PURUANT TO SENATE CONCURRENT RESOLUTION NO. 142, HOUSE DRAFT 1, SESSION LAWS OF HAWAII 2018, REQUESTING THE DEPARTMENT OF HEALTH TO CONVENE A WORKING GROUP TO EXAMINE PALLIATIVE CARE SERVICES AND DEVELOP RECOMMENDATIONS TO EXPAND PALLIATIVE CARE SERVICES IN HAWAII

PREPARED BY

STATE OF HAWAII
DEPARTMENT OF HEALTH

DECEMBER 2018
Executive Summary

Senate Concurrent Resolution 142, House Draft 1, Session Laws of Hawaii 2018, requested the Department of Health to convene a working group to look at expanding palliative care services in Hawaii. The Department of Health is requested to collaborate with Kōkua Mau and the American Cancer Society Cancer Action Network in this effort.

SCR 142 requested that the palliative care working group focuses on:

1. The current state of palliative care services offered in Hawaii;
2. The capacity of current palliative care providers;
3. The geographic areas where significant gaps in palliative care services exist;
4. Opportunities to collaborate with key stakeholders who are positioned to craft a strategy and plan for improving and expanding the provision of high-quality palliative medicine and palliative care services in Hawaii;
5. The feasibility for financial support of a long-term expansion of palliative care services in Hawaii;
6. A plan for ongoing data gathering for purposes of monitoring and quality improvement of palliative care in Hawaii;
7. Engagement strategies for educating the public about palliative care and hospice care to empower people to make informed decisions about wishes for care when faced with a serious illness; and
8. Any other strategies that would improve palliative care services in Hawaii.

To capture the current state of palliative care, the working group created a survey that focused on palliative care programs, both within hospitals and hospice facilities as well as health insurers. The survey was sent out to thirty organizations with a requested response date. The working group held three in-person meetings, with participants representing hospice providers, hospital systems, health insurers, physicians, health care professionals, community health organizations, and health care associations.

As a result of discussions and input by various stakeholder to develop recommendations pursuant to Senate Concurrent Resolution 142, House Draft 1, for the Legislature, the working group recommends:

1. Develop a definition of palliative care to serve as a baseline expectation of what a patient can expect from a health care provider with a palliative care team or program.
2. Support education for the public on existing resources including hospice care, palliative care and Advance Care Planning.
3. Support education for professionals in primary palliative care to boost palliative care skills across the continuum of care.
4. Support the Hawaii State Department of Human Services’ (DHS) efforts to include palliative care services through the Med-Quest program, an important first step that could bridge the gap between government and private health insurance coverages.
5. Pursue a pilot program that would establish _____

The SCR 142 working group understands that developing solutions to increase palliative care service in Hawaii will likely require systematic changes to the state health care delivery system to make significant and lasting results. The group agreed that further discussion is necessary to further accomplish the goals of SCR 142, HD 1.
Senate Concurrent Resolution 142, House Draft 1, Session Laws of Hawaii 2018

Senate Concurrent Resolution 142, House Draft 1 (SCR 142), Session Laws of Hawaii 2018, was adopted by the Legislature on April 24, 2018. (Appendix A) Through this resolution, the Department of Health was requested to convene a palliative care working group, with the assistance of Kōkua Mau and the American Cancer Society Cancer Action Network Cancer Action Network, to make recommendations to increase palliative care services in the state.

Specifically, SCR 142 requested that the palliative care working group focuses on:

1. The current state of palliative care services offered in Hawaii;
2. The capacity of current palliative care providers;
3. The geographic areas where significant gaps in palliative care services exist;
4. Opportunities to collaborate with key stakeholders who are positioned to craft a strategy and plan for improving and expanding the provision of high-quality palliative medicine and palliative care services in Hawaii;
5. The feasibility for financial support of a long-term expansion of palliative care services in Hawaii;
6. A plan for ongoing data gathering for purposes of monitoring and quality improvement of palliative care in Hawaii;
7. Engagement strategies for educating the public about palliative care and hospice care to empower people to make informed decisions about wishes for care when faced with a serious illness; and
8. Any other strategies that would improve palliative care services in Hawaii.

The Hawaii State Department of Health, Office of the Deputy Director - Office of Planning, Policy, and Program Development, lead the implementation of SCR 142, HD 1. The Office of Planning, Policy, and Program Development is responsible for department-wide government relations and public policy, strategic planning, special projects, and technical assistance supporting compliance, administrative rulemaking, grants management, performance and practice management, and scientific services.

In partnership with the Department of Health, Kōkua Mau and the American Cancer Society Cancer Action Network Cancer Action Network committed to SCR 142 to ensure that the palliative working group would represent all interests in the community and promote meaningful dialogue on the issue. Kōkua Mau is the leader of statewide movement related to hospice care, palliative care, end-of-life care, and advance care planning and serves a network and central hub for local individuals and entities in these fields. Kōkua Mau does not provide clinical care but instead leverages partners’ innovative work to effect greater community change.

The American Cancer Society Cancer Action Network Cancer Action Network (ACS CAN) is the advocacy arm of the American Cancer Society Cancer Action Network and is invested in palliative care for cancer patients, caregivers, and their families. Palliative care is essential for cancer patients and their families by providing an added layer of support services and increasing quality of life. While all patients with a chronic disease benefit from palliative care, a cancer diagnosis often leads to a palliative care consult. In the fall of 2017, ACS CAN Hawaii Pacific staff reached out to cancer survivorship groups and volunteers to discuss policy issues in the 2018 session. The feedback received overwhelming favored palliative care as something that made the cancer journey for many survivors and caregivers manageable. It was
something they did not know about prior to their cancer journey, but after receiving palliative care during that journey it became a positive aspect of their recovery.

SCR 142 is modeled after palliative care advisory councils established through legislation in other states.¹ The Centers to Advance Palliative Care (CAPC), an organization dedicated to promoting palliative care nationally, adopted model language to convene palliative experts in each state to make recommendations to policy makers on to increase palliative care services in that state. SCR 142 is Hawaii’s version of this effort.

The Department of Health, Kōkua Mau, and ACS CAN compiled a list of organizations and individuals with knowledge and experience of delivering palliative care services in Hawaii. Feedback was also sought from these individuals to ensure that the working group would have adequate representation from all sectors of the palliative care community. (Appendix C) The working group convened three times during the interim and discussed all the issues identified in SCR 142. Despite meaningful discussions, on some issues the working group felt more time was needed. Since palliative care services are encompassed in the overall health care system, some of those system changes are required prior to implementing recommendations to further expand palliative care in Hawaii.

What is Palliative Care?

Palliative care is defined by the World Health Organization as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.²

The Centers for Medicare and Medicaid Services (CMS) defines palliative care as “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 to facilitate patient autonomy, access to information, and choice.”

Palliative care has a team approach that utilizes a team of clinicians, physician, nurse, social worker and chaplain who works with the person with serious illness and their loved ones. It is an extra layer of support that can be offered at the same time as curative treatments and can continue if curative treatments are completed.

There is often misunderstanding about palliative care and it is often confused with hospice and end-of-life care. While hospice is a type of palliative care, it is provided when there is a six month or less diagnosis and once curative treatments have stopped. All palliative care strives to provide the best quality of life for those with serious illness and their loved ones.

¹ Palliative care advisory council statutes have been adopted in 22 states. Two other states do not have legislation but have existing programs that model the same goals and objectives of the advisory councils. See Palliative Care Advisory Council Legislation, Centers to Advance Palliative Care. https://www.capc.org/payers-policymakers/policy-resources/ ² See WHO Definition of Palliative Care. http://www.who.int/cancer/palliative/definition/en/ <accessed 10/18/18>
The committee felt that public education is needed to understand palliative care and what services are available as well as for professionals to understand what it is and to foster timely referrals.

**Defining Palliative Care**

Establishing a definition for palliative care is an integral part of a policy supporting palliative care programs.

Palliative care is found in three distinct settings: for patients being treated in an inpatient hospital setting or staying at a hospice facility, in an outpatient setting, and patients receiving in-home palliative care services. The working group discussed the different setting for palliative care and wanted to make a distinction in a definition of palliative care that accounted for the unique characteristics within them.

The working group was unable to agree upon a definition of palliative care that would address the service in all three settings; the group decided that more time was needed to craft language that all parties could agree with as a baseline for setting expectation of what a palliative care program would entail and the services that the program would provide. Ideally, there would be one uniform definition of palliative care, however, at the end of the working group meetings in 2018, members realized that it would be hard to create a standard definition that would apply in all situations and health care settings.

Furthermore, palliative care does not come with its own set of specific CPT or HCPCS codes, which frustrates attempts to distinguish it from other disciplines, particularly for reimbursement but also outcomes measurement. As described in a subsequent section of this report, local palliative care may be organized into “programs” but not as “covered benefits” in their own right.

**Current state of Palliative Care in Hawaii**

Hawaii’s palliative care services are provided in hospice facilities and in the hospital and clinic setting, outpatient clinics and in the home, as provided by the differing benefits through Medicare and private health insurance plans. To establish the current state of palliative care in Hawaii, the group crafted a survey about each provider’s palliative care program and distributed the survey to thirty providers, insurers, and health care organizations. Unfortunately, only six of the thirty entities provided responses to the survey. (Appendix D) The responses that were received provide some insight into the variations between programs.

**Palliative Care in the Health Insurance Market**

Some form of Palliative Care is provided in most of the major hospitals in Honolulu including QMC, HPH, Kaiser and Castle. Maui Memorial has a small program as does Hilo Medical Center, but the remaining facilities do not yet offer in-patient palliative care programs. Queens Medical Center has an out-patient oncology palliative care clinic called “Supportive Oncology Clinic.”

In Home palliative care Providing in home palliative care is something that many of Hawaii’s health insurers have been considering, especially since two health plans offer a robust in-home palliative care benefit. Strategies to encourage reimbursement for palliative care programs and services is strongly recommended and may include examination of mandated benefits. However, the working group was unable to explore further strategies due to lack of standardization in definition and benefit design.
The Hawaii Medical Services Association (HMSA) offers an in-home palliative care program known as Supportive Care. The program is offered through specialized palliative care teams by all Hawaii hospices and provides up to three months of coverage in each calendar year. Started as a pilot in 2012, it is now provided across many lines of business. University Health Alliance (UHA) has a similar benefit except without limitations on duration of coverage for palliative care. The working group was informed that Ohana Health Plan is conducting a one-year pilot program, the result of which are not yet publicly available.

Working group members differed in their experience with costs. In general, working group members felt that palliative care was cost neutral and this is echoed by national results. Costs in some cases increased because additional consultations and treatments were provided, although most of the member agreed that cost savings were received further during the treatment or palliative care plan as a patient’s issues are better addressed. The working group explored other models at the state and federal level that addressed palliative care coverage and recommend a study to look at how other health plans in other states have approached the issue. The lack of accessibility to administrative and medical record data for private plans, however, makes comparisons difficult.

**Palliative Care Initiatives at the Federal Level**

Provider education was an issue that the working group discussed as a vital component to increasing awareness of palliative care. Provider education is an issue that was attempted to be addressed through federal legislation. During the 115th Congress (2017-2018), the Palliative Care and Hospice Education Training Act (PCHETA) was introduced. PCHETA would provide funds for palliative care centers of excellence – places where palliative care expertise could be fostered, as well as for teaching hospitals and other institutions to provide palliative care education and training. Despite PCHETA passing the United States House of Representatives on July 23, 2018, the legislation still must pass the U.S. Senate before the end of the 115th Congress. This legislation would fill in many gaps that exist in educating and training health care professionals about palliative care and when to engage patients in the discussion about quality of life options in end-of-life scenarios. As of December 2018, PCHETA passed only in the US House of Representatives.

**Coverage Through Medicare**

Medicare covers hospice care under Medicare Part A but does not cover Palliative Care that includes curative treatment. In order for Medicare beneficiary to qualify, the individual must be certified by a physician to be terminally ill and have 6 months or less to live, the individual agrees to receive only palliative care services for comfort instead of curative treatments, and the individual signs a statement that the individual elects to receive hospice treatment instead of other Medicare-covered benefits. While Medicare does cover palliative care services, this coverage is only for end-of-life and does not cover palliative care services in a broader scope of curative treatments for chronic disease and illness. Coverage is also limited to a 6-month or less prognosis.

The Hawaii Department of Human Services, which participated in one working group meeting, expressed interest in palliative care and may explore opportunities in the future for Medicaid and QUEST beneficiaries.

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3 See Hospice Care Coverage. [https://www.medicare.gov/coverage/hospice-care](https://www.medicare.gov/coverage/hospice-care) <accessed 11/26/18>
Exploring Other Models

The working group discussed the advances that California is making in palliative care. In 2014, California adopted Senate Bill 1004 (SB 1004), which required the California Department of Health Care Services (DHCS) to establish standards and provide technical assistance for Medi-Cal Managed Health Care Plans to ensure delivery of palliative care services to beneficiaries. Integrating palliative care practices, such as coordinated pain and symptom management, improves outcomes and quality of life for patients with serious illnesses. Implementation of SB 1004, however, required planning and research prior to rolling out what would consist of palliative care services under the enacting legislation.

The California model separates palliative care services into three distinct points in time: early palliative care, palliative care (covered by SB 1004), and hospice care. Under the model, early palliative consists of advanced care planning. Advance care planning services could include some palliative care services, but is mostly reserved for discussions about treatment, quality of life issues, and care and financial planning.

The California DHCS established criteria for the eligibility for palliative services under SB 1004:

1. The beneficiary is likely to or has started to use the hospital or emergency department as a means to manage his/her advanced disease.
2. The beneficiary has an advanced illness, with appropriate documentation of continued decline in health status, and is not eligible for or declines hospice enrollment:
   a. Congestive heart failure
   b. Chronic obstructive pulmonary disease
   c. Advanced cancer
   d. Liver disease
3. The beneficiary’s death within a year would not be unexpected based on clinical status.
4. The beneficiary has either received appropriate patient-desired medical therapy or is a beneficiary for whom patient-desired medical therapy is no longer effective.
5. The beneficiary and, if applicable, the family/patient-designated support person, agrees to:
   a. Attempt, as medically/clinically appropriate, in-home, residential-based, or outpatient disease management/palliative care instead of first going to the emergency department; and
   b. Participate in Advance Care Planning discussions.

Palliative care services required under rules developed by the California DHCS include the following:

1. Advanced care planning
2. Palliative care assessment and consultation
3. Plan of care
4. Palliative care team
5. Care coordination
6. Pain and symptom management
7. Mental health and medical social services

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4 See Appendix E, California Department of Health Care Services, All Plan Letter NO. 17-015, October 19, 2017.
5 Id.
These services must be covered by eligible individuals, regardless of age, any of the listed services deemed medically necessary for the individual. The working group was interested in the California model and adopt a version for Hawaii.

The California model for Medi-Cal patients was intended by palliative care groups to provide a model for the private insurance market to adopt. Despite implementation of SB 1004 beginning in 2017, the private insurance plans have not followed.

**Physician and Health Care Provide Education**

Physician and health care provider education was another discussion issue with the working group. Despite work being done on the federal level, the group felt that there is opportunity on the state level to encourage continuing education on palliative care. One aspect that is a focal point for the working group is the discussion about end-of-life care that a primary care physician has with a patient. This discussion is a difficult one; patients and their families often elicit emotional responses due to the nature of thinking about end-of-life stages in their medical care.

Physicians are not compensated for this discussion, something that becomes a barrier. Due to the nature of these conversations, discussing end-of-life options require time set aside from a physician’s time with other patients in a work day with a high volumes of medical care visits. The working group discussed coding and payment issues, although could not definitively conclude on any course of action that would resolve the issue. Some group members felt that a more extensive change in the health care delivery system was needed to address this issue. The working group decided more discussion was needed on this issue.

**Recommendations**

The working group agreed on several recommendations, some of which require further discussion. The recommendations are:

1. Develop a definition of palliative care. This definition will serve as a baseline expectation of what a palliative care program should provide and a minimum level of service that a patient can expect from a health care provider with a palliative care team or program.
2. Support provider and community awareness through education.
3. Support community efforts to include palliative care services through the health insurance and managed care plans, including publicly funded programs.
4. Pursue a pilot program to encourage referrals and the adoption of community standards care, including culturally competent dimensions for Hawaii’s population.

These recommendations reflect the evolving nature of palliative care in Hawaii and the increasing value to patient quality of life and health care system efficiency it brings.

**Continuing to Engage in Palliative Care**

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Members of the SCR 142 working group recognize the value of meeting to discuss issues facing palliative care in Hawaii and have agreed to future meetings beyond the publication of this report.
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A. Senate Concurrent Resolution 142, HD 1
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SENATE CONCURRENT RESOLUTION

REQUESTING THE DEPARTMENT OF HEALTH TO CONVENE A WORKING GROUP TO EXAMINE PALLIATIVE CARE SERVICES AND DEVELOP RECOMMENDATIONS TO EXPAND PALLIATIVE CARE SERVICES IN HAWAI'I.

WHEREAS, palliative care specializes in the management of physical symptoms, including nausea, pain, fatigue, and shortness of breath, as well as the emotional and spiritual distress caused by serious, chronic, or terminal conditions; and

WHEREAS, palliative care is defined by the World Health Organization as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual; and

WHEREAS, studies have shown that patients who had hospital-based palliative care visits spent less time in intensive care units and were less likely to be readmitted to the hospital after returning home; and

WHEREAS, in 2000, less than twenty-five percent of hospitals in the United States had a palliative care program, but by 2015, sixty-seven percent of hospitals in the country with fifty or more beds reported having palliative care teams; and

WHEREAS, the American Cancer Society Cancer Action Network advocates for policies that improve the lives of cancer patients by making treatment of pain and other symptoms and coordination of patient care standard protocol throughout a patient's treatment for cancer, starting at the point of diagnosis; and
WHEREAS, Kōkua Mau, Hawaii's hospice and palliative care organization, is a community benefit, nonprofit organization, composed of individual and organizational champions and supporters from hospitals, education, consumers, insurance, long-term care, and hospices; and

WHEREAS, efforts to increase the use and availability of palliative care services in Hawaii require public health care providers, advocates, and facilities to come together and discuss the challenges and issues faced by palliative care programs; and

WHEREAS, the Department of Health, Kōkua Mau, American Cancer Society Cancer Action Network, and other community partners are all committed to improving the quality of life through palliative care for people in Hawaii; now, therefore,

BE IT RESOLVED by the Senate of the Twenty-ninth Legislature of the State of Hawaii, Regular Session of 2018, the House of Representatives concurring, that the Department of Health is requested to convene a working group, with the assistance of Kōkua Mau and the American Cancer Society Cancer Action Network, to examine palliative care services and develop recommendations to expand palliative care services in the State; and

BE IT FURTHER RESOLVED that the working group is requested to collaborate with hospice and palliative care organizations, healthcare associations, health care facilities, insurers, patient advocacy groups, and other interested public health groups; and

BE IT FURTHER RESOLVED that the working group is requested to examine and identify:

(1) The current state of palliative care services offered in Hawaii;

(2) The capacity of current palliative care providers;

(3) The geographic areas where significant gaps in palliative care services exist;
Opportunities to collaborate with key stakeholders who are positioned to craft a strategy and plan for improving and expanding the provision of high-quality palliative medicine and palliative care services in Hawaii;

The feasibility for financial support of a long-term expansion of palliative care services in Hawaii;

A plan for ongoing data gathering for purposes of monitoring and quality improvement of palliative care in Hawaii;

Engagement strategies for educating the public about palliative care and hospice care to empower people to make informed decisions about wishes for care when faced with a serious illness; and

Any other strategies that would improve palliative care services in Hawaii; and

BE IT FURTHER RESOLVED that the working group is requested to submit a report of its findings and recommendations, including any proposed legislation, to the Legislature no later than twenty days prior to the convening of the Regular Session of 2019; and

BE IT FURTHER RESOLVED that subsequent to the submission of its report to the Legislature, the working group may convene annually or as necessary to discuss and update its findings and recommendations; and

BE IT FURTHER RESOLVED that certified copies of this Concurrent Resolution be transmitted to the Director of Health, Executive Director of Kōkua Mau, and Director of the American Cancer Society Cancer Action Network.
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Palliative Care Survey
SCR 142 Task Force

1. Provider name and contact information.

2. Palliative care service name and contact information.

3. Do you have a Palliative Care Program in place (separate from the Medicare Hospice Benefit)? If no, to whom do you refer patients to for this type of care?

4. When was your Palliative Care Program established?

5. Please describe the organization of your Palliative Care Program:

   a. What disciplines participate in the program (e.g., physicians, nurses, social work, chaplain, etc.)?

   b. How many of your physicians and nurses are Board Certified in Hospice & Palliative Medicine?

   c. Where are services provided, and approximately how many consultations are provided in each location – Inpatient consultation service, outpatient clinic, homecare?

   d. Is your program available 24/7/365?

   e. Does your program have Joint Commission Advanced Certification in Palliative Care? If not, are you considering it?

6. Please describe your Palliative Care Program patient services:

   a. What services are provided to patients (e.g., goals of care, bereavement, symptom management, family meetings, ADs, etc.)?

   b. What conditions / diagnoses are eligible to receive palliative care consultation and what conditions / diagnoses are most frequently served?

   c. What services most frequently provide referrals to your program – where are the majority of your patients from (e.g., oncology, intensive care, emergency department, etc.)?

   d. Are there automatic triggers to consider palliative care consults?
e. What percentage of your patients are discharged deceased to hospice? To outpatient palliative care? Other?

7. Does your program have both administrative and financial support? If not, what’s missing?

8. What metrics does your program use to track success (e.g., patient satisfaction survey, etc.)?

9. Are there annual reviews of your program? Are there quality projects or programs monitoring the effectiveness of your program?