# 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.

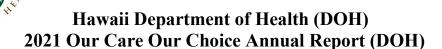
#### **Patient Access**

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. 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.

### **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 <a href="here">here</a>. The Department also has a website on the OCOCA with the required provider forms and information <a href="here">here</a>.



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.

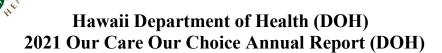
To meet eligibility criteria patients must be:

- 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:

	<b>Underlying Illness</b>	Type of	Ag	Education	Race	Sex
		Insurance	e			
1	Colon Cancer	Medicare/Private	84	Not	White	Male
				indicated		
2	Hepatocellular	Don't know type	70	Not	Not	Not
	Carcinoma	of insurance		indicated	indicated	indicated
3	Metastatic Breast	Medicare/Private	96	not	White	Female
	Cancer			indicated		
4	Metastatic	Medicare/Private	78	Master's	White	Male
	Melanoma			degree		
5	ALS	Private	59	not	Native	Male
				indicated	Hawaiian	
6	Metastatic Breast	Medicare/Private	61	H.S.	White	Female
	Cancer					
7	Esophageal	Private	61	Doctoral	White	Male
	Carcinoma					
8	Metastatic Lung	Private	55	not	White	Female
	Cancer			indicated		
9	Burkitt lymphoma	Medicare/Private	93	High	Asian	Male
	Stage IV w/bowel			School		
	involvement					
10	Multiple Myeloma	Medicare/Private	81	Doctoral	White	Male
	stage II Kappa light					
	chain, inflammatory					
	bowel disease,					
	failure to thrive					



Metastatic Merkel   Cell Carcinoma   C	2021 Our Care Our Choice Annual Report (DOH)							
Esophageal Cancer	11	Metastatic Merkel	Medicare/Private	81	Bachelors	Asian	Male	
Quest/Medicaid   School   Latino		Cell Carcinoma						
13   Complete Heart   not indicated   96   not   indicated     14   Metastatic Breast   Private   60   not   indicated     15   Metastatic Myxoid   Private   55   Bachelor   White   Male     16   Metastatic   Medicare/Private   75   not   Asian   Female     17   Stage IV prostate   Cancer with   metastases to bone     18   Metastatic   Don't know type   68   Bachelor   Native   Hawaiian     19   End stage heart   disease w/Sick Sinus   Syndrome, CHF & Atrial Fibrillation     20   Hepatocellular   Carcinoma   Carcinoma   Carcinoma     21   Cholangiocarcinoma   not indicated   86   not   White,   Female     10   indicated   Stage   Stage   Carcinoma   Not indicated   Stage   Carcinoma     21   Cholangiocarcinoma   Not indicated   Stage   Not   Male     22   Cholangiocarcinoma   Not indicated   Stage   Not   Male     24   Cholangiocarcinoma   Not indicated   Stage   Not   Male     25   Metastatic   Not indicated   Stage   Not   Male     26   Masters   White   Male     27   Cholangiocarcinoma   Not indicated   Stage   Not   Male     28   Masters   White   Male     29   Masters   White   Male     20   Masters   White   Male     21   Cholangiocarcinoma   Not indicated   Stage   Not   Masters     22   Masters   White   Male     23   Masters   White   Male     3   Masters   White   Male     4   Metastatic   Medicated   Not   Masters     4   Masters   Masters   Masters     5   Metastatic   Medicated   Not   Masters     5   Metastatic   Medicated   Not   Masters     5   Metastatic   Male   Masters     6   Masters   Masters   Masters     7   Masters   Masters   Masters     8   Masters   Masters     8   Masters   Masters     8   Masters   Masters     9   Masters     9   Masters     9   Masters     9   Masters     9	12	Esophageal Cancer	Hawaii	64	High	Hispanic,	Female	
Block  14 Metastatic Breast Cancer  15 Metastatic Myxoid liposarcoma  16 Metastatic Leiomyosarcoma  17 Stage IV prostate cancer with metastases to bone  18 Metastatic Don't know type Appendiceal Carcinoma  19 End stage heart disease w/Sick Sinus Syndrome, CHF & Atrial Fibrillation  20 Hepatocellular Carcinoma  10 Metastatic Don't indicated Native School Hepatocellular Carcinoma  10 Metastatic Don't know type of the part of insurance School Hawaiian Syndrome, CHF & Atrial Fibrillation  10 Metastatic Don't know type of the part of insurance School Hawaiian Syndrome, CHF & Atrial Fibrillation  20 Hepatocellular not indicated So Masters White Male Indicated Asian			Quest/Medicaid		School	Latino		
Metastatic Breast   Private   60   not indicated   Cancer	13	Complete Heart	not indicated	96	not	White	Female	
Cancer indicated		Block			indicated			
15   Metastatic Myxoid   Private   55   Bachelor   White   Male	14	Metastatic Breast	Private	60	not	White	Female	
liposarcoma  16 Metastatic Medicare/Private 75 not indicated  17 Stage IV prostate cancer with metastases to bone  18 Metastatic Don't know type 68 Bachelor Native Hawaiian Latino  19 End stage heart disease w/Sick Sinus Syndrome, CHF & Atrial Fibrillation  20 Hepatocellular Carcinoma  21 Cholangiocarcinoma not indicated 86 not indicated Asian    Indicated Asian   Indicated Asian   Indicated Asian   Indicated Asian   Indicated Asian   Indicated Asian   Indicated Asian   Indicated Asian   Indicated Asian   Indicated Asian   Indicated Asian   Indicated Asian   Indicated Asian   Indicated Asian   Indicated Asian   Indicated Asian   Indicated Asian   Indicated Asian   Indicated Asian   Indicated   Indicated Asian   Indicated   Indicated Asian   Indicated   Indicated   Indicated Asian   Indicated   Indic		Cancer			indicated			
Metastatic Leiomyosarcoma	15	Metastatic Myxoid	Private	55	Bachelor	White	Male	
Leiomyosarcoma indicated		liposarcoma						
17 Stage IV prostate cancer with metastases to bone  18 Metastatic Don't know type of insurance Carcinoma  19 End stage heart disease w/Sick Sinus Syndrome, CHF & Atrial Fibrillation  20 Hepatocellular Carcinoma  21 Cholangiocarcinoma not indicated 86 not indicated Asian  Private 54 Masters White Male  Bachelor Native Hawaiian Latino  Private 54 Masters White Male  Male  School Hawaiian School Hawaiian Male  Male  Torcinoma  Stage IV prostate of insurance with metastases to bone and indicated School Hawaiian white Male  Torcinoma Male  School Masters White Male	16	Metastatic	Medicare/Private	75	not	Asian	Female	
cancer with metastases to bone  18 Metastatic Appendiceal Carcinoma  19 End stage heart disease w/Sick Sinus Syndrome, CHF & Atrial Fibrillation  20 Hepatocellular Carcinoma  21 Cholangiocarcinoma  Don't know type 68 Bachelor Hawaiian Latino  Pemale High School Hawaiian School Hawaiian  Native Female School Hawaiian  Native Male School Hawaiian  Native Female Asian		Leiomyosarcoma			indicated			
metastases to bone  18 Metastatic Don't know type of the stage heart disease w/Sick Sinus Syndrome, CHF & Atrial Fibrillation  20 Hepatocellular Carcinoma  Cholangiocarcinoma Not indicated 80 Masters White Male Male School Carcinoma  Cholangiocarcinoma Not indicated 86 not White, Female indicated Asian	17	Stage IV prostate	Private	54	Masters	White	Male	
Metastatic		cancer with						
Appendiceal Carcinoma of insurance Hawaiian Latino  19 End stage heart not indicated 91 High Native Female disease w/Sick Sinus Syndrome, CHF & Atrial Fibrillation  20 Hepatocellular not indicated 80 Masters White Male Carcinoma  21 Cholangiocarcinoma not indicated 86 not white, Female indicated Asian		metastases to bone						
Carcinoma  Latino  19 End stage heart not indicated 91 High Native Female  disease w/Sick Sinus Syndrome, CHF & Atrial Fibrillation  20 Hepatocellular Carcinoma  Carcinoma  Carcinoma  Carcinoma  Latino  Hawaiian  School Hawaiian  Male  Carcinoma  Asian	18	Metastatic	Don't know type	68	Bachelor	Native	Male	
19 End stage heart disease w/Sick Sinus Syndrome, CHF & Atrial Fibrillation  20 Hepatocellular Carcinoma  21 Cholangiocarcinoma not indicated 86 not white, Female indicated Asian		Appendiceal	of insurance			Hawaiian		
disease w/Sick Sinus Syndrome, CHF & Atrial Fibrillation  20 Hepatocellular not indicated Carcinoma  21 Cholangiocarcinoma not indicated indicated Asian  School Hawaiian  Male  Asian		Carcinoma				Latino		
Syndrome, CHF & Atrial Fibrillation  20 Hepatocellular not indicated 80 Masters White Male Carcinoma  21 Cholangiocarcinoma not indicated 86 not White, Female indicated Asian	19	End stage heart	not indicated	91	High	Native	Female	
Atrial Fibrillation  20 Hepatocellular not indicated 80 Masters White Male  Carcinoma  21 Cholangiocarcinoma not indicated 86 not white, Female indicated Asian		disease w/Sick Sinus			School	Hawaiian		
20 Hepatocellular not indicated 80 Masters White Male Carcinoma 21 Cholangiocarcinoma not indicated 86 not White, Female indicated Asian		Syndrome, CHF &						
Carcinoma  21 Cholangiocarcinoma not indicated 86 not White, Female indicated Asian		Atrial Fibrillation						
21 Cholangiocarcinoma not indicated 86 not White, Female indicated Asian	20	Hepatocellular	not indicated	80	Masters	White	Male	
indicated Asian		Carcinoma						
	21	Cholangiocarcinoma	not indicated	86	not	White,	Female	
					indicated	Asian		
22 Liver Cancer Stage not indicated 82 not Asian Male	22	Liver Cancer Stage	not indicated	82	not	Asian	Male	
IV indicated		IV			indicated			



	2021 Our Care Our Choice Annuar Report (DOII)							
23	Metastatic	not indicated	75	Masters	Asian	Male		
	Pancreatic							
	Carcinoma							
24	Prostate Cancer	not indicated	70	Masters	White	Male		
25	Metastatic Prostate	not indicated	74	Bachelors	White,	Male		
	Cancer				Asian			
26	ALS	not indicated	71	not	Asian	female		
				indicated				
27	End Stage COPD	not indicated	64	Some	White	female		
				college				
28	Anorexia abnormal	not indicated	92	Masters	Pacific	Male		
	weight loss				Islander			
	enterocutaneous							
	fistula							
29	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 <u>here</u>.

During 2021, the Department staff was invited to participate in several online webinars in collaboration with Compassion and Choices. Webinars are accessible <a href="here">here</a>.

### **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.