individuals responded regarding how they currently collaborate or plan to collaborate with hospice and/or palliative care programs on Professional Education. Of those, 22 favor collaboration to include end-of-life topics in conferences, 17 favor collaboration to provide end-of-life training to cancer professionals and state workers; and 15 favor collaboration to integrate palliative and hospice into chronic disease programs.



Comments include:

AK: “Including hospice professionals on planning committees for conferences is one way we have tried to have that program have a voice in our programs. Especially when partnering with the Breast and Cervical Cancer CDC programs, we try to include caregiver and hospice education.”

IA: “One of our Implementation Groups is in the process of creating a palliative care DVD.”

ID: “The End of Life Coalition has a large annual conference in July.”

KY: “Objective 12.4: Increase health professionals’ provision of care that is sensitive to quality of life issues from diagnosis onward.

Strategies:

- Refer all patients to existing community support services in a supportive & timely manner.
- Increase referrals to hospice in a timely manner.
- Inform physicians & nurses about the provision of the ADA so that they may be able to assist cancer patients in obtaining entitlements under the statute.
- Educate providers regarding resources & referrals on all legal & ethical end of life care options & how best to discuss them with their patients.
- Educate providers on effective pain management procedures.
- Increase equitability of prescriptive practices amongst all Kentucky cancer survivors.”

“The integration of palliative care/hospice into chronic disease programs is address in our CAP in the following way:

Objective 12.5: Increase awareness of concept of cancer as a chronic disease.

Strategies:

- Include updated definitions of survivorship in cancer treatment messages.
- Conduct trainings for health professionals, community health workers & patient navigators on evolving concept of cancer survivorship.
- Promote & disseminate printed survivorship information, for both providers & patients, to medical facilities across Kentucky.
- Promote & disseminate information on effective pain management, from diagnosis onward.”

MI: “Have worked with MHPCO and funded them to provide EPEC training. In Michigan, the CCC has always had an EOL priority. Cancer is part of the Chronic Disease program. Palliative Care is part of the new Pain Management Program, which is housed in the state Bureau of Health Professions (licensing). The CCC has usually offered a breakout session at its annual meeting related to EOL care. In 2009 it will have a focus on the issues around cancer survivorship, which often include pain and symptom management.”

SD “Contact the Northern Plains Comprehensive Cancer Control Program in South Dakota. This was a collaborative Wellmark Foundation Grant with the South Dakota Comprehensive Cancer Control Program. . . .provided train-the-trainer on EOL and Palliative Care for caregivers to Native American Reservations.”

**Other Collaborative Activities** In response to a request for other collaborative activities that have worked well (or not), the following responses were given:

**Partner with statewide hospice and palliative care organization.**

AK “Our best collaboration was around the Palliative Care Symposium. It has continued to grow and change to the wonderful success of this year that was International...including New Zealand and Canada.”

MN “As a CCC program we don't do all of the things you listed, but we do have partners who are working in almost all of those areas. We have a center for excellence in Palliative care at Fairview University Hospital. They have provided leadership in this area. We also work closely with Hospice Minnesota, and organization that sounds like yours.”

“We've sent the pain management packet to a variety of other organization beside hospice i.e. nursing homes. We found that it is important to send the packet to an individual vs. an organization when follow-up was done to see if they received it and how they used it.”

NH “We partnered with the New Hampshire Hospice and Palliative Care Organization about a year ago. It has been a wonderful partnership. The Executive Director of NHHPCO is the chairperson of the palliation workgroup. NHHPCO has an annual conference each fall and brings in top speakers and presents cutting edge topics. It is an honor to work with them. Thanks for this opportunity to share.”

Chuuk, FSM “Collaborating with the Chuuk Women's Council (CWC) is the best partnership the Chuuk CCCP has developed since its inception. The CWC is a very active NGO doing health promotion and education in the community. Presently, they are actively collaborating with the Chuuk CCCP, the Diabetes Program, and the HIV/AIDS Program. The CWC believes it's their role as family caregivers to spearhead these activities because they are for their families.”



### **Survivor Care Plans.**

WA “Washington's Comprehensive Cancer Control Partnership has a committee on Survivorship, Palliative Care and End of Life Issues. While the state organization for palliative care is not on the committee, there are several committee members who work in health care settings solely with palliative care issues. The committee's current focus is on promoting the use of survivor care plans. It plans to strongly encourage attention to palliative care as a component of a quality survivor care plan. ... We are not focused as much on actual end of life issues as we are quality of life and survivorship. Just a slightly different perspective.”

### **Collaborate on Legislation.**

SD “We (South Dakota Comprehensive Cancer Control Program... SD CCCP) collaborated with the South Dakota Bar Association, South Dakota State Medical Association, South Dakota Hospice Organization, Countryside Hospice, Inc., South Dakota Association of Healthcare Organizations, Avera McKennan Hospice, Avera Health, LifeCircle South Dakota, and Sanford Health and Hospice on a brochure to educate South Dakotans on new legislation (at the time of first printing) regarding Advance Directives. This group also developed two PowerPoint presentations to educate both professional staff and the public. These are available to any groups wishing to use them as programs. There are classes available to get trained in the showing of these PowerPoints.”

Train the trainer workshops. “We (SD CCCP) also joint ventured with the Northern Plains Comprehensive Cancer Control Program (a Wellmark Foundation Grant) in a train-the-trainer workshop for caregivers for nine Tribal groups in South Dakota on End of Life and Palliative Care issues. Mini-grants were awarded to each Tribal group to take back to their communities to educate and share what was learned in the workshop. Formal documentation on this project is currently being written in order to publish and share.”

### **Physicians Orders for Life Sustaining Treatments (POLST)**

Several states mentioned that they are working on or have initiated POLST legislation and states are encouraged to examine it as state-of-the-art practice. POLST is designed to improve the quality of care people receive at the end of life. It is based on effective communication of patient wishes, documentation of medical orders and a promise by health care professionals to honor these wishes. Laws and initiatives exist across the country. For more information on Physicians Orders for Life Sustaining Treatments (POLST), visit [www.ohsu.edu/polst/](http://www.ohsu.edu/polst/)

### **Essential to involve staff not just volunteers**

“It might be useful to keep in mind that you need dedicated staff, not volunteers, to drive collaborative efforts. Everyone is eager to attend meetings and throw out ideas, but if you don't have staff taking notes, setting up meetings, etc. it will be hard to make progress.” This sentiment was also heard from representatives of hospice and palliative care organizations that had been collaborating with CCCPs.

“It might also be helpful to find out from collaborative members what they are willing to do even if they are only willing to come to a meeting and give their advice.”

“Our Consortium is a work in progress. Although we've been involved with palliative care for several years, for the past year we've been undergoing a reassessment of our activities and focus which has led to a significant shift in our way of doing things, which we are only now beginning to undertake, so much of what I have indicated on this survey are things that we are planning to do.”

### **Pain Initiative**

NC “Collaborated to establish an NC Pain Initiative. Also, will be working together to sponsor a 1 hour CME on "What Every Family Physician Should Know About Palliative Care" at the NC Academy of Family Physicians Annual Meeting in December, 2009. We also have a Palliative Care Work Group in place.”

### **Survey Results from State Hospice and Palliative Care Organizations**

A parallel survey was conducted with Executive Directors of state hospice and palliative care organizations. The same questions were asked and 21/50 responded. Results were similar although several executives knew nothing about CCC Coalitions or Programs. The executives gave important additional recommendations.

1. **Value people's time and be clear about why the cancer plan is important.** Many hospices and palliative care programs are interested in collaborating but also have a business to run. Attending too many meetings, especially where there is no visible collaboration or benefit, was negatively mentioned by several people.
2. **Find money to help co-sponsor events or contract work.** As mentioned, hospice and palliative care organizations are always looking for ways to make ends meet. They usually have a small (but dedicated) staff and therefore appreciate monetary sponsorship or collaboration as it recognizes the expertise and time spent by the organizations.

## Conclusion

The vast majority of respondents' comments focused on the benefits to CCCP of collaboration between the cancer community and palliative care and hospice organizations in their states. An increased focus on survivorship is enhanced by palliative care, as access to good palliative care during and after treatment can greatly improve quality of life. A palliative care team can help a person focus on positive treatment outcomes and symptom management, as their energy is not being drained by unrelieved symptoms and suffering.

### Recommendations to all CCCPs

1. Reach out to your state's Hospice and Palliative care organization and invite them to join the CCCP.
2. Educate the CCCP about palliative and hospice care and the resources available through those programs.
3. Educate the palliative and hospice care community about the CCCP's goals and programs.
4. Identify a champion in the palliative care community who will join the CCCP to facilitate communications and promote collaboration.
5. Identify areas of research that can benefit both groups to identify gaps, assess impact and making the case for collaborative activities.
6. Include palliative care in your state's strategic plans, not just for cancer.
7. Identify other policies areas where CCCP can collaborate including advance care planning, POLST legislation, hospice reimbursement, and barriers to pain management.
8. Create win-win partnerships between CCCP and hospice and palliative care organizations. For example:
  - a. Look for grant or contract money for collaborative work done with hospice and palliative care organizations.
  - b. Offer free tables at conferences and other opportunities to educate the broader cancer community about palliative and hospice care.

## Further References

### **Kōkua Mau – Hawaii’s Hospice and Palliative Care Organization**

Kokua Mau’s **vision** is a community where: *The people of Hawaii are treated with dignity, compassion and love throughout their lives.*

In order to achieve that vision, Kokua Mau’s **mission** is: *To weave a lei of caregiving and support so that the people of Hawaii facing serious illness can live in the place of their choice, with relief of pain and suffering, and according to their values, beliefs, and traditions.*

Kōkua Mau is an umbrella organization of individual and organizational champions and supporters from hospitals, education, consumers, insurance, long term care and hospices. Kōkua Mau is the central repository for all POLST related information for Hawaii. To learn more about Kokua Mau, visit the website [www.kokuamau.org](http://www.kokuamau.org)

### **Important National Organizations include**

1. American Academy of Hospice and Palliative Medicine [www.aahpm.org](http://www.aahpm.org)
2. Center to Advance Palliative Care [www.capc.org](http://www.capc.org)
3. Family Caregiver Alliance [www.caregiver.org](http://www.caregiver.org)
4. National Hospice and Palliative Care Organization [www.nhpco.org](http://www.nhpco.org)
5. National Comprehensive Cancer Network Clinical Guidelines in Oncology; Palliative Care (*palliative.pdf*)  
[http://www.nccn.org/professionals/physician\\_gls/f\\_guidelines.asp](http://www.nccn.org/professionals/physician_gls/f_guidelines.asp)
6. Palliative & End of Life Care Physician Performance Measurement Set (*palliative-end-of-life-care.pdf*) by the National Committee for Quality Assurance - The Physician Consortium for Performance Improvement®  
<http://www.capc.org/tools-for-palliative-care-programs/national-guidelines>

### **References**

1. Rao, Jaya, MD, MS, End of life is a public health issue. Journal of Preventive Medicine, [Volume 23, Issue 3](#) , Pages 215-220, October 2002
2. Development of Public Health Priorities for End-of-Life Initiatives. American Journal of Preventive Medicine, [Volume 29, Issue 5](#) , Pages 453-460, December 2005

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