Planning Grant for Expanding Community-Based Palliative Care Services in Hawaiʻi

Final Report

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HUI POHALA

Kōkua Mau
Continuous Care
A Movement to Improve Care

Papa Ola Lokahi
Nana I Ka Pono Na Ma

USC University of
Southern California

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Executive Overview

Many stakeholders across the state of Hawai'i are committed to improving care and quality of life for people living with serious illness and the people who care for them. In alignment with these statewide efforts, and to achieve health equity and improve the health and well-being of the people living in Hawai'i, the State of Hawai'i Department of Human Services Med-QUEST Division (MQD) identified a formal plan was needed to address the needs of people with serious illness through the implementation of palliative care services across settings. This would ensure there is a minimum standard and clear guidance for the delivery of these services, including through managed care organizations (MCOs), some of whom are already offering similar services via Medicare and/or commercial plan products. By implementing a plan to address the needs of people in the community and providers to increase access to palliative care services, it is projected that MQD would be able to mitigate the costs and improve alignment between goals for care and the care received for seriously ill people living in Hawai'i.

Palliative care is defined as *person- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering for the seriously ill*. Integrating 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. Delivered through an interdisciplinary team, palliative care services are intended to achieve the following goals:

1. Help people manage pain and other symptoms of a serious illness,
2. Ensure care received is person-centered, and
3. Help a person and their loved ones navigate medical decision making, and access medical and social services needed relating to the symptoms and stress of a serious illness.

This 10-month **Planning Grant for Expanding Community-Based Palliative Care Services in Hawai'i** is in anticipation of the need to expand high-quality community-based palliative care (CBPC) for eligible individuals throughout the state. The project engaged community members and organizations, clinicians, and healthcare organizations to inform an implementation plan that will ensure people living with serious illness have access to care, with special attention to promoting health equity across the state. Building upon the knowledge, experience, and ongoing work of Hui Pohala, Kōkua Mau, and Papa Ola Lōkahi, this planning project was undertaken to identify and prioritize recommendations as part of a comprehensive effort to expand high quality palliative care services across settings in Hawai'i.

This project engaged with many thoughtful and insightful stakeholders across the state, including community members, community-based organizations, clinicians, health plan care managers, and healthcare organizations. Stakeholders shared their views about the current state of services for individuals with serious illness, insights into gaps, and suggestions for preparing to meet the future needs of people living with serious illness in Hawai'i. This wealth of information was used to inform the prioritized, Hawai'i-specific recommendations found in this report, as the basis for a successful implementation of the requisite expansion of high-quality palliative care across community-based settings in the state of Hawai'i.

Of note, the focus of this project was on the roles of providers and the community in expanding community-based palliative care and services. The role of managed care organizations in this was outside the scope of this project.

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List of Abbreviations

Abbreviations found throughout this report include:

- **PC** = Palliative Care
- **CBPC** = Community-Based Palliative Care
- **PCP** = Primary Care Physician
- **SW** = Social Worker
- **CHW** = Community Health Worker
- **CM** = Care or Case Manager
- **JEDI** = Justice, Equity, Diversity, and Inclusion
- **MCO** = Managed Care Organization
- **SDOH** = Social Determinants of Health
- **CME/CE** = Continuing Medical Education/Continuing Education
- **HHIE** = Hawai'i Health Information Exchange

Introduction

The state of Hawai'i has a goal to improve care and quality of life for people living with serious illness and the people who care for them. Hawai'i's approach to palliative care is to systematically provide support to individuals facing a serious illness so they receive care in a setting of their choice, and in a manner that reflects and respects Hawai'i's diverse geography, ethnic composition, and culture.

The guiding vision for this goal includes education and engagement strategies across healthcare and other sectors, a trained and engaged workforce, policies and infrastructure that promote delivery of quality care (safe, timely, effective, efficient, equitable, person-centered), processes that connect the right patients to providers, and payment that covers the cost of delivering this care.

The State of Hawai'i Med-QUEST Division (MQD) has begun addressing the payment mechanism that supports that vision. Through a comprehensive engagement and design process, they have proposed a Palliative Care Services Benefit (the Benefit) currently under review for approval by the Centers for Medicare and Medicaid Services (CMS). Without addressing these payment barriers, the Medicaid reimbursement structure does not enable individuals to access interdisciplinary palliative services unless they are hospitalized, resulting in a significant gap. While implementation of a coordinated Benefit would increase access far beyond the limited and episodic services currently available, much must still be done to prepare providers and the community to ensure access to these services as they become available, and to deliver them in a way that improves the experience of care for the person living with serious illness, and their loved ones and care partners.

This 10-month **Planning Grant for Expanding Community-Based Palliative Care Services in Hawai'i** engaged community members and organizations, clinicians, health plan care managers, and healthcare organizations to inform an implementation plan that outlines: messaging and communication strategies to promote understanding and engagement with PC by patients, caregivers, and providers; workforce expansion and training; and infrastructure development. This plan's goal is to ensure adults and children living with serious illness have optimal access to care, with special attention to promoting health equity across the state.

Building upon the work and experiences of Hui Pohala, Kōkua Mau, Papa Ola Lōkahi, and other stakeholders in Hawai'i, new partners in this project added critical support and expertise **(see Attachment 1)**. Drawing on experience with similar work proved valuable, as did review of a prior stakeholder engagement, conducted previously during the Palliative Care Services Benefit design, as Hawai'i-specific solutions were developed. The active engagement and feedback from Hawai'i stakeholders were critical to the success of this project, helping to inform the approaches used, the information gathered, and providing important context to ensure diversity of perspectives were represented. These interactions built an understanding of current strengths of, and opportunities for, services currently available to people with serious illness across all care settings, and an understanding of the current level of knowledge and preferred communication, education, and messaging across geographies and cultures in Hawai'i.

A foundational concept of this project was based on the recognition that the historic systems of care have been built around the "80:20 rule." This means that current systems of care have been designed to work, as a rule, for "80% of people," resulting in the "other 20%" being treated as exceptions. This historic practice has directly contributed to disparities in healthcare, and ultimately disparities in health, which disproportionately impact underrepresented and disenfranchised populations. A guiding principle of this project was to invert this "80:20 rule" by focusing on designing high-quality community-based palliative care that works for those who have been historically underrepresented. There are a variety of factors

contributing to underrepresentation in healthcare design. In Hawaiʻi, the existing healthcare systems work well for a predominantly Honolulu-based non-native Hawaiian population (approximately 70% of the state's population lives on the island of Oʻahu with about 81% of those living in or near the city of Honolulu). One impact of this system design, for example, is that virtually all seriously ill children and their families must fly to Honolulu for specialty care and/or hospitalization – which compounds the factors of economics and receiving care outside one's cultural community. This principle was used to inform who and how we engaged with the many stakeholders throughout this project.

People living with serious illness receive support and care from many areas across their communities, both within and beyond healthcare settings. The engagement efforts also reflect this "360° view" of the current state, and future needs, for holistic care. This broad approach created an ability to rethink and broaden perspectives on solutions to expand PC services within resource constrained environments. This foundational concept, which is referred to in this report as "Expanding the Team," was used throughout the project and aligns with the approach used in asset mapping, by asking questions that give access to a wealth of knowledge from those doing the work locally, rather than an approach that uses a deficit viewpoint focusing exclusively on gaps.

This project explored two broad areas of emphasis: 1) Effective messaging and communication to engage community members and providers with palliative care, and 2) The workforce and infrastructure needed to care for people living with serious illness.

Member and provider engagement built an understanding of the current level of knowledge about palliative care, and the preferred communication, education, and messaging among the public and providers in the community. Through working with community-based stakeholders and leadership groups, the tailored messaging language and communication approaches were refined to ensure alignment and buy-in across diverse stakeholders. This resulted in a messaging and communication plan for subsequent implementation.

Assessments of the workforce explored requirements for building capacity and standardization of high-quality palliative care services with recommendations for education, training, and competency resources for the palliative care community. This assessment was focused in three areas:

1. **Capacity** – Defined as the ability to deliver more of the same care or new types of care to current patients or new patients. This assessment sought to identify where the current CBPC providers may be insufficient for the number of patients with serious illness, with attention to addressing the needs of the historically underserved.
2. **Capability** – Defined as structures and processes that allow for delivery of specific PC services, or aligned supporting services/activities (e.g., primary palliative care). This assessment identified the standard elements of CBPC programs across providers, to understand variations.
3. **Competency** – Defined as the knowledge, skills, and training needed to deliver comprehensive services to people living with serious illness, or to be familiar enough with PC to be an effective messenger (i.e., introduce clients/patients to the idea of PC). This assessment developed recommendations for expanding the palliative care-specific educational opportunities for all members of the palliative care community.

Through the methods described in the following section, the voices and experiences of many organizations and individuals, across many sectors throughout the state, are reflected in the recommendations found in this report. Of note, input from the interviews and focus groups was accepted as that person's truth; no effort was made to externally validate or negate a perspective brought forth.

Therefore, some themes may seem to conflict with the reader's understanding or perspective on a particular topic.

Of note, this project focused on the roles of providers and the community in expanding community-based palliative care and services. The role of Managed Care Organizations in this was outside the scope of this project.

Methods

This project was strengthened by a unique partnership between the leadership of local stakeholder organizations who have a long history and deep relationships across the state and supporting organizations that provided structure and fresh perspectives for the project. The leadership of Hui Pohala, Kōkua Mau, and Papa Ola Lōkahi, as trusted sources in the community, opened doors and connected the project to a wide array of participants. The partnership with Respecting Choices and the University of Southern California (USC) allowed participants to provide input to the project through facilitated interactions that were outside of their social and/or professional circles. Together, key individuals from these five organizations (in addition to Joy Soares, Program Specialist V: Policy and Program Development Office, Med-QUEST) constituted the Steering Committee for this project.

Additional content expertise was provided by a panel of subject matter expert advisors who have worked extensively to advance palliative care nationally, and who brought various perspectives ranging from policy advocacy, benefit development, program design, implementation, and evaluation.

An Advisory Council was established with membership as suggested by the Steering Committee, other key stakeholders in Hawaiʻi, and the Stupski Foundation. The Advisory Council provided unique knowledge and skills that complemented the knowledge and skills of the Steering Committee, and whose role was to make recommendations, validate and/or provide key information and materials to the steering committee. They functioned very effectively as ambassadors for the project and were key to opening doors to a greater constituency.

For names of the Steering Committee members, the expert advisors, and the Advisory Council, *see* **Attachment 1**.

This project began with a review of previous work conducted in Hawaiʻi and elsewhere, including the pioneering efforts in California, and the existing evidence provided by the panel of expert advisors. This informed the project design, which was then enhanced through active engagement and feedback from Hawaiʻi stakeholders and the content expert project advisors.

Kōkua Mau and Hui Pohala facilitated scheduling in-person introductory meetings with stakeholders across communities on four islands in May 2022, including four meetings on Kauaʻi, four on Maui, five on Hawaiʻi Island over two days, and three meetings on Oʻahu. The purpose of these was to introduce the planning project, solicit input on "who else" would be important to engage, and to garner interest in participating with the planned engagements. Several virtual meetings occurred after the onsite visit, to follow-up with additional participants that were suggested during the onsite meetings. For a summary of the organizations that engaged in one or more of the five engagement activities listed on the following page, *see* **Attachment 2**.

Communication and Messaging

A variety of methods was used to recruit three samples.

- **Patient/Caregivers Survey**

The budget prohibited a representative sample of the Hawai'i population. However, a concerted effort was made to engage a wide range of people from diverse backgrounds and from locations throughout O'ahu and Hawai'i Island. Individuals were randomly approached by the interviewers at community locations and at prearranged health clinics. Those eligible to participate in the survey included individuals with a chronic or serious medical condition or someone caring for a person with a chronic or serious medical condition, and who had Med-QUEST benefits. The survey was developed using a combination of existing measures and questions developed specifically for this survey.

- **Community-Based Palliative Care Teams Focus Groups**
  All current providers of CBPC across the Hawaiian Islands were identified, in partnership with Kōkua Mau and Hui Pohala, who provided introductory emails to each. Each agency was then contacted to schedule a focus group. CBPC directors were asked to invite team members who were involved in community and physician education and outreach and inpatient enrollment/engagement. A focus group protocol used in a previous study to understand challenges in patient enrollment challenges/facilitators experienced by home-based palliative care providers was adapted (Enguidanos et al., 2022).

- **Physicians and Nurse Practitioner Interviews**
  A variety of efforts were used to recruit a random set of respondents for this interview, including direct outreach to healthcare providers that offered care to Med-QUEST patients, asking directors of FQHCs to send email invitations to their providers to participate in the interviews, and Kōkua Mau reaching out to primary care physicians across the islands. An interview protocol used in a previous study to understand physician perspectives on palliative care referral was adapted (Enguidanos et al., 2022).

Capacity, Capabilities, and Competency

Several methods were used to engage a wide range of perspectives from the many different types of organizations that are involved in caring for, and providing services to, adult and pediatric individuals living with serious illness.

- **Electronic Survey**
  The survey was developed by building on previous assessments and the framework for palliative care standards. The intent of the survey was to gather objective information across organizational types, to be explored in subsequent facilitated focus groups. Survey responses were received from organizations that, in aggregate, provide services representing six islands (Hawai'i Island, Kaua'i, Lāna'i, Maui, Moloka'i, and O'ahu).

- **Focus Group and Interview Methods**
  Focus groups were assembled based on type of services provided and included many of the survey participants in addition to others, as recommended by the Steering Committee and Advisory Council. Overall, 14 focus groups were held in addition to five individual interviews. Focus group protocols were developed to understand challenges in current and future services for individuals living with serious illness, in the domains of capacity, capabilities, and competency. The protocol was then adapted specific to the focus group areas of content expertise.

The information gathered from each of the five activities described then went through an iterative process to ensure that the stakeholders on both the Steering Committee and the Advisory Council had an opportunity to provide review and feedback. They were requested to highlight areas of surprise, to provide guidance where something might "seem off", to elevate topics they were expecting to see that were not represented, and to add their own opinions or observations. Feedback and comments were then

integrated into the next iteration throughout the process. Of note, the input gathered from the interviews and focus groups was accepted as that person's truth; externally validating or negating these perspectives was outside the scope of this project. Therefore, some themes may seem to conflict with the reader's understanding or perspective on a particular topic.

This feedback process solicited input from the Steering Committee and Advisory Council at several key points in the project:

1. A summary of analysis from each of the five activities was provided by those on the project team who had been involved in each activity.
2. Major themes within the broad areas of communication and messaging, capacity, capability, and competency (see definitions above) which had been distilled by the content experts/panel of advisors, facilitated by Respecting Choices. For a condensed list of major themes, **see Attachment 4**.
3. Draft recommendations arising from the themes, as compiled by the content expert/panel of advisors, facilitated by Respecting Choices.

Through each iteration, reviewers generally indicated the findings confirmed either their knowledge or beliefs about the current state. When new ideas were brought forth, they indicated that the idea resonated with their understanding.

For a more detailed description of the methods just described, **see Attachment 3**.

Recommendations

The recommendations presented in this section represent a comprehensive set of activities that will build toward a future state in which there are trained and engaged workforce, policies and infrastructure that promote delivery of quality care (safe, timely, effective, efficient, equitable, patient-centered), and processes that connect the right patients to providers, including education and engagement strategies across healthcare and other sectors.

The recommendations are grouped sets of activities within the four broad categories of Communications and Messaging, Capacity, Capabilities, and Competency, as defined in the introduction of this report. In addition, there are several overarching recommendations that transcend these four categories.

The first overarching recommendation recognizes that there are varied efforts already underway to address some of the activities outlined below. For example, in addition to the palliative care improvement work, we are aware of non-palliative care specific work in the state to address topics such as caregiver training, the healthcare workforce pipeline, and community education. In addition, some of the recommendations that arose from stakeholder input may address processes that already exist in some places but are inconsistent or incomplete. Capturing existing efforts emanating from multiple sources (e.g., public health, policy, and healthcare generally), was beyond the scope of this planning project. An important step to complete before implementing any of the proposed recommendations would be to conduct an environmental scan to ensure that any overlapping/ complementary high value efforts underway are built upon and leveraged, avoiding wasteful duplication of efforts.

The second overarching recommendation recognizes the complexity of coordinating a wide base of stakeholders, across sectors, to achieve a comprehensive implementation of this set of recommendations. Building on the work of organizations like Hui Pohala and Kōkua Mau, we strongly recommend creating a Hawaiʻi specific, state-wide solution to catalyze effective implementation, that will generate collaboration to achieve standardized improvement, and can coordinate the short- and long-term goals, while

recognizing the uniqueness among islands and geographies. A wide array of stakeholders, including participating PC providers, health plans, and community-based and social service organizations could be charged with:

- Coordinating the various funding streams available from local, state, and federal sources to implement the various activities contained in the recommendations.

- Identifying opportunities to leverage work already underway toward these recommendations.

- Assigning who/what/when/how to activities as these prioritized recommendations are implemented over several years. For example, some will require state direction as a state initiative, while others will be driven through community groups.

- Building foundational policies, principles, and agreements for co-management, in partnership with referring providers and services.

- Standardizing how benefits function across plans, to the extent possible, to facilitate PC providers' participation with multiple plans, therefore serving a greater number of eligible participants. Examples of standardized functions could include a standardized intake process, standard assessment tools, workflows, common metrics and data reporting requirements, and a centralized patient experience survey.

- Communicating and coordinating in real-time between the community of providers and either the Department of Health and/or Med-QUEST. This would facilitate the flagging of any issues early, as a matter of routine, for prompt attention and resolution.

As noted previously, "Functioning as an Expanded Team" is a conceptual underpinning of all the recommendations. The concept creates broader solutions to expand PC services within resource constrained environments. It infers a system of care that includes PC specialists, multiple disciplines, and includes community-based support services, and requires processes that support intentional coordination of services around individuals with serious illness, their loved ones, and care partners. As a result, this project sought to explore what additional disciplines would be included using a broader lens, that could help address unmet needs of people living with serious illness, such as CHWs. It also sought to identify roles for services outside of the traditional healthcare system that are already encountering people with serious illness, such as Area Agencies on Aging, adult day programs, community service organizations, or faith communities, and to engage other healthcare agencies more effectively, such as home health, skilled nursing, and long-term care, in delivering PC.

In support of this concept, several of the community-based organizations (CBOs) that engaged in stakeholder input described a vision in which they could play a meaningful role in connecting people with serious illness to optimal care. For example, organizations in the community that are currently engaged in evaluating and addressing social determinants of health could be trained to integrate screening tools to identify individuals that would benefit from palliative care services. Another example was to use CHW's, who currently work in many of these CBOs and are of the cultural communities they serve, to also provide interpreter services for healthcare services rather than thinking of interpreters as yet another workforce to be developed.

The recommendations below are arranged as grouped sets of activities within the four broad categories of Communications and Messaging, Capacity, Capabilities, and Competency, as defined in the introduction of this report. Within each of these four broad categories, we have delineated three levels of prioritization that indicate a rationale for the sequencing of these activities. The highest priority recommendations are considered foundational to meeting the minimum expectations to deliver high quality CBPC in Hawai'i (**"Foundational to begin"**). Other recommendations are necessary to expand services to vulnerable populations, as would be important to consider when caring for Med-QUEST

beneficiaries (**"Necessary to expand to vulnerable populations"**), and still others may be longer term improvement activities (**"Optimization/Enhancements"**). Of note, all recommendations arose from the stakeholder input during this project; the fact that they may address a process that exists in some places may be because the process is inconsistent, incomplete, or reflects a lack of awareness of the activities.
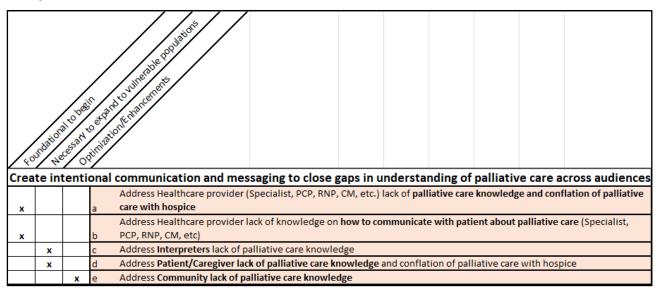
An additional note about the recommendations that follow: There are clearly unique needs and circumstances in areas with lower prevalence of people with serious illness, such as geographically less populated areas, or pediatric patients (where the number of seriously ill will be fewer, even in regions of higher population). While all populations deserve the same standard of care, the unique capabilities, and mechanisms to expand capacity in these areas with lower prevalence of eligible people may require different prioritization than for other populations. Just as the guiding principle of this planning project was an intent to invert the "80:20 rule" by focusing on expanded access designed to work for those who have been historically underrepresented, so too, the implementation phase will need to ensure the recommendations are implemented to meet the needs of "the 20%." For example, for populations with lower prevalence, it may be important to place a higher priority on creating competencies among existing providers, rather than on increasing the number of providers. For example, focusing skill development in providers that already deliver home-based services, or on increasing capacity through partnerships with PC specialists, supported by the capabilities of telehealth.

One example of this type of innovation described during stakeholder engagement was a future vision of collaboration and partnerships between specialists in healthcare-dense geographies with providers in distant communities, on other islands, with a goal of decentralizing specialty knowledge virtually. As examples, these partnerships could be between medical specialists in Honolulu with PC specialists or PCP providing care in rural communities, or these partnerships could be between PC specialists in Honolulu with PCP in rural communities. The primary goal would be to enhance access to specialists while keeping patients in their local community and supporting their existing provider relationships. Provider collaboration could take different forms, including joint visits with both providers present (one virtually) with the patient and their caregivers in the community, or telehealth visits between a remote specialist and the patient using the space and technology of the office of their established provider in their home community. Other stakeholders spoke of collaboration that could provide a structured, virtual training and mentorship program to advance primary palliative care skills across the state. It appeared that there may be several early experiences underway testing these types of services, but they are not yet prevalent or scalable.

Overview of Recommendations

Foundational to begin	Necessary to expand to vulnerable populations	Optimization/Enhancements		
Create intentional communication and messaging to close gaps in understanding of palliative care across audiences				
x			a	Address Healthcare provider (Specialist, PCP, RNP, CM, etc.) lack of **palliative care knowledge and conflation of palliative care with hospice**
x			b	Address Healthcare provider lack of knowledge on **how to communicate with patient about palliative care** (Specialist, PCP, RNP, CM, etc)
	x		c	Address **Interpreters** lack of palliative care knowledge
	x		d	Address **Patient/Caregiver lack of palliative care knowledge** and conflation of palliative care with hospice
		x	e	Address **Community lack of palliative care knowledge**
Build capacity within and beyond specialty palliative care; Expand the team				
x			a	Capacity to **identify and refer** appropriate patients for PC, including children
x			b	Capacity to provide **primary PC** (especially important as specialty PC builds capacity)
	x		c	Capacity to expand current **specialty PC programs** and services
	x		d	Capacity to **support families** and care partners
		x	e	Capacity to train up **non-PC providers to become specialty PC** and create new programs
		x	f	Develop a coordinated **workforce pipeline**
Build capabilities within and beyond specialty palliative care; Expand the team				
x			a	Capability to **identify and refer** appropriate patients for PC, including children
x			b	Capabilities improve **coordination of care** across the broader team caring for PC patients
	x		c	Capability for **specialty PC programs** and services to reach referring providers/patient populations
	x		d	Enhance **JEDI capabilities** (policies, structures, and processes) as an intentional area of focus
	x		e	Identify **funding to support upfront investment** in administrative function to support specialty PC meet new benefit requirements (e.g. IT capabilities; updating billing system; robust case management system)
Build and enhance palliative care and JEDI competencies across the expanded team				
x			a	Enhance **primary PC competencies of mid-career** professionals in non-PC settings, caring for people with serious illness (e.g., PCP, med specialties)
	x		b	**Map current PC educational resources** - and those being planned.
	x		c	Create a **path to interprofessional Palliative Care Certification**
	x		d	Enhance **JEDI competencies** (education, skills, mentoring, and diversify sources of information/perspectives represented) as an intentional area of focus
		x	e	Develop **central hub of PC educational resources**, to be accessed by PC community **and** by others caring for people with serious illness
		x	f	Support enhancement of **specialty PC competencies**
		x	g	Attend to the "bridge" between education and competency
		x	h	Integrate primary PC principles into **pre-professional curricula** required in early training of all disciplines that incorporate PC education and core skills, appropriate to role

Create intentional communication and messaging to close gaps in understanding of palliative care across audiences.

Foundational to begin	Necessary to expand to vulnerable populations	Optimization/Enhancements		Create intentional communication and messaging to close gaps in understanding of palliative care across audiences
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x			b	Address Healthcare provider lack of knowledge on **how to communicate with patient about palliative care** (Specialist, PCP, RNP, CM, etc)
	x		c	Address **Interpreters** lack of palliative care knowledge
	x		d	Address **Patient/Caregiver lack of palliative care knowledge** and conflation of palliative care with hospice
		x	e	Address **Community lack of palliative care knowledge**

*Each **overarching theme** has several associated communication recommendations (how and where) immediately followed by specific messaging recommendations (specific wording and style/why).*

a. **Address Healthcare Provider (Specialist, PCP, RNP, CM, etc.) lack of palliative care knowledge and conflation of palliative care with hospice.**

   i. Develop multiple approaches of communicating/educating array of healthcare providers about PC.
   Messaging recommendation: Include self-paced, online training (#1), use palliative care providers as in-person trainers in clinics (#2), provide in-person training as part of required in-services (#3). CME to accompany all education.

   ii. Create, test, and adopt universal approach/messaging around PC, while adapting where necessary to remain culturally sensitive.
   Messaging recommendation: Universal education (see recommendations around universal assessment tool and referral process) to include standard messaging across all organizations, entities, and workforce involved in introducing and explaining palliative care, as distinct from end-of-life or hospice.

   iii. Include all clinical staff in palliative care communication and education training.
   Messaging recommendation: Focus on CMs/SWs as initial audience for this education.

   iv. Palliative care providers to give monthly feedback about patients to referring physicians.
   Messaging recommendation: This feedback loop is to keep physicians informed on patient progress and also improve knowledge of palliative care.

b. **Address Healthcare Provider lack of knowledge on how to communicate with patient about palliative care (Specialist, PCP, RNP, CM, etc.).**

   i. Provide provider training in communication to patients/family members around PC.
   Messaging recommendation: Develop template/script for use; role-play to build competence.

   ii. Provide provider training in making a warm hand-off to CMs and PC providers.
   Messaging recommendation: Recognizing that all physicians will not be comfortable in communicating about PC, this recommendation focuses on providing basic language

physicians can use in handing off patients to others for in-depth palliative care communication (e.g., CMs, SWs).

   iii. Clinic leadership to conduct monthly review of success of PC referrals/uptake.
   Messaging recommendation: Conduct the review in regular meetings to elevate importance of PC.

   iv. Track palliative care referrals made by CM as dashboard.
   Messaging recommendation: Track referrals to measure outcomes and increase accountability and access to PC.

c. **Address Interpreters lack of palliative care knowledge.**

   i. Provide training on serious illness communication for interpreters.
   Messaging recommendation: Tap into existing training modules that exist.

   ii. Expand pool of trained interpreters with local people (number of interpreters and number of languages available).

   iii. Expand availability (24/7 coverage) and modalities (online, telephone, in-person) available.

d. **Address Patient/Caregiver lack of palliative care knowledge and conflation of palliative care with hospice.**

   i. Create, test, and adopt universal brochures in multiple languages using standard content but with presentation and description reflecting cultural and ethnic sensitivity.
   Messaging recommendations: Brochure to contain many pictures and low literacy text. Can include area for personalization by the palliative care provider/agency. Definition of PC needs to include description of services provided and members of the team; need to highlight that don't have to forego other care.

   ii. Incorporate multiple modalities/learning styles.
   Messaging recommendation: Preferred communication from healthcare provider and friends/family. Patient videos in reception area and stories in brochures.

   iii. Conduct work to determine how to best describe PC across languages ("palliative" has no translation in many languages)
   Messaging recommendation: Definition of PC needs to include description of services provided and members of the team; need to highlight that don't have to forego other care.

e. **Address Community lack of palliative care knowledge.**

   i. Statewide public health messaging campaign (education and awareness) for PC; build on the importance of stories, trusted relationships, and leveraging informal channels of communication that exist in the communities.
   Messaging recommendations: Engage with faith communities, radio, social media/Facebook/cultural events, and other ideas for moving it out of the healthcare environment. Partner with media outlets and obtain funding for media campaign, successful strategies that have been previously used by public health campaigns in Hawaiʻi and in the U.S.

   ii. Seek funding for oversight by a local agency to support other organizations to host events related to palliative care, advance care planning, etc.
   Messaging recommendation: Organizations serving diverse populations may apply for funding related to PC education.

Build capacity within and beyond specialty palliative care; Expand the team.

Foundational to begin	Necessary to expand to vulnerable populations	Optimization/Enhancements		
				Build capacity within and beyond specialty palliative care; Expand the team
x			a	Capacity to **identify and refer** appropriate patients for PC, including children
x			b	Capacity to provide **primary PC** (especially important as specialty PC builds capacity)
	x		c	Capacity to expand current **specialty PC programs** and services
	x		d	Capacity to **support families** and care partners
		x	e	Capacity to train up **non-PC providers to become specialty PC** and create new programs
		x	f	Develop a coordinated **workforce pipeline**

a. **Increase capacity to identify and refer appropriate patients for PC, including children.**
   i. **Mapping:** Define and identify who in the community, across settings, regions, and services, are encountering people with serious illness and are already evaluating their needs. Scope should include faith-based, community-based, and public health resources that already exist.
   ii. **Engage/Incent:** Create strategy for engaging/incenting identified organizations and staff, that are in a position to identify and refer, to "staff up" and "train up" for primary PC skills.
   iii. **Function as expanded team:** Formalize intentional partnerships and collaborations/workflows to identify, communicate, and refer across wide array of services currently involved with people with serious illness (Many examples of such opportunities were given, e.g., staff currently assessing for SDOH could also assess for PC, such as home health, chaplains; EMS currently responding to falls in the home, etc.).

b. **Increase capacity to provide primary PC (especially important as specialty PC builds capacity).**
   i. **Mapping:** Define and identify the current (non-PC) providers of the patient population with serious illness, and overlay current/future patient demand, by region.
   ii. **Engage/Incent:** Create strategy for engaging/incenting identified organizations and staff, to "staff up" and "train up."
   iii. **Function as expanded team:** Create partnerships between regions that have specialty PC capacity with non-PC providers in regions that don't have specialty PC, to include capabilities such as joint-telemedicine visits, case reviews, mentoring, etc. (See capabilities for more detail.). Primary PC is valuable as an end and as a bridge strategy – all providers that have contact with seriously ill individuals need to have primary PC skills. Ensuring adequate primary PC skills is an important way to protect the scarce and relatively expensive specialty services from being deployed to manage basic things, like hospice education or basic ACP support.

c. **Increase capacity to expand current specialty PC programs and services.**
   i. **Mapping:** Map capacity of existing PC programs and services and overlay expected patient demand, by region, to assess baseline capacity and current/future need.

ii. **Engage/Incent:** Create strategy for engaging/incenting identified organizations and staff, to "staff up" and "train up" to offer specialty PC services to more patients.

iii. **Function as expanded team:** Partner with existing home-based (non-PC) teams/services to add specialty PC. Partner with residential facilities (e.g., nursing homes, care homes, etc.) to expand CBPC strategically and intentionally beyond private residencies. Identify services provided outside of the specific PC programs and define scope of practice and workflows to leverage those services (buy vs. build) (e.g., Who else is involved in coordinating care or assessing for SDOH?).

d. **Increase capacity to support families and care partners.**

i. **Mapping:** Define and identify the resources (current and in development) available to support families and loved ones.

ii. **Engage/Incent:** Create strategy for engaging/incenting identified organizations and staff, to "staff up" and "train up" to add services specifically for family/loved one support.

iii. **Function as expanded team:** Create intentional partnerships and workflows to leverage community assets that intentionally support family/loved ones of patients with serious illness.

e. **Increase capacity to train up non-PC providers to become specialty PC and create new programs.**

i. **Mapping:** Identify where non-PC providers may be interested in developing specialty PC, especially in practices that are already offering home-based care for seriously ill patients (e.g., home-based primary care; geriatric home visits, etc.).

ii. **Engage/Incent:** Create strategy for outlining advantages of additional certification (e.g., It may open up PC reimbursement if adapt to meet the Benefit requirements.).

f. **Develop a coordinated and sustainable workforce pipeline.**

i. **Mapping:** Define and identify other workforce development efforts that currently exist, that can be leveraged to support this work. Recognize these other efforts may be outside of PC and outside of traditional "healthcare," e.g., efforts through Department of Health, etc.

ii. **Engage/Incent:** Workforce pipeline should be centralized and shared; add PC specialty to the shared workforce pipeline efforts that are currently underway.

iii. **Function as expanded team:** partnerships and workflows. Cross train the pipeline to support functions (appropriate to the role) that will leverage PC capacity (e.g., certain screening assessments).

iv. **Recruit the workforce strategically and with intentionality:** Prioritize workforce development programs that develop interest in younger communities (e.g., high schools). Prioritize workforce development programs that focus on recruiting a diverse workforce. Create opportunities for vocational rehab or new skills training for lay caregivers to become CHWs or other formal roles that could support the serious illness population. Prioritize efforts to recruit an internal-Hawai'i/Hawai'i resident workforce, as people of the community are invested to stay/less likely to leave the state.

v. **Create shared retention strategies:** Incentives/rewards for PC organizations to have "well-being" programs; funding that could be applied for to develop staff well-being programs. Perform review of wages for the workforces providing these services (in the home) to inform the published wage index. For PC messaging, (roles that will help identify and refer) recruit people from the community who bring trusted relationships.

Build capabilities within and beyond specialty palliative care; Expand the team.

Foundational to begin	Necessary to expand to vulnerable populations	Optimization/Enhancements		Build capabilities within and beyond specialty palliative care; Expand the team
x			a	Capability to **identify and refer** appropriate patients for PC, including children
x			b	Capabilities improve **coordination of care** across the broader team caring for PC patients
	x		c	Capability for **specialty PC programs** and services to reach referring providers/patient populations
	x		d	Enhance **JEDI capabilities** (policies, structures, and processes) as an intentional area of focus
		x	e	Identify **funding to support upfront investment** in administrative function to support specialty PC meet new benefit requirements (e.g. IT capabilities; updating billing system; robust case management system)

a. Build capability to identify and refer appropriate patients for PC, including children.

    i. Develop mechanisms for entities that have a role in identifying and referring, to incorporate identification of individuals appropriate for PC into existing screening tools and workflows.

    ii. Develop mechanisms for entities that have a role in identifying and referring, to leverage use of data to identify individuals appropriate for PC.

    iii. Develop incentive for programs to stop competing on ability to identify patients and instead compete on what they do for them.

    iv. Develop shared, statewide algorithms for identification of individuals appropriate for PC, pulling information from electronic medical records and claims, where available. Put in hands of those in role to identify and refer.

b. Build capabilities to improve coordination of care across the broader team caring for PC patients.

    i. Define roles and responsibilities that support coordination between the PC providers and the MCOs.

       o Define agreed upon roles and communication between health plan case manager(s) and CBPC practice care managers, e.g., who is the accountable person, and why/when/for which services (e.g., Who supports transition from hospital?).

       o MCOs need an administrative role within case management services to oversee coordination of the coordinators.

       o Define standard intake and Benefit approval process.

       o Define and agree upon standard assessment tools, workflows, roles, data reporting mechanisms.

       o MCOs should have medical directors for PC services.

    ii. Develop policies, principles, and agreements for co-management between specialty PC and the broader clinical team of PCP, specialists, and referrers, that include at least the following:

       o Define agreed upon service standards for referrals (information sent; turnaround time from referral to assessment; feedback to referrer).

- o Design and adopt standardized referral assessment forms and workflows.
- o Design and adopt standardized symptom management assessment forms, clinical pathways, and workflows.
- o Define and agree upon which service has primary responsibility for specific issues, e.g.:
  - − management of symptoms; is specialty PC to primarily manage or function as consultant and make recommendations to PCP?
  - − performance of assessments; which ones?
  - − referral to services to meet needs as they are identified.
- iii. Identify funding mechanism/incentives for participation with the Hawai'i Health Information Exchange (HHIE) to enhance transfer of standardized medical information to support both referrals and co-management.

c. **Develop capability for specialty PC programs and services to reach referring providers/patient populations.**
   i. Perform mapping assessment to identify current capabilities for telemedicine across geographic locations for both PCP and specialist PC, to include connectivity and relative comfort of providers in providing care this way.
   ii. Develop strategies and workflow that leverage the use of virtual visit capabilities in ways that will be acceptable to patients.
      - o For example, telemedicine joint-visits between geographic locations with specialty capacity and PCP locations with unmet need/demand is an effective strategy to manage small, scattered population that wouldn't support a dedicated specialty PC service.
      - o Advantages: overcomes patient resistance to telemedicine/telehealth, as patient remains local in PCP office; more cost effective to pay both providers for that visit than travel; education/mentoring of PCP happens as a collateral benefit thereby enhancing the "hub and spoke" model by using locations that have resources and expertise to be a hub for many locations.
   iii. Identify funding mechanisms/incentives to support practices to build these telehealth capabilities, where needed.

d. **Enhance JEDI capabilities (policies, structures, and processes) as an intentional area of focus.**
   i. Create standards for translation of community and patient-facing materials, to include specified languages based on populations served, and using best practices in health literacy.
   ii. Create standards for interpreter availability with an emphasis on special training in supporting serious illness conversations.
   iii. Create integrative models of care to incorporate traditional health practices.

e. **Identify funding to support upfront investment in administrative function, supporting specialty PC in meeting new Benefit requirements** (e.g., IT capabilities; updating billing system; robust case management system).

Build and enhance palliative care and JEDI competencies across the expanded team.

Foundational to begin	Necessary to expand to vulnerable populations	Optimization/Enhancements		Build and enhance palliative care and JEDI competencies across the expanded team
x			a	Enhance **primary PC competencies of mid-career** professionals in non-PC settings, caring for people with serious illness (e.g., PCP, med specialties)
	x		b	**Map current PC educational resources** - and those being planned.
	x		c	Create a **path to interprofessional Palliative Care Certification**
	x		d	Enhance **JEDI competencies** (education, skills, mentoring, and diversify sources of information/perspectives represented) as an intentional area of focus
		x	e	Develop **central hub of PC educational resources**, to be accessed by PC community **and** by others caring for people with serious illness
		x	f	Support enhancement of **specialty PC competencies**
		x	g	Attend to the **"bridge"** between education and competency
		x	h	Integrate primary PC principles into **pre-professional curricula** required in early training of all disciplines that incorporate PC education and core skills , appropriate to role

a. **Enhance primary PC competencies of mid-career professionals in non-PC settings, caring for people with serious illness (e.g., PCP, med specialties).**

    i. Define primary PC competencies required, by discipline.

    ii. Identify currently available resources focused on "primary PC competencies," by target (i.e., discipline), content, and by type (in-person vs. self-directed vs. remote/online).

    iii. Identify and prioritize gaps in resources; create programs to fill the high priority gaps.

    iv. Disseminate broadly, with emphasis on mid-career professionals.

b. **Map current PC educational resources – and those being planned.**

    i. Develop taxonomy for the depth of education/knowledge required for each discipline/role - INCLUDING those in non-PC fields.

    ii. Map the educational resources by target for the education (i.e., discipline), content of the education, and by type of education (in-person vs. self-directed vs. remote/online).

    iii. Identify and prioritize gaps.

c. **Create a path to Interprofessional Palliative Care Certification.**

    i. Create path to allow prescribers who are focused on practice of specialty PC to attest to pathway toward Board certification.

    ii. Create path to allow similar attestation for non-prescribers on the specialty PC team on a path toward PC certification specific to their role.

d. **Enhance JEDI competencies (education, skills, mentoring, and diversify sources of information/perspectives represented) as an intentional area of focus.**

    i. Weave through all activities below as a standard for all education.

e. **Develop central hub of PC educational resources, to be accessed by PC community and by others caring for people with serious illness.**

       i.   Provide training and real-time mentoring and support.

       ii.   Ensure resources remain current, evidence based, encourage best practices, and stay active/useful/available across the state.

      iii.   Hub charged with seeking solutions to ongoing inequities or challenges to accessibility of educational resources.

f. **Support and incent enhancement of specialty PC competencies.**

       i.   Focus on supporting mid-career professionals transitioning to practice on specialty PC teams.

       ii.   Disseminate and make available broadly.

g. **Attend to the "bridge" between education and competency.**

       i.   Specify the domains of "what/who/how/when."
- What education is needed, for whom, how and when will it be delivered relative to learner's need to know the skill.
- Tailor scope of content to the roles, recognizing that different roles need different skills and content.

       ii.   Integrate the support/tools/workflows that will be used in practice into all education, specific to the learner's role, to enable putting the new knowledge and skills into practice. Link the training to the role and the tools they will use in their workflow.

      iii.   Integrate resources for reinforcement of the education to help gain confidence and competence, as PC education is put into practice, e.g., broad-based virtual learning with hub/spoke clinical mentorships.

h. **Integrate primary PC principles into pre-professional curricula required in early training of all disciplines** (MD, SW, RN, Chaplain, CHW, interpreters, etc.) **that incorporate PC education and core skills, appropriate to role.**

       i.   Move education about PC upstream into pre-professional education.
- ALL disciplines will require base knowledge (e.g., advantages of PC and what it offers; how to recognize patient who would benefit) and skills (e.g., communication skills training for shared decision making, goals of care, advance care planning).
- CLINICAL disciplines require additional base knowledge (e.g., pain and symptom assessment; how to do a PC assessment, how to screen and refer, etc.).

Limitations

This report represents only the perspectives of those that participated through the surveys, interviews, and focus groups, along with the insights and perspectives of the Steering Committee, Advisory Committee, and consultants. This report is not intended to be representative of the state of Hawaiʻi nor of the stakeholder groups included in our data collection processes. Thus, results of this report should be interpreted prudently. The aim was to identify opportunities to improve palliative care communication and provision across the state, and therefore, focused on identifying gaps and opportunities. It was beyond the scope of this project to highlight the myriad of current programs, efforts, and resources currently focusing on expanding palliative care across the state of Hawaiʻi. Implementation of these recommendations will need to consider and coordinate with existing work in the arena of palliative care.

ATTACHMENT 1

Membership of Steering Committee, Expert Advisors, and Advisory Council

Steering Committee Members

- **Rae Seitz**, MD, CEO, Hui Pohala
  Hui Pohala is a growing coalition of diverse stakeholders working to improve access to high-quality palliative care throughout Hawai'i. https://huipohala.org/

- **Jeannette Koijane**, MPH, Executive Director, Kōkua Mau
  Kōkua Mau is a statewide movement to improve care for those with serious illness and their loved ones. https://kokuamau.org/about/key-staff/

- **Sheri Daniels**, EdD, Executive Director, Papa Ola Lōkahi
  Papa Ola Lōkahi's mission is to improve the health status and wellbeing of Native Hawaiians and others by advocating for, initiating, and maintaining culturally appropriate strategic actions aimed at improving the physical, mental, and spiritual health of Native Hawaiians and their 'ohana (families) and empowering them to determine their own destinies. http://www.papaolalokahi.org/

- **Susan Enguidanos**, PhD, Associate Professor of Gerontology, University of Southern California
  Susan conducts research in the field of palliative care, including home-based models and has conducted extensive research in investigating ethnic variation in access to and use of care. Susan led the development of public and provider messaging, working primarily with Kōkua Mau to conduct individual interviews and focus groups to develop communication approaches and effective messaging to improve the access to care for those with serious illness. https://gero.usc.edu/faculty/enguidanos/

- **Stephanie Anderson**, DNP, Executive Director, Respecting Choices
- **Carole Montgomery**, MD, Executive Medical Director, Respecting Choices
- **Kathleen Ziemba**, LCSW, Director, Program Operations, Respecting Choices
  Respecting Choices achieves their mission by working directly with healthcare and community organizations to redesign systems, so people get care tailored to what matters most to them. In addition to leading the overall project, Respecting Choices led the provider and community-based organizational workforce assessments of the capacity, infrastructure, and competencies with a goal of expanding access to high-quality palliative care in the state of Hawai'i. https://respectingchoices.org/about-us/respecting-choices-missionvision/

- **Joy Soares**, Program Specialist V: Policy and Program Development Office, Med-QUEST Division, State of Hawai'i Department of Human Services
  The State of Hawai'i Med-QUEST Division (MQD) provides eligible low-income adults and children access to health and medical coverage through managed care plans. https://humanservices.hawaii.gov/mqd/

Subject Matter Experts/Panel of Advisors

- **Torrie Fields**, MPH, C-TAC, https://thectac.org/

- **Shirley Otis-Green**, MSW, MA, ACSW, LCSW, OSW-CE, FNAP, FAOSW, Collaborative Caring, http://collaborativecaring.net/

- **Kathleen Kerr**, BA, Transforming Care Partners, https://www.transformingcarepartners.com/

- **Brynn Bowman**, MPA, Chief Executive Officer of the Center to Advance Palliative Care (CAPC) https://www.capc.org/

- **Allison Silvers**, MBA, Chief Health Care Transformation Officer, Center to Advance Palliative Care, https://www.capc.org/about/leadership-and-capc-team/allison-silvers/

Advisory Council Members

- **Annie Chen**, MD, Hawaiʻi Pacific Health Medical Group, Medical Director, Palliative Care, Kapiʻolani Medical Center

- **Kapono Chong-Hanssen**, MD, Medical Director, Hoʻola Lahui Hawaiʻi

- **Merlita Compton**, MPH, Director Elder Care, Kōkua Kalihi Valley

- **Sheri Daniels**, EdD, Executive Director, Papa Ola Lokahi

- **Michael Duick**, MD, Medical Director, Mālama Ola

- **Daniel Fischberg**, MD, PhD, FAAHPM, Queen's Medical Center, Palliative Care

- **Sulma Gandhi**, DrBA, MSc, Hawaiʻi Health Program Officer, Stupski Foundation

- **Brenda Ho**, RN, MS, CEO, Hawaiʻi Care Choices

- **Kimberly Kobayashi**, Program Manager, Community First Hawaiʻi

- **Jeannette Koijane**, MPH, Executive Director, Kōkua Mau

- **Wes Lo**, CEO, Ohana Pacific Health

- **Ken Nakamura**, MC, Division Chief, Neo/Perinatal Specialists, Kapiolani Medical Center

- **Rae Seitz**, MD, CEO, Hui Pohala

- **Ai Tanaka**, Caregiver Perspective, Senior Business Partner, Hawaiʻi Medical Service Association

- **Mia Taylor**, MSN, FNP-BC, APRN-Rx, Director, Community and Post-Acute Care Services, The Queen's Health Systems

- **Lorrie Wong**, PhD, RN, CHSE-A, Interim Associate Dean, University of Hawaiʻi School of Nursing

- **Stephanie Anderson**, DNP, Executive Director, Respecting Choices, and Project Director

- **Kathleen Ziemba**, MSW, LCSW, Director, Program Operations, Respecting Choices, and Project Team Member

ATTACHMENT 2

List of Organizations Engaged in Onsite Visits, Surveys, Focus Groups, and/or Interviews

Through the focus groups, individual interviews, surveys, and onsite visit, we sought a variety of perspectives, and engaged diverse participation for both adult and pediatric individuals living with serious illness across many islands, including Hawaiʻi, Kauaʻi, Lānaʻi, Maui, Molokaʻi, and Oʻahu. Individuals represented these groups:

- People living with serious illness/patients
- Caregivers of people living with serious illness
- Spiritual and Faith-based Groups
- Micronesian and Samoan communities
- Native Hawaiian Physician Group
- Native Hawaiian Health Centers
- Hawaiʻi Primary Care Association/Federally Qualified Health Centers
- Community Health Workers
- Community Based Organizations (e.g., social service organizations)
- Home Health Providers
- Residential Care Providers
- Pediatric Physicians
- Primary Care Settings
- Medical Specialties
- Emergency Physicians
- Care Managers/Certified Medical Administrative Assistants
- Palliative Care and Hospice Organizations
- Health Plan Care Coordinator Teams
- Educators
- Elderly Affairs
- Long Term Care, Skilled Nursing Facilities, Assisted Living Facilities
- Advisory Council

Participants included individuals from the following organizations or groups:

People living with serious illness	
Participants	Community/Island(s)
Caregivers of family members living with serious illness	Hawaiʻi Island, Oʻahu
People living with serious illness	Hawaiʻi Island, Kauaʻi, Maui, Oʻahu

Spiritual and Faith Based Organizations	
Role or Organization Name	Community/Island(s) Served
Spiritual counselor	Hilo
Hongpa Hongwanji Buddhist Temple	Kona, Hawaiʻi Island
Oʻahu Jewish Community	Oʻahu
Pacific Health ministries	State-wide
Oʻahu Professional Chaplains	Oʻahu

Native Hawaiian Health	
Organization Name	Community/Island(s) Served
ʻAhahui o nā Kauka, Association of Native Hawaiian Physicians	State-wide
Ke Ola Mamo	Oʻahu
Hui Mālama Ola Nā ʻŌiwi	Hilo
Nā Puʻuwai	Molokaʻi, Lānaʻi
Hui No Ke Ola Pono	Maui
Kula No Nā Poʻe Hawaiʻi (CBO serving Native Hawaiian Homesteads)	Oʻahu

Federally Qualified Health Centers and other Health Centers	
Organization Name	Community/Island(s) Served
Hawaiʻi Primary Care Association	State-wide
Hoʻōla Lāhui Hawaiʻi Kauaʻi Community Health Center**	Kauaʻi
Kōkua Kalihi Valley Comprehensive Family Services	Oʻahu
Waimānalo Health Center	Oʻahu
Queen Emma Clinics	Oʻahu

**Also a Native Hawaiian Health System

Community Based Organizations	
Organization Name	Community/Island(s) Served
The Queen's Post-Acute and Community Network	Hawaiʻi Island, Kauaʻi, Molokaʻi, Oʻahu
Hawaiʻi Department of Health, Executive Office on Aging	State-wide
Hawaiʻi County Office of Aging	Hawaiʻi Island
Community First	Hilo, Hawaiʻi Island
East Hawaiʻi I.P.A. dba Big Island Docs	Hawaiʻi Island
Kaʻū Rural Health Community Association, Inc.	Kaʻū, Hawaiʻi Island
I Ola Lahui Behavioral Health Services	Oʻahu

Home Health Care, Senior Care, and Long-Term Care	
Organization Name	**Community/Island(s) Served**
Bayada Home Health	Hawaiʻi Island, Kauaʻi, Maui, Oʻahu
Attention Plus Care, Home Health	Oʻahu
CareResource Hawaiʻi	Hawaiʻi Island, Molokaʻi, Oʻahu
Ohana Pacific Health Home Health Care and Long-Term Care	Hawaiʻi Island, Kauaʻi, Maui, Oʻahu
Life Care Center of Kona	Kona, Hawaiʻi Island
Ohana Case Management (residential care management)	Oʻahu
Healthcare Association of Hawaiʻi, leadership committees for Home Health and for Long Term Care	State-wide
Hale Mohalu (senior housing)	Oʻahu

Pediatrics	
Organization Name	**Community/Island(s) Served**
Hawaiʻi Pacific Health, Kapiolani Medical Center for Women and Children	State-wide

Healthcare Systems	
Organization Name	**Community/Island(s) Served**
Hawaiʻi Permanente Medical Group, Department of Primary Care	Hawaiʻi Island, Kauaʻi, Maui, Oʻahu
Adventist Health Castle	Oʻahu
The Queen's Health System, Department of Medical Specialties	State-wide
The Queen's Health System, Department of Hematology/Oncology	State-wide
The Queen's Health System, Home Based Primary Care (House Calls Program)	Oʻahu
Hawaiʻi Pacific Health, Wilcox Medical Center	Kauaʻi
Queens North Hawaiʻi Community Hospital Cancer Center	Hawaiʻi Island
VA Pacific Islands Health Care System	State-wide
Hawaiʻi Health Systems Corporation	State-wide
Hawaiʻi Emergency Physician Agency	State-wide

Palliative Care Providers	
Organization Name	**Community/Island(s) Served**
Hawaiʻi Care Choices	Hilo, Hawaiʻi Island
North Hawaiʻi Hospice	North Hawaiʻi
Hospice of Kona	Kona, Hawaiʻi Island
Kauaʻi Hospice	Kauaʻi
Hospice Maui	Maui, Molokaʻl, Lānaʻi
Islands Hospice	Maui, Oʻahu
The Queen's Medical Center West, Inpatient Palliative Care	Oʻahu
The Queen's Health System, Department of Palliative Care	Oʻahu
Mālama Ola Health Services	Oʻahu
Bristol Hospice Hawaiʻi LLC	Oʻahu
Navian Hawaiʻi	Oʻahu
St. Francis Hospice	Oʻahu

Health Plan Care Coordinators	
Organization Name	**Community/Island(s) Served**
Hawaiʻi Medical Service Association (HMSA)	State-wide
Ohana Health Plan	State-wide
AlohaCare	State-wide
United Health Care	State-wide
UHA Health Insurance	State-wide

Educators	
Organization Name	**Community/Island(s) Served**
Hawaiʻi Island Family Medicine Residency	Hawaiʻi Island
Chaminade University	State-wide
John A. Burns School of Medicine, Departments of Family Medicine and Geriatrics	State-wide
Hawaiʻi/Pacific Basin Area Health Education Center (AHEC)	State-wide
Hawaiʻi Interprofessional Education (HIPE)	State-wide

ATTACHMENT 3

Methods, Detailed Description

Methods (*Communication and Messaging*)

A variety of methods was used to recruit three samples (patients/caregivers, community-based palliative care teams, and physicians and nurse practitioners).

- **Patient/caregivers:** The budget prohibited a representative sample of the Hawaiʻi population. However, a concerted effort was made to engage a wide range of people from diverse backgrounds and from places throughout Oʻahu and Hawaiʻi Island. Individuals were randomly approached by the interviewers at community locations including healthcare clinics (through previous arrangement), shopping centers, and laundromats. (**Note:** A small portion on islands outside of Oʻahu and Hawaiʻi Island were interviewed by telephone.)

  Survey Development. The survey was developed using a combination of existing measures and questions developed specifically for this survey. Modified questions from the Health and Retirement Survey on advance care planning, advance directives, and healthcare proxies were used. In addition, questions about palliative care knowledge were taken from the Health Information National Trends Survey 5, Cycle 2. The remainder of the questions were developed by the study team and reviewed by palliative care experts including physicians, a social worker, educators, and policy makers.

  Eligibility Criteria. Those eligible to participate in the survey included individuals with a chronic or serious medical condition or someone caring for a person with a chronic or serious medical condition (e.g., cancer, COPD/lung disease, heart disease, liver disease, kidney disease), and who had Med-QUEST benefits (or "patient" had Med-QUEST).

- **Community-based palliative care teams:** All current providers of CBPC across the Hawaiian Islands were identified. Kōkua Mau and Hui Pohala provided introductory emails to each of the CBPC agencies. Each agency was then contacted to schedule a focus group. To note, at the time recruitment of agencies began, Hawaiʻi experienced another surge in COVID-19 cases, hampering the ability to engage all teams.

  CBPC directors were asked to invite team members who were involved in community and physician education and outreach and inpatient enrollment/engagement.

  Focus Group Protocol and Implementation. A focus group protocol used in a previous study to understand challenges in patient enrollment challenges/facilitators experienced by home-based palliative care providers was adapted (Enguidanos et al., 2022). The protocol was then reviewed by the study team and palliative care experts including physicians, educators, and policy makers. Due to the surge in COVID-19 experienced in Hawaiʻi during the time of the focus groups, the focus groups were conducted using an online meeting platform. Participants joined the meeting from either their individual locations or as a group gathered at the agency.

- **Physicians and Nurses:** A variety of efforts were used to recruit a random set of respondents for this interview, especially reaching people who were not currently providing PC or hospice services. First, a list of healthcare providers that offered care to Med-QUEST patients was obtained, and

direct outreach to each occurred. Next, the directors of FQHCs were contacted and asked to send email invitations to their providers for participation in the interview. Working in partnership, Kōkua Mau reached out to primary care physicians across the island. Physicians that participated in the engagement for workforce (described below), and who were not experienced palliative care providers, were also contacted to either participate in the interview or reach out to their colleagues. All healthcare providers were interviewed via telephone.

Interview Protocol. An interview protocol used in a previous study to understand physician perspectives on palliative care referral was adapted (Enguidanos et al., 2022). The protocol was then reviewed by the study team and palliative care experts including physicians, educators, and policy makers.

Analysis. For quantitative data frequencies, cross tabulations and regression analysis were run to understand the relationship between the responses and the demographics of the participants. For qualitative data, two evaluators independently reviewed the transcripts and identified primary themes falling under each of the thematic categories that structured the interview/focus group protocol. Evaluators met, discussed the themes, and reached 98% agreement on themes.

Methods (*Capacity, Capabilities, and Competency*)

Several methods were used to engage a wide range of types of organizations and individuals to participate in both an electronically administered survey, as well as facilitated focus groups and interviews. The intent was to capture the perspectives of current/future needs across the many different types of organizations that are involved in caring for, and providing services to, individuals living with serious illness (adults and pediatrics).

- **Introductory meetings**, conducted in-person from May 16 – May 20, 2022. Partnering with Kōkua Mau and Hui Pohala in Hawaiʻi to provide introductory emails, they also facilitated scheduling of these in-person meetings. The purpose of these meetings was to introduce the planning project, solicit input on "who else" would be important to engage, and to garner interest in participating with the planned survey and focus groups. Conversations included discussions of current state and future opportunities. A variety of virtual meetings occurred later, to follow-up on additional participants that were suggested during the onsite meetings.

- **Survey Methods**

  Survey Development. The survey, delivered electronically, was developed by building on previous assessments and the framework for palliative care standards. The intent of the survey was to gather objective information across organizational types, to be explored further in subsequent facilitated focus groups.

  Survey Respondents. Surveys were sent via email by members of the Steering Committee who live and work in Hawaiʻi, with a two-minute video of introduction/request to complete the survey, and an attached two-page description of the project. A link to access the survey in Qualtrics was within the body of the email. Of the 105 surveys sent, the response rate was 47%, and included respondents from the following subgroups, representing the following islands: (Hawaiʻi Island, Kauaʻi, Lānaʻi, Maui, Molokaʻi, and Oʻahu)
  - o Palliative Care and Hospice Organizations
  - o Native Hawaiian Health Centers
  - o Federally Qualified Health Centers
  - o Specialty care providers/Hospital-based services
  - o Community based organizations

- o Home Health/Home Care agencies
- o Residential settings/Residential Care
- o Cultural or Faith-based Organizations

Survey Analysis. For quantitative data, frequencies, and cross tabulations were run to understand the relationship between the responses and the service-type of the participants. For qualitative data, two evaluators independently reviewed the transcripts and identified primary themes falling under each of the thematic categories. Evaluators met, discussed the themes, and reached agreement on themes.

- **Focus Group and Interview Methods**

Focus Group Determination. Focus groups were determined based on type of services provided across the state and included many of the survey participants in addition to others as recommended by Steering Committee and Advisory Council members. Overall, 14 focus groups were held, in addition to five individual interviews conducted due to inability to attend a focus group. A total of 62 individuals participated. Focus group types were as follows:
  - o Medical Specialties
  - o Primary Care Providers
  - o Care Managers/Certified Medical Administrative Assistants
  - o Hawaiʻi Primary Care Association/Federally Qualified Health Centers
  - o Caregivers
  - o Native Hawaiian Physician Group
  - o Faith/Spiritual Groups
  - o Home Health Providers
  - o Health Plan Care Coordinator Teams
  - o Pediatric Physicians
  - o Emergency Physicians
  - o Educators
  - o Community Health Workers
  - o Advisory Council

Focus Group and Interview Protocol and Implementation. Focus groups were conducted using an online meeting platform, facilitated by one project lead, and another project participant who co-facilitated and took notes for later analysis. Focus group protocols were developed for adult and pediatric providers, to understand challenges in current and future services for individuals living with serious illness, in the domains of capacity, capabilities, and competency. The protocol was then adapted specific to the focus group areas of content expertise.

Focus Group Analysis. For qualitative data, two evaluators independently reviewed the transcripts and identified primary themes falling under each of the thematic categories that structured the interview/focus group protocol. Evaluators then met, discussed the themes, and reached agreement on themes and any specific recommendations that were made by focus group participants.

The themes from each of the activities described above were then reviewed in aggregate and summarized into overarching themes and reviewed by Steering Committee and Advisory Council for feedback. After integrating feedback, the themes were then distilled into recommendations in the areas of Messaging and Communication, Capacity, Capabilities, and Competencies (as defined above).

ATTACHMENT 4

List of Summary Themes

Communication and Messaging Themes

A. **Healthcare provider** lack of palliative care knowledge (Specialist, PCP, RNP, CM, etc.)

B. **Healthcare provider** lack of knowledge on how to communicate with patient about palliative care (Specialist, PCP, RNP, CM, etc.)

C. **Interpreters** lack of palliative care knowledge

D. **Patient/Caregiver** lack of palliative care knowledge

E. **Community** lack of palliative care knowledge

Capacity Themes

A. **Lack of resources:** Consistent theme around lack of resources – across disciplines and specialties

B. **Staff recruitment and retention is challenging**

C. **Lack of capacity to make referrals:** Lack of time, workflow, and space for conversations

D. **There is a "community of services"** involved with the serious illness population currently

E. **Conflation of hospice and palliative care** impacts current and future capacity

Capability Themes (structures and processes)

A. **Virtual visits:** Potential to increase use of telephonic and virtual capabilities for all services

B. **Transportation**: Lack of transportation creates barriers to access to PC or specialist

C. **Transitions of care:** Not enough attention to what happens when patients transition out of the hospital and coordination of services to support caregivers

D. **Infrastructure requirements for new Benefit:** Many questions about what changes in infrastructure and processes will be needed to access and deliver on this new Benefit

E. **Interpretive services:** Use of interpreters and/or availability of bilingual staff inconsistent and appeared lacking

F. **Transfer of medical information and communication between providers** is inadequate and inefficient

G. **Challenging to identify appropriate patients,** with expressed desire for automation

H. **Lack of clear roles and responsibilities,** between health plan and provider organization, and between primary care and specialty PC

I. **Challenging to match available services to patients' needs across communities**

Competency Themes

A. **Broad lack of understanding of palliative care** (what it is and how to talk about it) creates barriers to referrals

B. **Symptom management**, especially for pain and in patients with substance use disorder, was an identified opportunity for improvement across the healthcare field, including within PC

C. **Education** currently aimed at emphasis on knowledge, not skills; training offered but isn't integrated into role or workflow

D. **General lack of assessments** being done, including primary assessments (for referrals and eligibility for PC) and secondary assessment (for care planning/unmet needs, e.g., symptoms, spiritual distress, social determinants of health (SDOH)

F. **Bias and culturally responsive care were significant issues brought forth;** trust issues definitely impact whether referral accepted/acted on by patient

G. **Challenge to attain and maintain competence** if the learner doesn't have a chance to use and grow their new skills

E. **Non-provider roles on the team are important**, and the requisite competencies to collaborate and function as a team are unique