REPORT TO THE THIRTY-SECOND LEGISLATURE STATE OF HAWAII 2022

PURSUANT TO ACT 2, SESSION LAWS OF HAWAII 2019 (HB2739 H.D. 1)

ESTABLISHES THE OUR CARE, OUR CHOICE ACT

Prepared by the Department of Health Office of Planning, Policy, and Program Development

July 1, 2022



Executive Summary

The information compiled in this report covers the collection period from January 1, 2021 through end of December 31, 2021.

During this reporting period, there were a total of seventy (70) qualified patients who received aid-in-dying prescriptions of which forty-nine (49) patients died. Of those patients who died, there where twenty-nine (29) patients who ingested the aid-in-dying medication. As indicated on forms collected, DDMA was the primary medication prescribed followed by DDMAPh. DDMP2 was the least prescribed medication. Compared to last years' report, DDMP2 was the most prescribed medication. There was one complication indicated whereas the prolonged time to death was approximately 12 hours.

Some form of cancer was indicated as the underlying illness for most patients who died. The status of twenty-one (21) qualified patients who received the aid-in-dying medication is unknown. An unknown patient status occurs when a follow-up form is not received by the Department. Follow-up forms are dependent upon the patient's designee to return the form to the attending physician who then mails the form to the Department as report #2.

The eligibility process from the first oral request to the date of receipt of the written prescription was an average of 41 days. The average waiting period between the first and second oral request was 32 days. Patients who received services from within large, well-networked organizations had the shortest waiting periods compared to private practicing providers in the community.

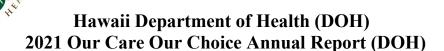
Patient Access

To meet requirements under the OCOCA, Hawaii is the only state that requires a third health care provider to conduct a mental capacity evaluation. Additionally, patients may have difficulty in finding a participating physician due to Hawaii's growing severe physician shortage statewide especially due to the pandemic which exacerbated the shortage.

According to Hawaii's 2021 Physician Workforce Report provided to the legislature annually by the University of Hawaii, the greatest shortage is primary care statewide. <u>Patients considering medical aid in dying are encouraged to start early, talk with your physician, and ensure your attending physician documents the date of your first oral request in your medical record. If the initial attending physician opts-out from participating, patients can continue the process with another attending physician.</u>

Participating Providers

New providers are highly encouraged to seek guidance from the Department or participating providers on the process. The most cited guidance document that have been helpful to physicians is the "Timeline Eligibility Process" accessible here. The Department also has a website on the OCOCA with the required provider forms and information here.



Attending Providers: There was a total of twenty-one (21) attending physicians who wrote prescriptions during this reporting period. Oahu had the largest number of participating attending physicians at fourteen (14), three (3) on Hawaii island, one (1) on Kauai, and three (3) on Maui.

Consulting Providers: There was a total of thirty-six (36) consulting providers. Oahu had the largest number of participating consulting providers at twenty-four (24), nine (9) on Hawaii island, two (2) on Kauai, and one (1) on Maui.

Counseling Providers: Counseling providers are either a psychiatrist, psychologist, or licensed clinical social worker. There was a total of sixteen (16) counseling providers who conducted mental capacity evaluations. Oahu had the largest number of participating counseling providers at nine (9), five (5) on Hawaii island, and two (2) on Maui. There were no counseling providers on Kauai.

Introduction

Act 2, Session Laws of Hawaii (SLH) 2018, authorized Hawai'i residents with a terminal illness and six (6) months or less to live may request medical-aid-in-dying prescriptions under the OCOCA. To help patients and providers understand the process required by law, the DOH launched a new page on its website where all required forms, instructions, and frequently asked questions can be accessed.

The law establishes eligibility criteria and safeguards to ensure a secure, compassionate, and patient-centered end-of-life process. There are also additional regulatory requirements to address concerns about misuse. Patients interested in seeking a prescription are encouraged to enroll in hospice.

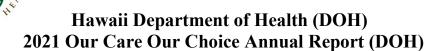
To meet eligibility criteria patients must be:

- 1. Age 18 or older an a Hawai'i resident;
- 2. Able to take the prescribed medication themselves;
- 3. Able to make two oral requests not less than 20 days apart to their attending physician;
- 4. Able to provide one written request after meeting eligibility criteria from all three (3) health care providers; and
- 5. Mentally capable to make an informed decision.

Details of the eligibility process may be accessed on the DOH's website here: http://health.hawaii.gov/opppd/ococ/

Reportable Information

The DOH collected the following reportable information during the period January 1, 2021 through December 31, 2021 (envelopes post-dated not later than December 31, 2021). Below is the reportable information:

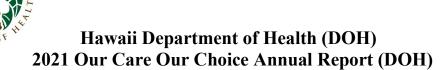


- The number of qualified patients for whom a prescription was written: <u>70</u>
- The number of known qualified patients who died each year for whom a prescription was written: <u>111</u>

2019	2020	2021
28	34	49

- The cause of death of the qualified patient(s): metastatic lung cancer, colon cancer, metastatic breast cancer, hepatocellular carcinoma, metastatic melanoma, amyotrophic lateral sclerosis, metastatic prostate cancer, esophageal carcinoma, Burkitt lymphoma stage IV with bowel involvement, multiple myeloma stage II kappa light chain inflammatory bowel disease, metastatic Merkle cell carcinoma, advanced non-squamous NSCLC, metastatic leomyosarcoma, stage IV prostate with metastases to bone, appendiceal carcinoma, end state heart disease with sick sinus syndrome/CHF/atrial fibrillation, aortic artery ulceration, end stage COPD, and anorexia abnormal weight loss enterocutaneous fistula.
- The total number of prescriptions written: <u>70</u>
- The total number of prescriptions for all years beginning with 2019: <u>137</u>
- The total number of qualified patients who died while enrolled in hospice or other similar palliative care program: <u>79</u>
- The number of known deaths in Hawaii from a prescription written per five-thousand deaths in Hawaii: <u>72</u>
- The number of attending providers who wrote prescriptions: <u>21</u>
- Location of attending providers who wrote prescriptions:

Kauai	Oahu	Maui	Hawaii Island
1	14	3	3



• Of the people who died as a result of self-administering a prescription, the individual's:

Underlying Illness	Type of	Age	Education	Race	Sex
	Insurance				
Colon Cancer	Medicare/Private	84	Not	White	Male
			indicated		
Hepatocellular	Don't know type	70	Not	Not	Not
Carcinoma	of insurance		indicated	indicated	indicated
Metastatic Breast	Medicare/Private	96	not	White	Female
Cancer			indicated		
Metastatic	Medicare/Private	78	Master's	White	Male
Melanoma			degree		
ALS	Private	59	not	Native	Male
			indicated	Hawaiian	
Hepatocellular	Don't know type	70	not	Not	Not
Carcinoma	of insurance		indicated	indicated	indicated
Metastatic Breast	Medicare/Private	96	not	White	Female
Cancer			indicated		
Esophageal	Private	61	Doctoral	White	Male
Carcinoma					
Metastatic Lung	Private	55	not	White	Female
Cancer			indicated		
Burkitt lymphoma	Medicare/Private	93	High	Asian	Male
Stage IV w/bowel			School		
involvement					
Multiple Myeloma	Medicare/Private	81	Doctoral	White	Male
stage II Kappa light					
chain,					



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inflammatory bowel					
disease, failure to					
thrive					
Metastatic Merkel	Medicare/Private	81	Bachelors	Asian	Male
Cell Carcinoma					
Esophageal Cancer	Hawaii	64	High	Hispanic,	Female
	Quest/Medicaid		School	Latino	
Complete Heart	not indicated	96	not	White	Female
Block			indicated		
Metastatic Breast	Private	60	not	White	Female
Cancer			indicated		
Metastatic Myxoid	Private	55	Bachelor	White	Male
liposarcoma					
Metastatic	Medicare/Private	75	not	Asian	Female
Leiomyosarcoma			indicated		
Stage IV prostate	Private	54	Masters	White	Male
cancer with					
metastases to bone					
Metastatic	Don't know type	68	Bachelor	Native	Male
Appendiceal	of insurance			Hawaiian,	
Carcinoma				Latino	
End stage heart	not indicated	91	High	Native	Female
disease w/Sick			School	Hawaiian	
Sinus Syndrome,					
CHF & Atrial					
Fibrillation					
Hepatocellular	not indicated	80	Masters	White	Male
Carcinoma					



Cholangiocarcinoma		86	not	White,	Female
			indicated	Asian	
Liver Cancer Stage	not indicated	82	not	Asian	Male
IV			indicated		
Metastatic	not indicated	75	Masters	Asian	Male
Pancreatic					
Carcinoma					
Prostate Cancer	not indicated	70	Masters	White	Male
Metastatic Prostate	not indicated	74	Bachelors	White,	Male
Cancer				Asian	
ALS	not indicated	71	not	Asian	female
			indicated		
End Stage COPD	not indicated	64	Some	White	female
			college		
Anorexia abnormal	not indicated	92	Masters	Pacific	Male
weight loss				Islander	
enterocutaneous					
fistula					
ALS	not indicated	81	not	White	Female
			indicated		

Community Education and Training Events

There is no budget allocated to the Department for the administration and reporting of the Our Care, Our Choice Act. The Department's role is primarily to collect and report data and provide guidance to the public. Provider forms, patient information, and reports are accessible here.

During 2021, the Department staff was invited to participate in several online webinars in collaboration with Compassion and Choices. Webinars are accessible here.

Legislative Recommendations

In closing, the DOH continues to maintain the following recommendations on the OCOCA as reported in 2019 and 2020.



- 1. Waiver of any waiting periods if the attending provider and consulting provider agree that patient death is likely prior to the end of the waiting periods.
- 2. Given access to health care providers is limited, the DOH recommends authorizing advance practice registered nurses to serve as attending providers for patients seeking medical aid in dying.

If you should have any questions regarding the report, please contact the DOH Office of Planning, Policy, and Program Development at 586-4188.