



**KŌKUA MAU**  
*Continuous Care*  
**A Movement to Improve Care**

# Mapping Palliative Care in Hawai‘i

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Chelsea Hirano, UH School of Nursing

With support from Jeannette Kojane, MPH, Executive Director Kōkua Mau

For further information please contact [info@kokuamau.org](mailto:info@kokuamau.org)

**Kōkua Mau • PO Box 62155 • Honolulu HI 96839 • [kokuamau.org](http://kokuamau.org)**

## Executive Summary

Palliative care is an important component of medical care and can yield many benefits for those with a severe illness. It assists with relieving the symptoms, pain and stress of illness by providing medical, emotional and social support. It benefits patients by also allowing them to receive curative treatment simultaneously. Over the last twenty years, palliative care has grown across the United States including Hawai‘i. However, because some may confuse it for hospice, palliative care is not always implemented promptly or appropriately. As a statewide network of organizations and individuals committed to improving care, Kōkua Mau aims to expand access to palliative care throughout the state of Hawai‘i and initiated a project to map the availability of palliative care across the state.

In order to achieve this goal, surveys were sent out to local organizations who were known to have programs in the inpatient, outpatient, and community-based settings. Of the respondents, seven inpatient palliative care programs, two outpatient programs, and nine community-based programs participated. We assessed elements such as referral sources, common locations where consults are initiated, and common diagnoses of palliative care patients. Overall, the survey results revealed that programs increased palliative care consults in all settings between 2018 and 2019. Furthermore, in light of the coronavirus pandemic, most if not all programs have adapted to utilize tele-health.

Despite the fact that these palliative care programs have made a positive impact for many patients and families across Hawai‘i, most respondents recognized the gap in palliative care as well. Participants across all settings emphasized the need for more palliative care. In the inpatient setting, all of the organizations admitted to feeling as if they are not seeing everyone in their setting that they should be seeing. Reasons for this were that palliative care consults come too

late, there is insufficient staffing, or there is a lack of awareness among the community and health care providers. Outpatient palliative care respondents reported the need for wider coverage for supportive and concurrent care, in addition to building more interdisciplinary palliative care teams.

This report reviews palliative care and its significance. It also reveals the findings from the surveys that were conducted for inpatient, outpatient, and community-based settings. Lastly, it explores the gap in palliative care in Hawai‘i and suggests recommendations to move forward.

## **Mapping Palliative Care in Hawai‘i**

Palliative care is an important type of medical care that is growing in significance across the United States as people are beginning to realize the quality care palliative care provides to patients. Palliative care helps with the management of pain and symptoms of severe illness, as well as facilitates goals of care conversations and coordinates care. Not only does it improve quality of life for patients, but it also leads to reductions in the costs of care and yields quality outcomes for health care organizations. Palliative care is especially significant and relevant during the COVID-19 pandemic. “The coronavirus means people are dying alone in ICUs. Families are having to make abrupt decisions at a distance about terminal care” (Stone, 2020). Palliative care can help to manage symptoms and provide support for a patient when their family cannot be there with them. Thus, it is imperative to understand and utilize palliative care, its benefits, and opportunities for development as we move forward.

Kōkua Mau is a statewide Movement to Improve Care comprised of individual and organizational champions and supporters from hospitals, education, consumers, insurance long term care and hospices (Kōkua Mau, 2019). As the leader of statewide movement related to hospice care, palliative care, end-of-life care, and advance care planning, Kōkua Mau took the initiative to launch a project to map palliative care in Hawai‘i, its accessibility, and learn more about the accomplishments of palliative care programs within the community.

### **What is Palliative Care**

First and foremost, it is essential to understand what palliative care is. Palliative care is specialized medical care that is available to people with a serious illness. Examples of serious illnesses include cancer, heart failure, chronic respiratory diseases, end stage organ failure, dementia, and more. As defined by the Center to Advance Palliative Care (CAPC), this type of

care aims to provide relief from the symptoms, pain, and stress of the illness (About palliative care, n.d.). The goal of palliative care is to improve quality of life for both the patient and their family by providing medical, emotional, social, and practical support. Furthermore, palliative care is delivered by a team of interdisciplinary professionals who work with the patient's other doctors to develop and enhance their plan of care.

While palliative care is often confused or used interchangeably with the term "hospice," the two are completely separate entities. Hospice is an approach to end-of-life care that is employed when it is no longer possible to cure a serious illness or if a patient chooses to stop curative treatments. It provides comfort care to a patient with a terminal illness whose doctor believes he or she has six months or less to live (National Institutes of Health (NIH) – National Institute on Aging, 2017). On the other hand, palliative care is available to patients at any stage of a serious illness and can be provided in conjunction with curative treatment. It focuses more on the patient's needs rather than prognosis.

### **Importance of Palliative Care**

Palliative care is best provided from the point of diagnosis and may help patients to better understand their choices for medical treatment. By treating the patient as a whole instead of just treating the disease, palliative care improves quality of life through assistance with symptom management, durable medical equipment (DME) acquisition, social, emotional & spiritual support, and communication on goals of care. Palliative care lowers the burden of an illness by managing symptoms such as pain, shortness of breath, loss of appetite, depression, and anxiety. In addition to coordination and communication of care plans, it also allows time and support for patient and family counseling. This in turn, can lead to smoother health care system encounters.

Palliative care has been shown to improve resource utilization and lower health care costs for both patients and hospitals. By ensuring that resources are matched appropriately to patient and family needs and priorities, they can be utilized in a more effective manner. As reported by CAPC, palliative care can reduce emergency room visits, ICU utilization, hospital admissions and length of stay, and hospital readmission rates. More specifically, palliative care lowers hospital admissions by 50%, reduces inpatient readmissions by 48%, and decreases hospital/ED transfers from skilled nursing facilities by 43% (The case for palliative care, n.d.).

### **Overview of Palliative Care in Hawai‘i**

The aim of this project was to map palliative care in Hawai‘i, identify its availability and accessibility, as well as identify the gaps and opportunities for improvement. The project looked into palliative care programs located in inpatient, outpatient and community-based settings to obtain a broad overview. One of the few studies done on the gaps in palliative care was conducted by the California Health Care Foundation in the years 2014 and 2017. The study served as a guide for this report in order to compare across states. In order to begin mapping palliative care, surveys were created and sent out to hospitals, clinics and organizations across the state of Hawai‘i that were known to have some type of palliative care program. The surveys are located in Appendices A, B and C. Results of the survey mostly reflected data from the 2019 year. In general, the number of palliative care consults increased from 2018 to 2019, showing an improvement in initiative and accessibility. Despite this finding, 100% of the respondents expressed that they felt as though they are not seeing everyone that they should be seeing. There is clearly opportunity for growth as the need is there.

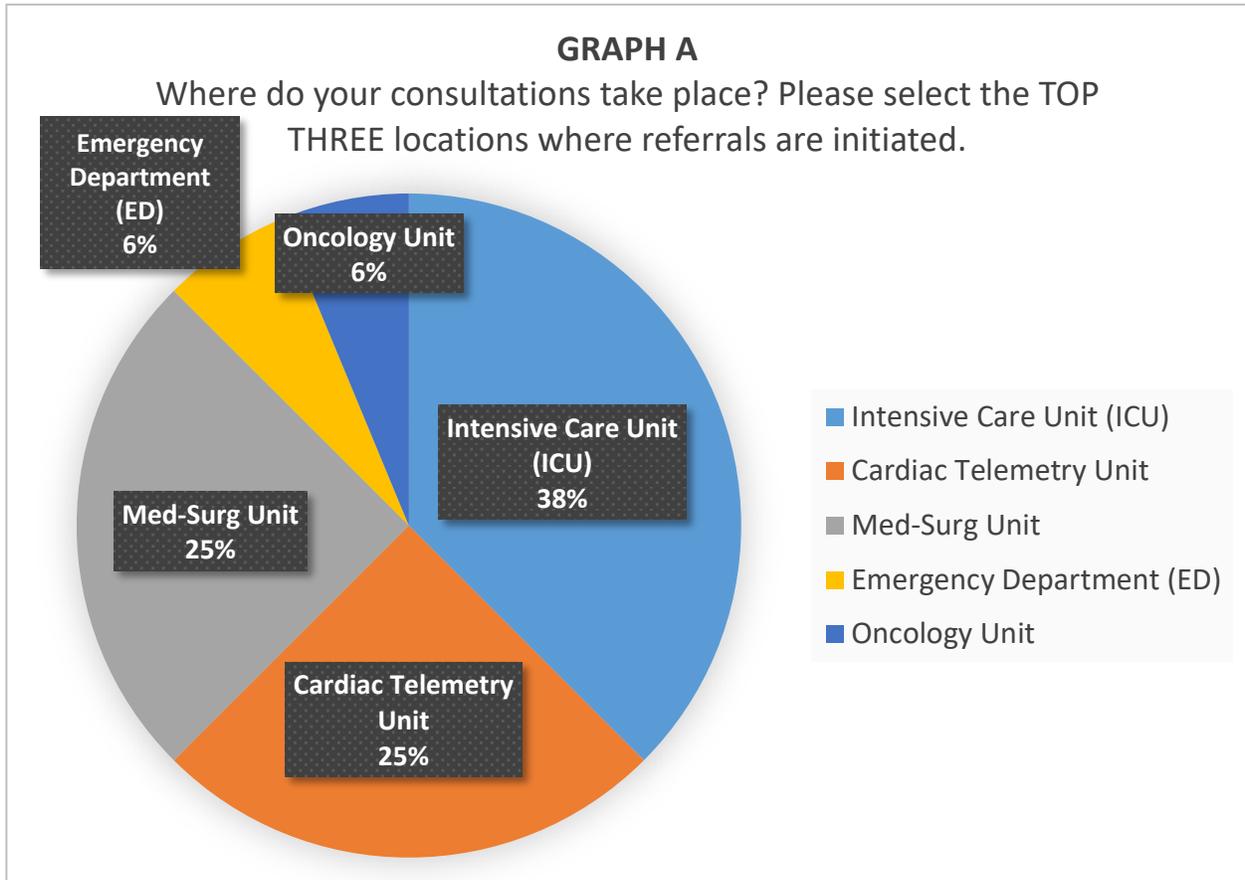
## *Inpatient*

Using the definition provided by the California Health Care Foundation in their report of palliative care in California, we were able to collect data on Hawai‘i’s inpatient palliative care programs. According to the California study, inpatient palliative care is “delivered to seriously ill hospitalized patients, usually by an interdisciplinary team (typically, but not always, composed of physician, nurse, social worker, and chaplain) that provides consultation to other hospital staff” (California Health Care Foundation, 2018).

Of the seven inpatient programs in Hawai‘i surveyed, five organizations reported having a program that corresponds with the definition of inpatient palliative care as outlined by the California Health Care Foundation. One organization stated that their program does not align exactly with the set definition, however they do offer palliative care services. The other organization described their program as a consult service. There are two different models being used in Hawai‘i: two of the programs operate primarily on a co-management model, while the other five programs primarily use a consultation model. Unfortunately, Kaiser declined to participate in this study so their inpatient program could not be included.

When comparing the number of inpatient palliative care consults from 2018 to 2019, all respondents reported an increase over the span of one year. In the year 2018, the number of consults from all the participating programs totaled 1,814. By the end of 2019, the number of consults increased by about twenty percent, totaling 2,189. Despite this increase, all of the participants reported they felt as if they are not seeing everyone in their setting that they should be seeing. The top three locations where referrals are initiated in the adult inpatient setting include the intensive care unit (ICU), cardiac telemetry unit, and medical-surgical unit, in that order. Other locations where consultations take place are reflected in Graph A. This excludes

Kapi‘olani Medical Center for Women and Children as their pediatric palliative care population was different from the other adult populations. Please refer to page 12 for further details on Kapiolani’s pediatric palliative care program.



The top three diagnoses of adult inpatient palliative care patients were cancer, followed by cardiovascular disease, then chronic lower respiratory disease. Other top diagnoses were advanced kidney disease, end stage organ failure, neurologic/neurodegenerative, and medically complex/frail. Each diagnosis presents its own challenges and often requires an interdisciplinary team of specialists to help devise and implement patients’ plan of care. For instance, the palliative care team at Hawaii Pacific Health (HPH) involves a physician, an advanced practice registered nurse (APRN), a social worker, and a chaplain. Of all the respondents, the Queen’s Medical Center proved to have the largest palliative care team, comprised of three physicians,

two APRN's, two social workers, and one chaplain. Another facility's palliative care team included one social worker, one pharmacist, and one health psychologist. Most programs were equipped with some kind of nurse, either APRN or RN, and a social worker.

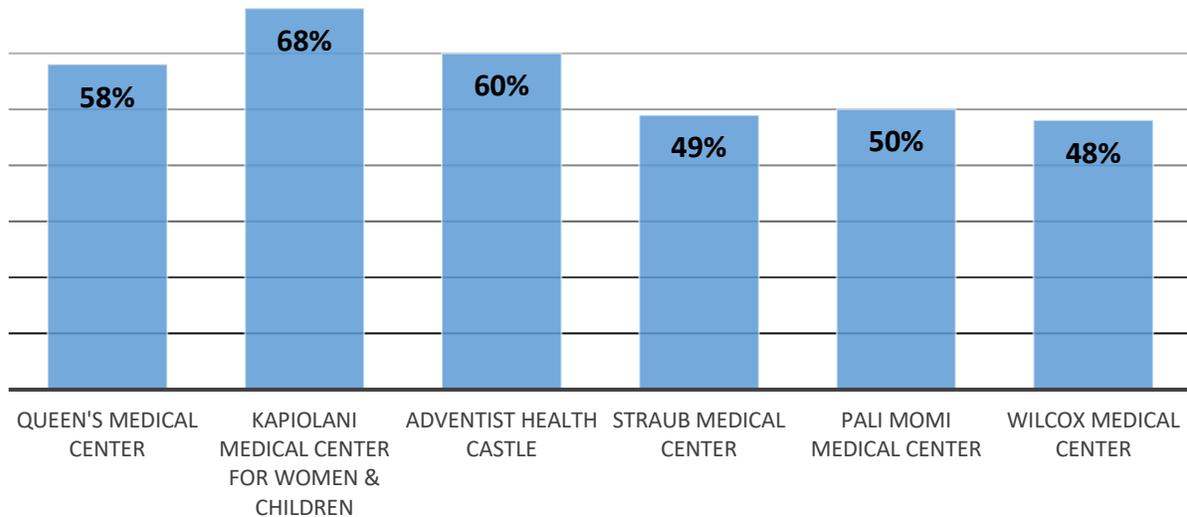
In addition to the listed diagnoses, there are several referral criteria or triggers that the inpatient palliative care programs use in order to identify appropriate patients. Each facility had different criteria. The Queen's Medical Center said their palliative care patients have an order from their attending physician. Adventist Health Castle uses triggers such as multiple hospital admissions, the need for pain management, metastatic cancer diagnosis, or patient or family request. Hawaii Pacific Health – Straub, Pali Momi and Wilcox stated they do not use any specific triggers or criteria to identify appropriate patients. Kapi'olani Medical Center for Women and Children use triggers such as bone marrow transplant or a life-limiting or life-changing diagnosis, as well as criteria that are often specific to the pediatric population such as extensive NICU triggers like low birth weight, severe prematurity, and anomalies with poor prognosis for recovery.

Outcomes of Hawai'i's inpatient palliative care programs were also surveyed and assessed. In order to assess response time and efficiency, programs were asked to estimate the percentage of palliative care consultations, which were received within three days of admission, as depicted in Graph B. After palliative care was initiated, discharge disposition was assessed as well. Graph C shows the percentages of inpatient palliative care patients transitioned to hospice. In this graph, Adventist Health Castle has the highest percentage of patients that were transferred to hospice. A possible reason for this might be that the facility is receiving patients much later in the disease process and perhaps are receiving patients too late. The percentages of palliative care patients who transferred to community-based palliative care is laid out in Graph D. Here, it is

interesting to note that the Queen's Medical Center appears to be doing well in referring their patients to appropriate resources, as the percentage of patients transferred to community-based palliative care is 37%. Unfortunately, Hawaii Pacific Health facilities do not collect this data and were unable to report on it. Lastly, Graph E displays the reported percentages of inpatient mortality for palliative care patients. All graphs only include information from the programs who agreed to share their data.

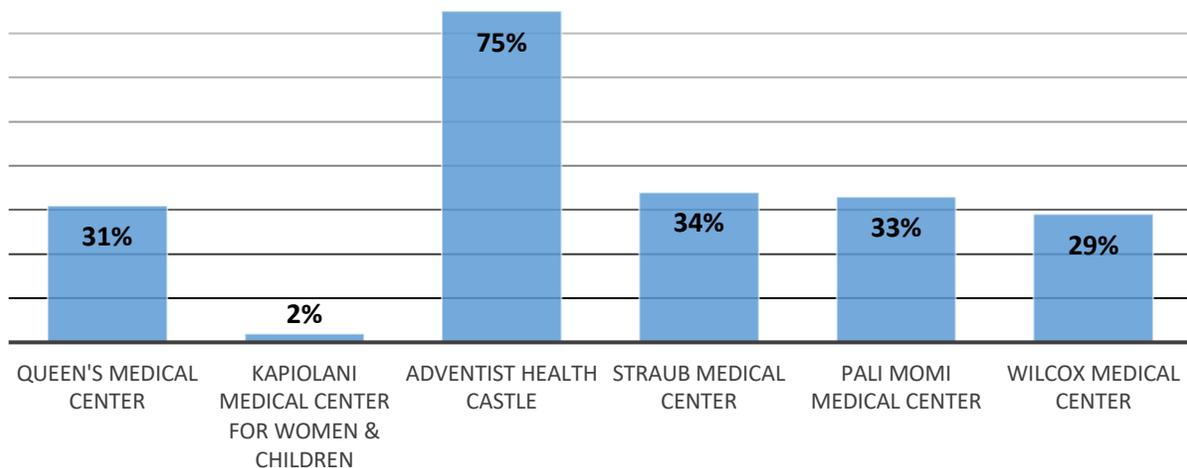
### Graph B

For the year 2019, can you estimate the percentage of palliative care consultations which are received within three days of admission?



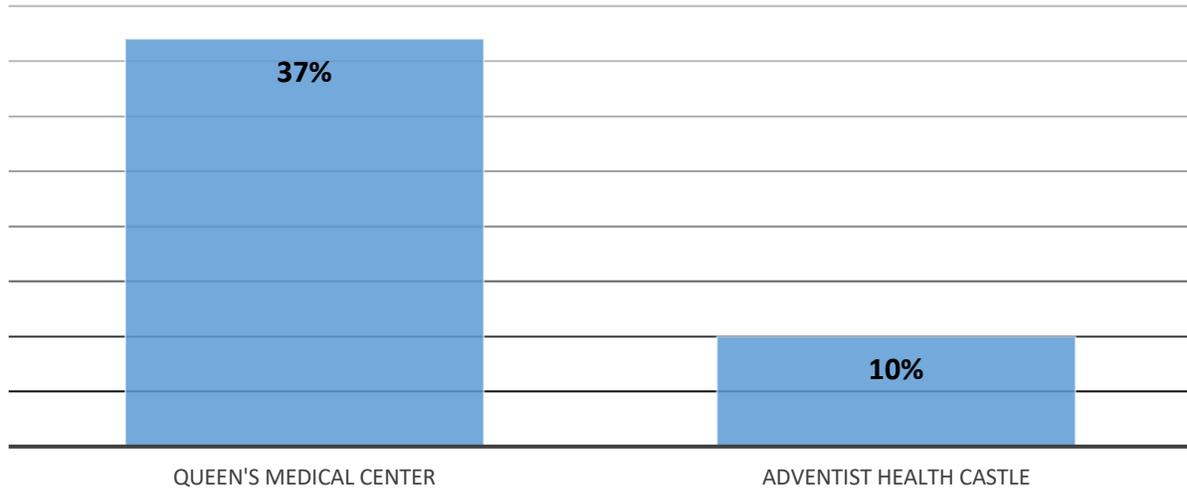
### Graph C

For the year 2019, can you estimate the percentage of palliative care patients who transition to hospice?



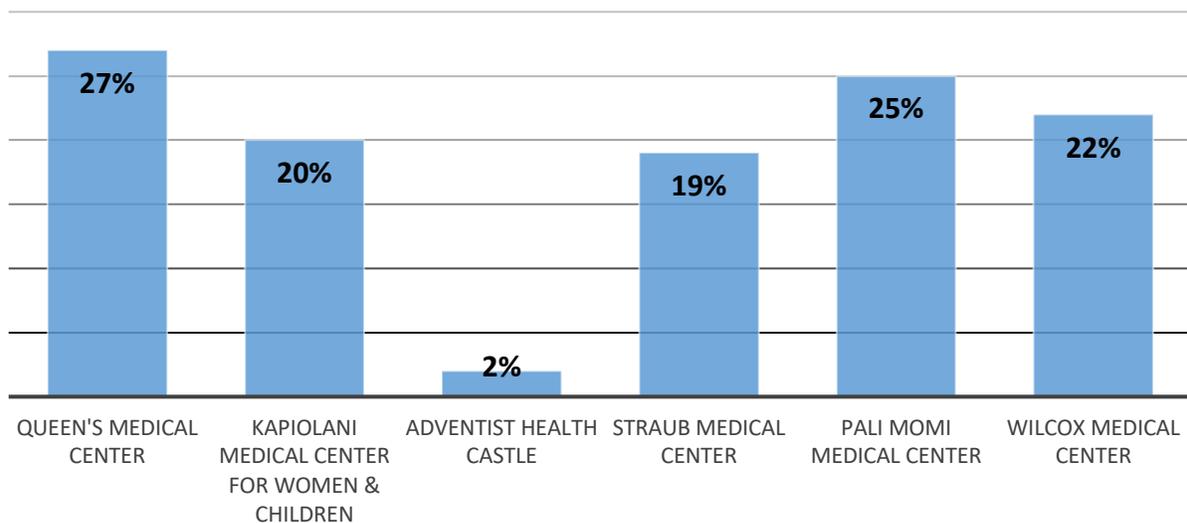
### Graph D

For the year 2019, can you estimate the percentage of palliative care patients who transfer to community-based palliative care?



### Graph E

For the year 2019, can you estimate the percentage of inpatient mortality for your palliative care patients?



## *Pediatric Palliative Care*

Kapi‘olani Medical Center for Women and Children has a unique palliative care population of pediatric patients and is the only pediatric program of its kind in Hawai‘i. Their pediatric palliative care patients typically have different illness or conditions compared to adult palliative care patients. The top five diagnoses of their patients are cancer, prematurity, congenital anomalies, severe HIE, and anoxic brain injury. As a result, the top locations where referrals are initiated and consultations take place include the NICU, PICU, and oncology unit. Kapi‘olani reported that palliative care is automatically initiated for certain conditions such as low birth weight, severe prematurity, bone marrow transplant, and anomalies with poor prognosis for recovery. Regarding the discharge disposition of their patients in 2019, 2% transition to hospice. The estimated inpatient mortality equated to 20%.

### **Inpatient palliative care takeaway points**

- **5 out of 7 participating inpatient organizations reported they have a palliative care program that corresponds with the definition of inpatient palliative care as outlined by the California Health Care Foundation.**
- **All respondents reported an increase in the number of palliative care consults from 2018 to 2019.**
- **Most programs were equipped with some kind of nurse, either APRN or RN, and a social worker, with the Queen’s Medical Center holding the largest palliative care team comprised of 3 physicians, 4 APRN’s, 2 social workers, and 1 chaplain.**
- **The top three locations where referrals are initiated in the adult inpatient setting are the ICU, cardiac telemetry unit, and medical-surgical unit, in that order.**
- **There are a variety of referral mechanisms or triggers for inpatient palliative care depending on the facility: an order from the patient’s attending physician, multiple hospital admissions, the need for pain management, metastatic cancer diagnosis, patient and/or family request, or a life-limiting or life-changing diagnosis where the patient and family needs support for medical decision-making.**
- **There is a discrepancy between inpatient facilities in discharge disposition as depicted in Graphs C through E.**

- **100% of respondents felt as if they are not seeing everyone they should be seeing.**

### ***Outpatient***

Although there is a deficit of outpatient palliative care clinics in Hawai‘i, the existing programs are extremely beneficial for patients. Currently, there are three outpatient palliative care programs. The Queen’s Cancer Center has a team of palliative medicine specialists who provide pain management and palliative care, among various other services. Their palliative care system is a supportive oncology program that is embedded in the Cancer Center. The team is comprised of three physicians and four APRN’s, each with individual panels. The staffing consists of three scheduled physician half-day clinics per week. Ad hoc visits with a physician or APRN are available five days per week as needed for appointments such as urgent visits, oncology visits, or coordination of chemotherapy and radiation. Patients must have the criteria of active cancer and receiving oncology care at a Queen’s Medical Center-based office. The program reported that their referral sources rarely come from primary care providers, but instead come from medical oncologists, radiation oncologists, and surgeons. The top three reasons for referrals include pain management, determining goals of care or advance care planning, and support for the patient and their family.

The other outpatient program stems from Straub Medical Center’s Geriatric and Palliative Clinic. The program provides geriatric and palliative care consults as well as palliative consults for medical aid in dying. According to Dr. Minaai, the clinic’s focus is “transitioning patient and family with serious illness or end-of-life issues through death with the goal of love, peace, and gratitude – assisting with spiritual suffering for patients and their loved ones.” The program is managed by a physician and an APRN, who receive referrals from primary care providers, oncologists, and neurologists. Top reasons for referrals involve end-of-life

discussions, advance care planning, and dementia accompanied with behavioral change. The Straub Geriatric and Palliative Clinic accepts all patients without the need for specific criteria.

When asked to compare the number of palliative care consults from 2018 to 2019, the Queen's Cancer Center reported an increase from 99 consults in 2018, to 106 consults in 2019. The Straub Geriatric and Palliative Clinic provided 332 consults in 2018 and 366 consults in 2019. In comparing the number of days from referral to the initial visit, Queen's reported an average of eleven days. On the other hand, Straub reported they do not have supportive data available, but there is a waitlist of at least one month. When asked to report on their outcomes, the Queen's Cancer Center revealed that they use Palliative Care Quality Network (PCQN) metrics to track symptom burden, referrals to hospice, and more. Straub Geriatric and Palliative Clinic expressed the positive outcome of their patients transitioning with their individual goals of care supported, and peacefully passing on with the guidance of their *ohana*.

Since conducting the survey, we learned that Kapi'olani Medical Center provides outpatient palliative care consults as well. In 2019 there were a total of 30 consults. These consults were broken down as follows: Four consults from pediatric oncology, 14 consults from gynecologic oncology, two consults from breast oncology, and 10 consults from perinatal oncology. Kapiolani's outpatient palliative care consults are not included in our calculations of sufficiency since data was only provided for 2019 and not 2018.

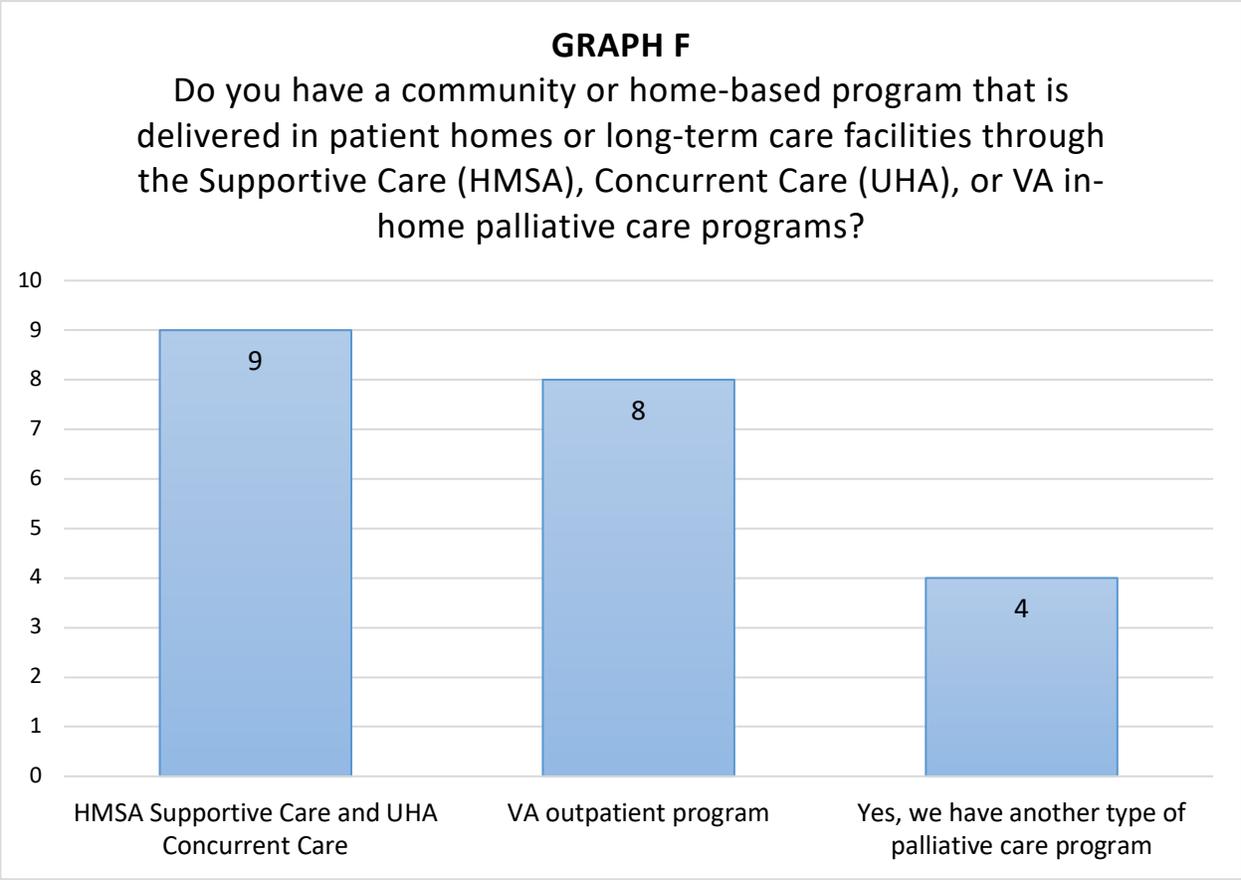
### **Outpatient palliative care takeaway points**

- **While it is positive that these outpatient palliative care clinics exist, there are various differences between the programs and the way they operate.**
- **Queen's reported their referral sources rarely come from primary care providers, but instead come from medical oncologists, radiation oncologists, and surgeons. This may be an indication that there is an opportunity to increase palliative care awareness for primary care providers.**

- **Currently, palliative care programs do not have standardized measures to gauge outcomes. Moving forward, we should aim to implement standard measures and metrics across all facilities.**

### *Community-based*

In addition to inpatient and outpatient settings, Hawai‘i’s community-based palliative care was also assessed. Nine community-based palliative care programs participated in the survey. The participating programs are located on Oahu, Maui, Kauai, and Hawai‘i Island, providing a comprehensive assessment across the state. As depicted in Graph F, all of the nine programs reported that they participate in at least one or a combination of Supportive Care from HMSA, Concurrent Care from UHA, or the VA in-home palliative care program. In conjunction with these standardized programs, four of the respondents shared that they offer another type of palliative care program as well. Islands Hospice specified that they have a pilot community-based program, consisting of a small select group of patients. Navian Hawaii reported an additional program called Integrated Care. Moreover, Hawaii Care Choices in Hilo also has a general community-based palliative care program. The additional program from Kauai Hospice utilizes a palliative care physician, APRN, and MSW services.



All but one of the community-based palliative care programs confirmed they are a registered Medicare Part B provider. Besides Medicare Part B, some organizations revealed they are certified with other health plans such as Kaiser, HMAA, Aloha Care, and United Health Care. All organizations expressed the desire for other health plans to offer palliative care coverage. When assessing the number of consults, the numbers generally increased from the year 2018 to 2019. Only one of the respondents reported a decrease in the number of patients served. The total number of reported consults in 2018 was 521. Subsequently, the programs reported 613 new admissions in 2019.

**Community-based palliative care takeaway points**

- **All of the nine programs reported that they participate in at least one or a combination of Supportive Care from HMSA, Concurrent Care from UHA, or the VA in-home palliative care program.**

- **The number of community-based palliative care consults generally increased from 2018 to 2019.**
- **All participants would like other health plans to offer palliative care coverage.**

### ***Kōkua Mau’s work/contributions***

Kōkua Mau is the leader in a statewide movement related to hospice care, palliative care, end-of-life care, and advance care planning. The organization has had multiple initiatives to improve and develop palliative care across Hawai‘i. In April 2020, they hosted a statewide Palliative Care Summit reviewing the current state of palliative care and suggestions for expanding care. Palliative Pupus has been hosted by Kōkua Mau on a bi-monthly basis since 2009. This clinical case study encourages those involved in palliative care to come together to network and discuss cases, challenges, ideas, and opportunities with each other. By promoting networking among clinicians in a variety of fields, this event fosters improved interdisciplinary care for Hawai‘i’s palliative care patients.

Kōkua Mau also hosts monthly meetings on the last Thursday of every month. The meetings are open to all and provide updates about events in the community. A variety of topics are discussed each month and typically feature one or more guest speakers. Yet another program of the organization is the eNewsletter. By signing up for the newsletter, one can expect to receive updates of current events relating to palliative care, advance care planning, and other health care news. A plethora of other resources are also accessible on Kōkua Mau’s actively managed website.

### **Supplemental Care Programs**

In addition to palliative care programs, some hospices provide supplemental services that are available to Hawai‘i’s community, not just hospice patients. These programs exist as a result

of unmet needs in the community and various hospice organizations acknowledged this gap and decided to create and implement supplemental care programs to provide an extra layer of support. The detailed table of supplemental care programs across Hawai‘i can be found in Appendix D.

### **The Gap/ Opportunities for improvement**

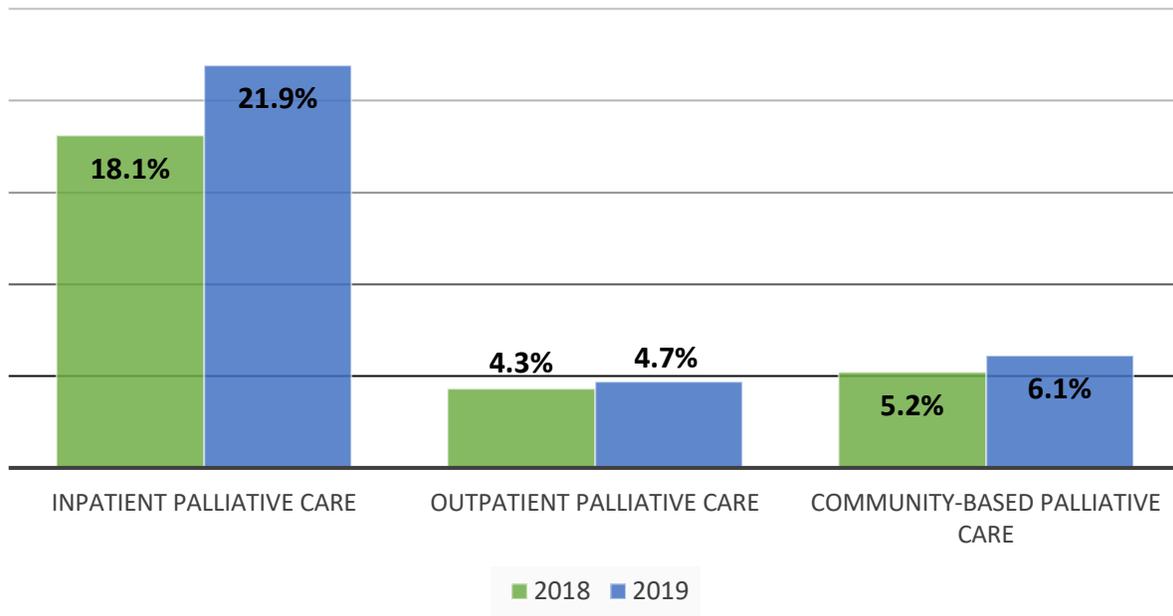
Now that the survey has been completed and data has been collected, what is the gap in palliative care in Hawai‘i? Using the California study as a guide, we focused on the need for palliative care among those in the last year of life. In order to assess the availability and sufficiency of Hawai‘i’s palliative care programs, we compared the number of patients served to the need for palliative care, estimated using the number of deaths in 2017. The California study provided a low estimate of need and high estimate of need. The low estimate of need was calculated by taking the number of people dying from seven conditions that were specified in the County Health Status Profiles that commonly need palliative care. The seven conditions were Alzheimer’s disease, cancer, cerebrovascular disease (stroke), chronic liver disease & cirrhosis, chronic lower respiratory disease, coronary heart disease, and diabetes. The high estimate of need equated to the total number of deaths excluding those caused by accidents, homicides, or suicides (California Health Care Foundation, 2018).

In the year 2017, there was a total of 11,505 deaths statewide in Hawai‘i. (Centers for Disease Control and Prevention (CDC), 2018). According to the CDC, the number of deaths in Hawai‘i that were due to the stated seven medical conditions totaled 7,145 in the year 2017 – giving us the low estimate of need. In order to find the high estimate of need in Hawai‘i, we totaled the number of deaths due to accidents, suicides, or homicides in 2017, which was 1,089 deaths, and subtracted it from the total number of deaths statewide in Hawai‘i in 2017, which

was 11,505. The result of the high estimate of need was 10,416. Thus, it can be estimated that about 7,145-10,416, or an average of 8,781 people need palliative care per year in Hawai‘i. In order to make things simpler, we rounded up and used the approximation that about 10,000 people need palliative care per year in Hawai‘i.

According to our survey results, there were 2,189 inpatient palliative care consults in 2019. Based on the rough estimate that about 10,000 people die per year in Hawai‘i, we can estimate that the sufficiency of palliative care in the inpatient setting is about 21.9%. This means that 21.9% of those who needed palliative care actually received it in the inpatient setting. As for the outpatient setting, there were 472 consults in 2019, leading to the conclusion that roughly 4.7% of those who needed palliative care received it in the outpatient setting. Finally, there were 613 community-based palliative care consults in 2019, meaning 6.1% of those in need of palliative care received it in the community-based setting. The estimated sufficiency of palliative care in Hawai‘i is depicted below in Graph G, comparing 2018 to 2019.

**Graph G**  
Sufficiency of palliative care in Hawai'i  
2018 vs. 2019



It is clear that many palliative care programs are aware of this gap. According to the conducted survey, it is noteworthy that 100% of inpatient palliative care respondents felt as if they are not seeing everyone in their setting that they should be seeing. When asked to estimate the gap of patients they are not seeing that would be appropriate, inpatient palliative care programs responded with values anywhere from 4%-50% more cases than they are currently seeing.

There also appears to be a gap in community-based palliative care as well. Most of the community-based palliative care programs stated they could increase capacity to see more palliative care patients in their setting. Some elements listed that are needed in order to increase current capacity were more referrals, more participating insurance plans to cover costs, increased staffing and funding to do so, and community awareness and education. Respondents felt that

barriers to providing more palliative care include lack of insurance benefit coverage for meaningful services, fragmented and insufficient payment or reimbursement, and knowledge deficit among community and health care providers as to palliative care versus hospice.

### **Recommendations for Palliative Care in Hawai‘i**

In an article titled, “Ensuring high-value care for people with serious illness,” CAPC listed categories for improving palliative care. Using CAPC’s domains of specialty workforce, payment, quality and standards, clinical skill building, and public and provider awareness, our recommendations to improving Hawai‘i’s palliative care are listed below. Our project surveyed programs across all settings on ways to enable earlier and wider access to palliative care. The suggestions are outlined as follows:

#### ***Specialty Workforce***

- Inpatient palliative care expressed the need for more outpatient palliative care clinics in order to move things upstream and improve continuity of care.
- Increase support and staffing to allow for earlier involvement at the time of recognition of severe illness.
- Outpatient palliative care programs expressed the need for increased diversity in interdisciplinary care/additional team members.
- One proposition supported greater interdisciplinary training in primary palliative care skills.
- There is a need for expansion of pediatric hospice and community-based palliative care services in Oahu as well as on neighbor islands.

#### ***Payment***

- Outpatient palliative care suggested wider coverage for Supportive and Concurrent Care & stronger payer-provider relationships.
- Similar to the suggestions made by outpatient programs, community-based palliative care organizations proposed to increase Supportive Care services and benefits to widen the end-stage diagnosis codes.

- Another suggestion was to aim to remove the time limit on Supportive Care benefits.
- Respondents advocated for expanded access through other health plans available throughout Hawai'i.

### ***Quality and Standards***

- Currently, palliative care programs do not have standardized measures to gauge outcomes. Moving forward, we should aim to implement standardized measures and metrics across all facilities.
- Programs would like to see a movement to initiate palliative care at the time of diagnosis for all age groups.

### ***Clinical Skill Building***

- Outpatient palliative care referral sources rarely come from primary care providers, but instead come from medical oncologists, radiation oncologists, and surgeons. This may be an indication that there is an opportunity to increase palliative care education for primary care providers.
- Encourage efforts such as increased opportunities for locally based End-of-Life Nursing Education Consortium (ELNEC) courses for physicians and nurses.

### ***Public & Provider Awareness***

- The most frequently reoccurring suggestion was to increase publicity, education, and awareness of palliative care to both the community and health care providers.
- Sharing about positive impacts of palliative care may help to facilitate awareness.
- Programs recommended better education and resources to help everyone understand the scope and benefits of palliative care programs.
- Participants also recommended more marketing to community physicians to inform them of Supportive Care options

### **Conclusion**

Palliative care is an important type of medical care that provides numerous benefits. Not only does it help patients to manage symptoms and stress of an illness, but it yields positive outcomes for patients' families as well as health care systems. There is an increasing need for palliative care as it gains more recognition. Using the California study as a guide, we were able

to begin efforts to map palliative care in Hawai'i. We discovered what programs currently exist, their accessibility, sufficiency, and opportunities for improvement. Overall we learned that palliative care programs are growing throughout the state. Despite this growth, most programs revealed that they feel as though they are not seeing everyone that they should be seeing in their setting or that they can increase current capacity. By implementing a set definition of palliative care, increasing awareness and education of the topic, and publicizing appropriate resources, we can help to enable earlier and wider access to palliative care.

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## Appendix A

### **Inpatient Palliative Care Survey**

*On behalf of Kōkua Mau, we would like to invite you to participate in our research study that aims to learn more about the state of palliative care in Hawai'i.*

*The purpose of this project is to assess the state of palliative care in Hawai'i. We hope to learn more about the available resources pertinent to palliative care, as well as the gaps in our systems and communities. Furthermore, we are looking to compare the status of inpatient and community-based palliative care.*

*We are asking you to participate because you are a part of a hospital setting which may already have palliative care services in place, or may help to improve palliative care services in the future.*

*If your hospital system has multiple sites where palliative care is offered, please complete one survey PER SITE.*

#### **1. Do you have a program that corresponds with this definition?**

Inpatient Palliative Care (IPPC) is delivered to seriously ill hospitalized patients, usually by an interdisciplinary team (typically, but not always, composed of a physician, nurse, social worker, and chaplain) that provides consultation to other hospital staff.

- Yes
- No
- Other...

#### **2. How many consults did you have in the year 2018? In 2019?**

**3. Are you adequately staffed to respond to all legitimate referral consultation requests? If not, what percentage of consultations for referrals are you unable to respond to? (Please enter the percentage into the "other" option)**

- Yes
- No
- Other...

**4. Do you think you are seeing everyone in your setting that you should be seeing? Please enter any comments into the "other" option.**

- Yes
- No
- Other...

**5. Do you have an estimate of the gap of patients you are not seeing that would be appropriate? How many more cases could you see?**

**6. What is the model for your program?**

- Primarily Consultation model

- Primarily Co-management model
- Other...

**7. What type of disciplines, and how many of each, are involved in your team?**

Select all that apply, then enter the number of each using the "other" option below, in addition to listing any additional personnel not mentioned. (e.g. In the "other" option, list: 1 physician, 1 APRN, 2 RN's, etc.)

- Physician
- Advanced Practice Registered Nurse (APRN)
- Registered Nurse (RN)
- Social Worker
- Chaplain
- Volunteers
- Other...

**8. Where do your consultations take place? Please select the TOP THREE locations where referrals are initiated.**

- Emergency Department (ED)
- Intensive Care Unit (ICU)
- Med-Surg Unit
- Oncology Unit
- Cardiac Telemetry Unit
- Neuro Unit
- Other...

**9. What are your referral criteria? Does your program use triggers or other procedures to identify appropriate patients?**

**10. What age groups does your program serve? Please rank from greatest percentage served to lowest percentage served.**

|             | 1 = Greatest %        | 2                     | 3                     | 4                     | 5 = Lowest %          | N/A                   |
|-------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 0-20 years  | <input type="radio"/> |
| 21-40 years | <input type="radio"/> |
| 41-60 years | <input type="radio"/> |
| 61-80 years | <input type="radio"/> |
| 80+ years   | <input type="radio"/> |

**11. Please select the TOP FIVE diagnoses of your patients.**

- Cancer
- Cerebrovascular Disease (Stroke)
- Advanced Kidney Disease
- Advanced Liver Disease & Cirrhosis
- Chronic Lower Respiratory Disease
- Cardiovascular Disease
- Other...

**12. For the year 2019, can you estimate the percentage of palliative care patients who transition to hospice?**

**13. For the year 2019, can you estimate the percentage of inpatient mortality for your palliative care patients?**

**14. For the year 2019, can you estimate the percentage of palliative care patients who transfer to community-based palliative care?**

**15. For the year 2019, can you estimate the percentage of palliative care consultations which are received within three days of admission?**

**16. It is our goal to enable earlier and wider access to palliative care. Where do you see the opportunities for your program?**

**17. Please share any ideas that you have for expanding palliative care in Hawaii.**

Thank you for your participation!

## Appendix B

### **Outpatient Palliative Care Survey**

*On behalf of Kōkua Mau, we would like to invite you to participate in our research study that aims to learn more about the state of palliative care in Hawai'i.*

*The purpose of this project is to assess the state of palliative care in Hawai'i. We hope to learn more about the available resources pertinent to palliative care, as well as the gaps in our systems and communities. Furthermore, we are looking to compare the status of inpatient and community-based palliative care.*

*We are asking you to participate because you are a part of an outpatient setting which may already have palliative care services in place, or may help to improve palliative care services in the future.*

*If your system has multiple sites where outpatient palliative care is offered, please complete one survey PER SITE.*

**1. Do you have an outpatient palliative care clinic?**

- Yes
- No
- Other...

**2. If you answered "yes" to the previous question, how many consults did you have in the year 2018?**

**3. How many consults did you have in the year 2019?**

**4. Please describe your program.**

**5. What type of disciplines, and how many of each, are involved in your team?**

**Select all that apply, then enter the number of each using the "other" option below, in addition to listing any additional personnel not mentioned. (e.g. In the "other" option, list: 1 physician, 1 APRN, 2 RN's, etc.)**

- Physician
- Advanced Practice Registered Nurse (APRN)
- Registered Nurse (RN)
- Social Worker
- Chaplain
- Volunteers
- Other...

**6. Do you use tele-health in your palliative care program? If yes, how so? What percentage of consults use tele-health? If no, do you have plans to do so in the near future? Please use the "other" option to comment.**

- Yes

- No
- Other...

**7. What are your criteria for accepting patients?**

**8. What are your outcomes?**

**9. How many days are there from referral to the initial visit?**

**10. What are your referral sources?**

**11. What are the top 3 reasons for referrals?**

**12. It is our goal to enable earlier and wider access to palliative care. Where do you see the opportunities for your program?**

**13. Please share any ideas that you have for expanding palliative care in Hawaii.**

Thank you for your participation!

## Appendix C

### **Community-Based Palliative Care Survey**

*On behalf of Kōkua Mau, we would like to invite you to participate in our research study that aims to learn more about the state of palliative care in Hawai'i.*

*The purpose of this project is to assess the state of palliative care in Hawai'i. We hope to learn more about the available resources pertinent to palliative care, as well as the gaps in our systems and communities. Furthermore, we are looking to compare the status of inpatient and community-based palliative care.*

*We are asking you to participate because you are a part of a community-based setting which may already have palliative care services in place, or may help to improve palliative care services in the future.*

*If your system has multiple sites where community-based palliative care is offered, please complete one survey PER SITE.*

**1. Do you have a community or home-based program that is delivered in patient homes or long-term care facilities through the Supportive Care (HMSA), Concurrent Care (UHA), or VA in-home palliative care programs? Select all that apply.**

- Yes, we participate in Supportive Care from HMSA and Concurrent Care with UHA
- Yes, we participate in the VA outpatient program
- Yes, we have another type of palliative care program (Please describe using the "other" option)
- No, we do not have a program that corresponds with this definition
- Other...

**2. In these palliative care programs, how many patients did you see in the year 2018? Please list the numbers for Supportive Care via HMSA, Concurrent Care via UHA, and any additional programs.**

**3. In these palliative care programs, how many patients did you see in the year 2019? Please list the numbers for Supportive Care via HMSA, Concurrent Care via UHA, and any additional programs.**

**4. Are you already a registered Part B provider?**

- Yes
- No

**5. Are you certified with the other health plans? If yes, which ones? Please use the "other" option to comment.**

- Yes
- No
- Other...

**6. What are the barriers to providing more palliative care?**

**7. Are you able to increase capacity to see more palliative care patients?**

- Yes
- No
- Other...

**8. What do you need to increase your current palliative care capacity?**

**9. Do you use tele-health in your palliative care program? If yes, how so? Check all that apply.**

- Yes
- No
- Communication through text messaging
- Video conferencing for provider visits
- Video conferencing for communication
- Biometrics
- Other...

**10. If you do not use tele-health in your palliative care program, do you have plans to do so in the future? Please use the "other" option to make any comments.**

- Yes
- No
- We are exploring our options
- Other...

**11. Do you offer programs that support patients and families beyond Palliative Care and Hospice? If so, please list their names and a basic description. We will follow up to get further information. Please include a website if applicable.**

**12. In terms of earlier and wider access to palliative care, where do you see the opportunities for your program?**

Thank you for your participation!

## Appendix D

### Supplemental Care Programs

| Organization                | Name of program(s) | Team members providing the service  | Description of services  | Referral required?   | Payment information (Insurance, out-of-pocket, etc.)                                 |
|-----------------------------|--------------------|---|--|--|--|
| Bristol Hospice             | Bright Moments     |   | Non-pharmacological approach to assisting patients with End-Stage Dementia (ESD).  |  |  |
|                             | AIM                | Team members include 4 APRN's, 1 social worker, a care coordinator and a medical assistant. | The AIM program provides in-home primary or palliative care services, lasting 2-4 weeks as needed. Team members make weekly visits and provide services such as PT/OT referrals, assisting with coordinating supplies, etc.  | Can be referred from a hospital, or self-referred.                                       | Accepts insurance or self-pay for those who do not have insurance.                   |
| Hawai'i Care Choices (Hilo) | Kupu Care          | APRN, RN, social worker overseen by physician (medical director).                           | Kupu Care focuses on relief from the symptoms caused by treatment (chemotherapy, radiation, dialysis). It is consultative in nature, does not include hands-on care. Includes education and case management, pain management, psycho-social support, develops a plan of care and connects the patient and family with community resources. | Patients can self-refer, (10% physician referral, majority referred from Hilo Hospital). | Billed as FFS for RN/LCSW visits, can also be paid for out-of-pocket or via charity. |
|                             | Kupu Palliative    | Board-certified physicians, advanced practice   | Pre-hospice services which does not have a 6-month diagnosis,  | Patients can self-refer, (10%  | Billed as FFS for RN/LCSW visits, can also   |

|                 |  |  |  |  |  |
|-----------------|--|--|--|--|--|
|                 | Care (Utilizing Concurrent and Supportive Care benefits) | professionals, nurses, social workers, chaplains, aides.   | and allows curative treatment. Utilizing HMSA Supportive Care and UHA Concurrent Care benefits for Palliative Care.  | physician referral, majority referred from Hilo Hospital). | be paid for out-of-pocket or via charity.  |
| Islands Hospice | Islands Transitional Care                                | Team is comprised of nurses and medical social workers. A social worker and registered nurse will follow-up with the patient 1-2 times per week. | Free, non-billable program that works to help patients transition from the hospital to the community, as well as prevent hospital readmissions. It is a 30-day program that provides medication reconciliation upon discharge, assists with applications for resources such as transportation/ Handivan or Medicare/Medicaid, and works with other community providers to improve communication and continuity of care. The program does not provide DME or medications. |  | No cost  |
| Kauai Hospice   | Palliative Medicine Partners                             | Medical director, APRN, social workers, chaplains, aides.  | Palliative care is specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain, and stresses of a complex illness – whatever the diagnosis. The goal is to improve quality of life for both patient and the family. Patients generally have a life-threatening   | Self-referral, or referred by Wilcox Health.               | Billed on a daily visit, through UHA/HMSA/V A, Palliative benefits, no extensions available, but team will do consults with PCP. |

|                     |                   |  |   |   |   |
|---------------------|-------------------|--|---|---|---|
|                     |                   |  | medical condition and are likely to need assistance with symptom management. The patients usually have a complicated medical problem and are suffering from numerous symptoms that need additional management and coordination.   |   |   |
| Navian Hawai'i      | Integrated Care   | Nurse practitioner & social worker follows-up with the patient at least once per month until patient stabilizes or transitions to hospice. | Not hospice care, patients can still receive curative treatment while in the Integrated Care Program. It is a palliative care program that is not time-limited. Services include symptom management, disease education & monitoring, community resource referrals, caregiver support, etc. Criteria for the program include cancer stage 3 or 4, end-stage renal disease, COPD, congestive heart failure, and end-stage neuro degenerative diseases (ALS, dementia, etc.). Potential patients must have a medical diagnosis/needs as well as social work needs (emotional support, advance health care planning needs, referral needs). | No physician referral required. Can be direct referral from a spouse, neighbor, etc. However, they do receive referrals from physicians or social workers in the hospitals. | All forms of insurance are accepted and patients are not billed, except for those with Medicare Part B. Patients with Medicare Part B may be billed a co-pay of \$10-30 per face-to-face visit. |
| St. Francis Hospice | CARE Plus Program | The team for the program is  | Since CARE Plus is not a palliative care  | No physician  | There is no cost and no time  |

|  |                       |  |   |  |                                     |
|--|-----------------------|--|---|--|-------------------------------------|
|  |                       | <p>comprised of 4 full-time social workers and a part-time nurse practitioner.</p> | <p>program, they are able to serve a much larger client base through the program. Described as a care coordination program, it works to provide education, referrals, assist with completing paperwork and so forth. It is run on a Social Work Model, with a Nurse Practitioner overseeing services. There is no medical management component to this program.</p> | <p>referral required. Can be referred by a physician, or can be self-referred as well.</p> | <p>limitation for the services.</p> |
|  | <p>Other services</p> |  | <p>Other services provided by St. Francis includes bathing program, Homelessness Ministries, preschool, adult day care, transportation services, meals, assisted living facility, and many other partnerships.</p>  |  |                                     |