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# *SURVIVORSHIP SERVICES AT HAWAI‘I COMMISSION ON CANCER (COC) ACCREDITED SITES*

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**THOMPSON SCHOOL**

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# Introduction

*The Commission on Cancer (CoC) is a program of the American College of Surgeons that sets standards for optimal cancer care and recognizes programs that meet these standards.*

## CoC Accreditation

The CoC accreditation is a three-year accreditation with requirements for annual reviews for specific standards across the “full continuum of cancer—from prevention to survivorship and end of life care—while addressing both survival and quality of life.”<sup>1(piv)</sup>

Currently there are eight cancer programs in Hawai‘i accredited by the CoC:

- Kaiser Foundation Hospital (Moanalua)
- Kapi‘olani Medical Center for Women and Children
- Kuakini Medical Center
- Pali Momi Medical Center
- Queen’s Medical Center (Punchbowl)
- Straub Clinic and Hospital
- Tripler Army Medical Center
- Wilcox Memorial Hospital

## CoC Survivorship Standards

In 2020, the CoC released new accreditation standards, which included changes to the survivorship standard among other changes. Whereas the 2016 guidelines included Standard 3.3 for Survivorship Care Plans (SCP) with treatment summaries to be administered to eligible survivors within 6 months after completing treatment, and within one year of cancer diagnosis,<sup>2</sup> the 2020 guidelines no longer require SCP. Instead, Standard 4.8 requires a Survivorship Program, with a program coordinator and multidisciplinary team with the duties of developing and documenting at least three survivorship services for cancer survivors annually, one of which can be an SCP. Other types of services include screening programs for cancer recurrence, screening for new cancers, seminars for survivors, rehabilitation services, nutritional services, psychological support

services, support groups, formal referrals to specialists (e.g., cardiology, pulmonary, fertility counseling, sexual dysfunction services), financial support services, and physical activity programs.<sup>1</sup> Services can be offered either onsite or through referrals to external resources at other facilities or in the community.

## Hawai‘i Comprehensive Cancer Coalition (HCCC) Quality of Life Action Team

The Hawai‘i State Department of Health’s (HDOH) Comprehensive Cancer Control Program convenes communities and partners with the goal of reducing the burden of cancer in Hawai‘i.<sup>3</sup> Toward this effort, the HDOH operates the HCCC, under which there are four action teams that convene around the following areas: prevention, early detection, equitable access to care, and quality of life.<sup>4</sup> The HCCC’s Quality of Life Action Team comprises cancer survivors, caregiver advocates, and representatives from the HDOH, UH Cancer Center, and various healthcare systems. Members collaborate to address issues that affect the lives of cancer survivors and others battling the effects of cancer. In recent years, their focus has been on survivorship supports and services.

## Study Aim

The HDOH Comprehensive Cancer Control Program and HCCC Quality of Life Action Team sought to understand the landscape of survivorship services in Hawai‘i and the gaps and challenges that exist. HDOH contracted the Healthy Hawai‘i Initiative Evaluation Team of the University of Hawai‘i’s Thompson School of Social Work and Public Health to conduct interviews with representatives from each of the eight CoC sites about their Survivorship Services and Programs.



## Methods

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In November and December of 2020, representatives from six of Hawai‘i’s eight CoC accredited sites participated in an online interview lasting between 45 and 60 minutes each. A representative from a seventh site responded to the interview questions in writing. Due to recent staffing changes, a representative of the eighth site, Wilcox, was not able to be interviewed. However, the representative from Kapi‘olani reported that all four Hawai‘i Pacific Health (HPH) sites (Kapi‘olani, Pali Momi, Straub, and Wilcox) will be accrediting under one application in 2021. Therefore, services reported by Kapi‘olani represent many of the services that will be offered across the entire HPH system and some of the services reported for accreditation by the sites individually may change as services are streamlined.

The list of CoC site key informants was provided by the HDOH Comprehensive Cancer Control Program. Key informants held various roles across the continuum of cancer care at their sites including: Chief Medical Officer, Surgeon, Nurse Practitioner, and Clinical Nurse Navigator, Cancer Committee Chair, Survivorship Program Coordinator, etc. All participating key informants were based in hospitals or clinics on O‘ahu, but one program reported

providing services to Maui patients and another reported hosting a support group on Moloka‘i.

The interview guide was developed in collaboration with the HDOH Comprehensive Cancer Control Program and the HCCC Quality of Life Action Team. Questions were designed to capture:

1. Sites' awareness of the new CoC accreditation standards for survivorship.
2. What sites' current survivorship services include.
3. The three services sites plan to offer to meet the new standard.
4. How COVID-19 has affected the survivorship services sites offer.
5. Any challenges sites have in providing survivorship services.
6. Key informant perspectives on what the greatest challenges are for cancer survivors in the state.
7. What key informants feel the HDOH Comprehensive Cancer Control Program and HCCC Quality of Life Action Team could do to better support cancer survivors in Hawai‘i.

# Differences in Survivorship Services Across CoC Sites

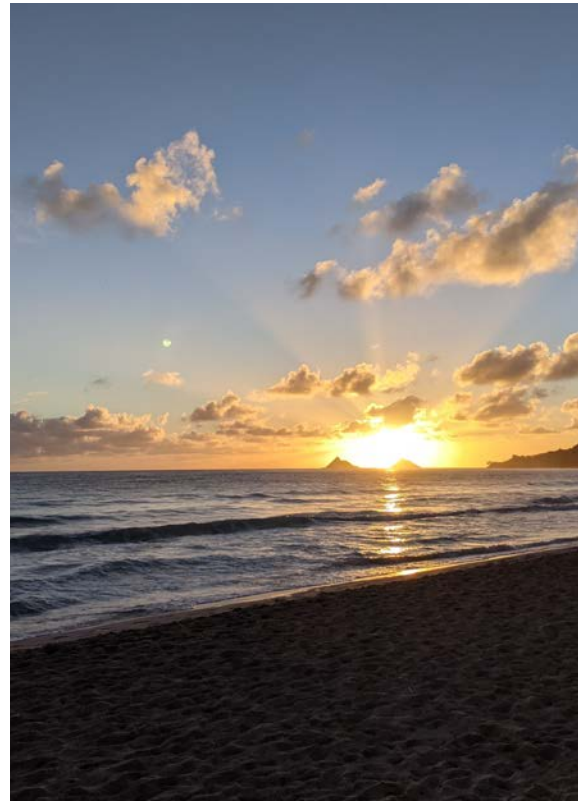
## Survivorship Services Overview

Stakeholders were asked to identify the survivorship services they offer to cancer survivors either on site or through referrals to outside resources, as well as the three services their sites are planning to offer as part of their Survivorship Program for CoC re-accreditation. Services offered by site are shared in the table on page 06.

## Differences in Survivorship Services Across Sites

Hawai'i CoC sites offer many of the survivorship services suggested by the CoC in the 2020 guidelines. However, sites vary in the resources they have allocated specifically to survivorship, how they offer survivorship services, and how they determine eligibility for services. For example, Queen's, Straub, Kapi'olani, and Pali Momi reported that they have survivorship programs or clinics with staff that are dedicated to the administration of SCP and connecting survivors with services, while Kaiser, Kuakini, and Tripler reported that their staff in their service lines or specialty clinics (e.g., surgery, radiation therapy, oncology, gynecology oncology) provide SCP and refer patients to services.

Also, all of the sites described the survivorship services their hospital offers for patients following the broad definition of survivorship that encompasses those with a new diagnosis through those needing end of life care. However, two of the sites limit eligibility in their specific survivorship programs to survivors who have completed active treatment.



***“So, we kind of promote that you're a survivor from the time of diagnosis, but depending on the situation, we use it different ways....for entering the survivorship program, or having a survivorship visit, a formal visit, it's usually at the completion of active treatment.”***

Finally, some of the sites with fewer dedicated survivorship resources are able to provide certain support services (e.g., psychological supports) to cancer survivors because they are standard resources that they offer to all patients, including survivors. Because the goal of this study was to establish the landscape of survivorship services offered by CoC accredited sites, services are summarized and categorized in this report. However, the differences between sites need to be kept in mind while reading this report.

# Survivorship Services by Site



**SURVIVORSHIP SERVICES OFFERED**



**SERVICES OFFERED FOR RE-ACCREDITATION**

SURVIVORSHIP SERVICES	HPH*/ KAPI'OLANI	PALI MOMI CLINIC**	STRAUB CLINIC	QUEEN'S	KAISER***	KUAKINI***	TRIPLER
SCP/TREATMENT SUMMARIES	✓	✓	✓	✓	✓	✓	✓
TRANSPORTATION SERVICES	✓	✓	✓	✓	✓	✓	✓
NUTRITIONAL SERVICES	✓	✓	✓	✓	✓	✓	✓
REFERRALS TO SPECIALTY CARE	✓	✓	✓	✓	✓	✓	✓
PALLIATIVE CARE	✓	✓	✓	✓	✓	✓	✓
SPIRITUAL CARE	✓	✓	✓	✓	✓	✓	✓
NEW CANCER SCREENING	✓	✓	✓	✓	✓	✓	✓
REHABILITATION SERVICES	✓	✓	✓	✓	✓	✓	✓
SUPPORT GROUPS	✓	✓	✓	✓	✓	✓	
COMPLEMENTARY/ ALTERNATIVE TREATMENTS	✓	✓	✓	✓	✓	✓	
CANCER RECURRENCE SCREENING	✓	✓	✓	✓	✓		✓
PSYCHOLOGICAL/ PSYCHIATRIC SERVICES	✓	✓	✓	✓	✓		✓
FINANCIAL SUPPORTS	✓	✓	✓	✓	✓		
SEMINARS FOR SURVIVORS/ PATIENT ED	✓	✓	✓	✓		✓	
PHYSICAL ACTIVITY PROGRAMS	✓						

\*Hawai'i Pacific Health (HPH). The HPH/Kapi'olani representative responded on behalf of both Kapi'olani and the whole HPH health system.

\*\*The survivorship services offered in Pali Momi's outpatient clinic include: SCP/treatment Summaries, transportation services, support groups, referrals to specialty care, seminars for survivors/patient education, complementary/alternative treatments, and cancer recurrence screenings.

\*\*\*Kaiser and Kuakini had not yet decided which three services they would report for their re-accreditation.

# Hawai'i Survivorship Services

## Survivorship Services Offered

All sites offer SCP and treatment summaries, transportation services, nutritional services, referrals to specialty care, palliative care, and spiritual care, new cancer screening, and rehabilitation services to cancer survivors or their patients in general. Physical activity programs, financial supports, and seminars for survivors/formal patient education are the least commonly offered services.

Sites offer **SCP and treatment summaries**, in part due to the 2016 CoC accreditation requirement for these services. In fact, one stakeholder expressed surprise that the CoC was no longer requiring SCP after sites had put so much effort into their systems to provide this service to meet the accreditation requirement. Despite the fact that SCP are no longer required for accreditation, all of the sites reported that they would be offering SCP in the future. Most of the stakeholders reported survivors utilize the SCP as a way to reflect on their cancer journey, remember what their treatment entailed, and help them to know what to expect for follow-up care. One stakeholder also felt that the SCP has benefits for the care team.

*“...[I]t really isn't about a piece of paper. It's the piece of paper that helps us connect with the patient and have a comprehensive overview with them.”*

For **transportation support and services**, sites offer taxi vouchers or referrals to the Handi-van. Many of the sites relied on the American Cancer Society's (ACS) support to offer these transportation services and expressed that ACS cut-backs during the pandemic have reduced their ability to offer transportation services.

All of the hospitals offer either **palliative care, Physician Orders for Life-Sustaining Treatment (POLST) completion, or advanced care planning** for survivors. However, not every site had a palliative care team or services as part of their specific survivorship programs due to eligibility requirements for their survivorship programs (e.g., receiving curative treatment, cancer stages 0-III). Also, some sites reported handling those services elsewhere in the continuum of care, such as in their radiology, oncology, or surgery service lines. One site reported referring out to a palliative care service organization for some survivors. Additional information about in-patient, outpatient, and in-home palliative care services offered statewide that were beyond the scope of this report can be found at <https://kokuamau.org/palliative-care/>.

All sites also offer **rehabilitation services**.

However, the type of services offered vary by site and include physical therapy (PT), occupational therapy (OT), and lymphedema treatments. Only Tripler and Queen's reported that they provide lymphedema treatments on-site.

**Cancer support groups** are offered on-site by all of the sites except Tripler. Tripler had a program for 25 years, but have not had a program for the past few years. They are currently working with ACS to partner with another hospital to try to do a joint hospital support group. Also, nearly all of the sites offer some form of **complementary or alternative treatment**, such as healing touch, medical massage, or referrals to acupuncture or naturopathic doctors. However, none of the sites reported that they offer traditional Hawaiian healing practices.

Only two of the sites, Kuakini and Tripler, did not offer **financial supports** specifically for cancer survivors. However, the Tripler representative explained that for their military population, financial supports are generally not necessary.

**“Our population is a little bit unique in that aspect that rarely are there out-of-pocket expenses for treatment. Fortunately, our beneficiaries are able to get their cancer care I would say, in-house here, for no cost. Meaning, there are no costs from insurance...no copays for any of their visits...no copays for any of their medications.”**

Only Kapi‘olani offers a **physical activity program for cancer survivors**, in partnership with the Rehab Hospital of the Pacific and the UH Cancer Center. Additional unique services reported by sites include weekend arts expression programs (Kaiser), pet therapy (Straub), and a knitted knockers prosthetics program for breast cancer (Pali Momi).

**Three Services for Accreditation**

At the time of the interview, five of the sites had decided on the three survivorship services they would offer for accreditation. However, three of these five sites are part of HPH and will be accrediting together, so services they reported separately may change as they streamline services. SCP and treatment summaries and seminars for survivors/formal patient education were the most commonly identified services that will be offered for accreditation. Other services include nutritional services, referrals to specialty care, rehabilitation services, new cancer screenings, physical activity programs, and psychological/psychiatric services.

**Justification for Three Survivorship Services**

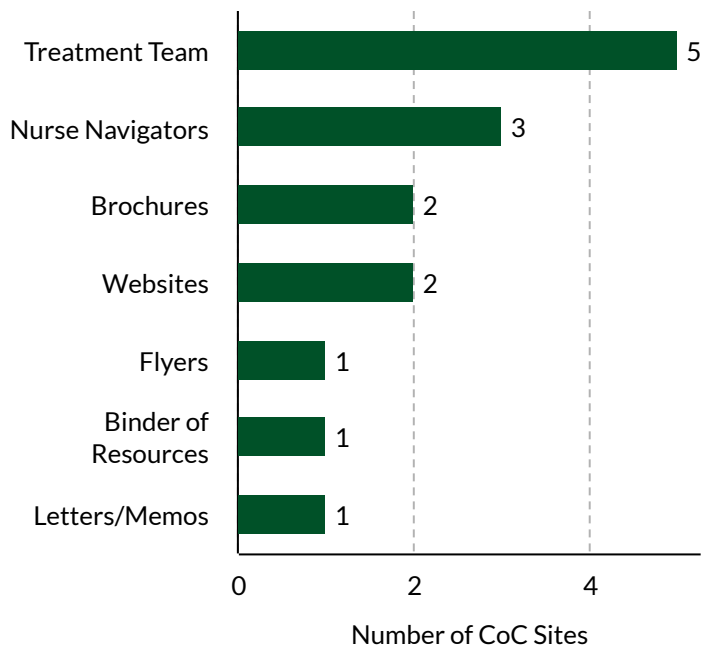
The sites that decided on the services they would offer, gave the following reasons for their selections:

- The service is already offered and done well
- They already invested resources and time into establishing the service
- It is a service they want to improve upon

**How Survivors Learn about Available Services**

Stakeholders reported multiple methods of informing survivors of the survivorship services available to them. The most common methods are through referrals by the treatment team (physicians, nurse practitioners, radiology department, etc.) or nurse navigators at time of diagnosis or during treatment visits. Brochures, websites, flyers, binders of resources, and letters or memos mailed to survivors are additional methods that sites use to notify survivors of the different survivorship services available to them.

**How Survivors Learn about Services**





# COVID-19 Impacts on Survivorship Services

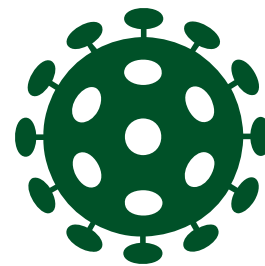
All but two of the key informants reported COVID-19 disrupted survivorship service delivery and resource availability for patients, at least temporarily. Key informants reported **fewer in-person visits and services** to support survivors (e.g., healing touch, pet therapy, physical activity programs, survivorship education events, specialty services, etc.), **cessation of support group meetings**, and **fewer transportation supports from ACS** as a result of the pandemic. One site reported that they have seen an increase in utilization of psychological support services and another reported that the pandemic has resulted in staffing shortages and delays in filling position gaps.

Nearly all sites reported that because of the pandemic, **they increased their use of telehealth to expand virtual patient support**. Sites reported going over SCP virtually and conducting other virtual visits.

While many support groups were paused with the intention of resuming when safety restrictions allowed in-person visits, some hospitals used the opportunity to start virtual support groups.

*“We've been pretty successful with using telehealth services to connect with the patients and also, provide their treatment summaries, and survivorship care plans. We have an electronic system...which is our way of communicating with patients in general, but we can provide the care plans through that.”*

One stakeholder expressed concern that we may see long-term impacts from the pandemic due to the fact that people are afraid to go to the hospital right now and so are missing their regular preventive cancer screenings (e.g., Pap tests, mammograms, etc.).



# Challenges in Providing Survivorship Services

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Hospitals were also asked about challenges they face in providing survivorship services. Across sites, stakeholders identified a **lack of funding for survivorship services and staff-capacity as key challenges**. Some stakeholders shared that they need additional staff to provide services. However, they lacked funding to support survivorship staff (e.g., patient navigators, case management) or a survivorship department. Tripler faces additional staffing challenges with military deployments and staff turnover. In general, stakeholders reported that staff time is often limited and some worry about delivering SCP and ensuring adequate patient follow-up with these staffing constraints. One stakeholder also noted that competing priorities and new initiatives make it challenging to provide survivorship services.

*“I think the bottom line is financial... We know that we lack some case management and nurse navigators, but we've advocated to try to get these positions funded. A lot of times, ultimately, there just isn't funding for positions of that nature. And so again, that's why a lot of these responsibilities to do the survivorship falls onto the physicians to complete.”*

*“...without really developing a department specifically for [survivorship services], it can be difficult to meet all the standards...that are being put forward by CoC...it will require an investment of funds in an environment where money is kind of increasingly tight for all hospitals systems.”*

One stakeholder also said that the distances and time patients need to travel to get to back into the clinic for services makes it challenging to provide comprehensive survivorship supports for all survivors.

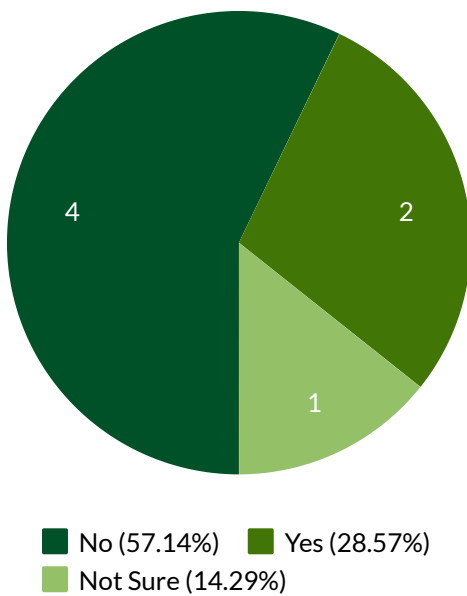
*“Travel distance. Time off work. We can provide the services for them, but some of the patients don't want to drive another hour back for the support group or through traffic trying to get home after services.”*

However, another stakeholder reported that the switch to virtual survivorship services, due to COVID-19, has helped their site to reduce this travel and time barrier, which has enabled them to connect better with their survivors.

# Improving Services within CoC Accredited Sites

Key informants were asked if they felt that the services offered by their site meet all the needs of their cancer survivors and if not, what services are needed to better support their cancer survivors.

**The majority of sites felt their services were not meeting all their cancer survivors' needs.**



Each of the sites indicated a different service was needed to better support their cancer survivors. This is likely due to the uniqueness of each of the programs and their patient populations. Additionally, even sites that reported that they were meeting their survivors' needs offered ways that improvements could be made. The services reported as needing the most improvement include:

- Patient navigation services (n=1)
- Financial supports (n=1)
- More complementary/alternative treatments (n=1)
- On-site support groups (n=1)
- Cancer-specific emotional support services (n=1)
- Transportation services not contingent on ACS (n=1)
- Transportation and lodging supports for those traveling from the neighbor islands or the Pacific Basin for treatment (n=1)
- Nutrition classes for survivors (n=1)
- A comprehensive survivorship clinic (n=1)

***“I would say that our cancer patients don't always have access to the resources they need.”***

## Biggest Needs for Hawai'i Cancer Survivors

Key informants were also asked to share their perspectives on what the biggest needs are for cancer survivors in Hawai'i. Needs identified included:

- Appropriate follow-up care
- Screening for new and recurring cancers, especially in the midst of the pandemic
- Better treatment for treatment side effects (e.g., neuropathy)
- More support groups
- Better access to education about their specific type of cancer to empower patients
- Better educational opportunities (e.g. lectures) and resources for survivors
- Better physical therapy and rehabilitation programs for survivors, especially after chemotherapy
- Nutrition classes and programs (e.g., Ornish Program) that are available and covered by insurance
- Financial supports for cancer treatment costs, airfare, and lodging
- Better diagnostic and treatment services for neighbor island survivors (e.g., PET CT Scans, clinical trials, adult bone marrow transplants)



## How HDOH and the Quality of Life Action Team Can Support Cancer Survivors in Hawai'i

Stakeholders were asked about how the HDOH Comprehensive Cancer Control Program and Quality of Life Action Team could help support cancer survivors and alleviate some of the challenges sites faced in providing survivorship services. The most common answer was **providing patient educational opportunities**. Stakeholders wanted to see patient educational forums to improve patient understanding of what survivorship is, what resources and services are available to them, and to educate them on general health topics (e.g., nutrition).

*“I don't know if the department of health could...help to kind of organize a forum by which some of these educational efforts could happen or form statewide support networks for patients.... That would be a nice way to include people from across, all kinds of islands and health systems and all that kind of stuff.”*

Stakeholders also wanted help sharing information across sites to improve patient access to resources. **Creating a statewide directory/resource hub** would enable sites to share available resources, like support groups, patient education events, or contacts for lymphedema therapists on neighbor islands.

*“...a hub where resources across the state for cancer survivors can be all pulled together. And that could be used as kind of a directory for all of us and patients.”*

Stakeholders wanted the resource hub to include both free services open to the public, as well as services to which they could refer patients.

***“If there was some network that we could access and tap into to provide patients when there's a gap with one service, that would be beneficial.... We don't necessarily always know what resources are free and available for all cancer patients. I think just having that information would be something that we could disseminate to patients.”***

All stakeholders expressed interest in **having the Quality of Life Action Team continue to host their annual survivorship conference for survivors, caregivers, and providers.** Stakeholders said the conferences were well attended and patient interest levels were high.

***“I think that [survivorship conference] would be great. And that would be something I think... some of my patients...I think they would really appreciate it.”***

One stakeholder felt it would be helpful for HDOH and the Quality of Life Action team to provide transportation services to fill gaps in accessing care brought to light by the pandemic.



### **Interest in Joining the Quality of Life Action Team**

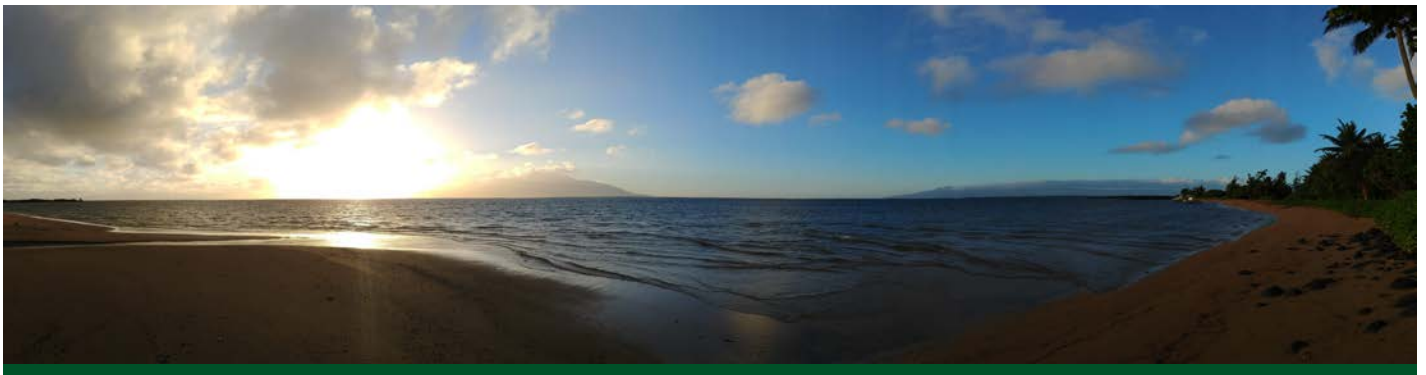
Stakeholders were asked if they would like to have a representative serve on the Quality of Life Action Team. There was general interest in being involved. However, a few stakeholders expressed they had little knowledge of what the Quality of Life Action Team and HCCC is and wanted more information before they committed to participating.

# Recommendations

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Based on the information provided by stakeholders, the Healthy Hawai'i Initiative Evaluation Team recommends the following action steps for the HDOH and Quality of Life Action Team.

- 01 Increase awareness of Quality of Life Action Team and expand membership** by reaching out to the CoC sites to inform them of meetings and activities, and to invite representatives to participate.
- 02 Hold regular collaboration opportunities** for CoC sites to share information about their services and strategies to meet accreditation.
- 03 Create a directory or hub of survivorship resources** that is accessible to survivors, caregivers, and providers.
- 04 Resume the survivorship annual conference** to educate survivors, caregivers, and providers, and collaborate with CoC sites that have held forums in the past.
- 05 Explore ways to expand transportation services for survivors** to fill gaps made apparent by COVID-19.



# Limitations

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Although we tried to get a thorough perspective of services, gaps, and needs by collecting data from each CoC accredited site and including different types of hospitals and members of the continuum of cancer care, our findings are limited. They only represent the perspectives from the 7 key informants with whom we were able to communicate. If we were to interview multiple people across the continuum of care at each site, we would have likely found additional gaps and needs.

Also, although the data in the report is summarized and categorized to share the landscape of survivorship services offered by CoC accredited sites, there are a number of differences between

sites that limit the ability to compare services across sites. The most significant differences between sites are in their survivorship resources, ways they offer services, and eligibility requirements. However, sites also have different program sizes, patient populations, accreditation program categories, and accreditation histories that make it inappropriate to compare resources between sites.

Finally, since we could not speak to a representative of Wilcox, the only CoC accredited site on the neighbor islands, the findings mainly represent O‘ahu survivorship services. As a result, this report is missing services, gaps, and challenges specific to neighbor island sites.

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# HEALTHY HAWAI'I INITIATIVE EVALUATION TEAM

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The Healthy Hawai'i Initiative Evaluation Team (HHIET) is a program within the University of Hawai'i at Mānoa's Thompson School of Social Work and Public Health. Established in 2000, as the external evaluation arm of the HDOH Healthy Hawai'i Initiative, the HHIET conducts program evaluations and research on the impact of policy, systems, and environmental change efforts to prevent chronic disease and promote health in Hawai'i. Evaluations and research cover a broad range of topics from assessing community resources for breastfeeding in the state, to evaluating the impact of the state's law requiring healthy beverages to be served with children's meals, to examining the effectiveness of electronic health record algorithms in identifying patients with undiagnosed prediabetes and diabetes. The HHIET is currently funded to conduct this work through a contract with the HDOH's Chronic Disease Prevention and Health Promotion Division.

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