

# REPORT TO THE THIRTY-THIRD LEGISLATURE STATE OF HAWAII

2023

Pursuant to Section 327L-14, Hawaii Revised Statutes, "Our Care, Our Choice Act," Reporting on the Number of Qualified Patients for Whom a Prescription Was Written Pursuant to Chapter 327L, and Other Required Information.

Prepared by the Department of Health

Office of Planning, Policy, and Program Development

November 27, 2023



#### **Executive Summary**

The information compiled in this report covers the collection period from January 1, 2022, through end of December 31, 2022. All data in this report come from the Attending Provider, Consulting Provider, and Counseling Provider forms required by law and received by the Department during the collection period.

During this reporting period, there were a total of sixty (60) qualified patients who received aid-in-dying prescriptions. Fifty-five (55) qualified patients died; of these 55 patients, thirty-seven (37) died due to ingesting aid-in-dying medication. Some form of cancer was indicated as the underlying illness for most patients who received aid-in-dying prescriptions. As indicated on forms collected, DDMAPh was the primary medication prescribed followed by DDMA. Compared to last years' report, DDMA was the most prescribed medication, followed by DDMAPh.

The eligibility process from the first oral request to the date of receipt of the written prescription was an average of <u>34 days</u>. The average waiting period between the first and second oral request was <u>25 days</u>.

#### **Patient Access**

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.

Further, Hawaii is the only state that requires a third health care provider to conduct a mental capacity evaluation. While the department is unable to quantify barriers to participating mental health providers for purposes of accessing OCOCA, the shortages in rural areas are well documented and include federal designations of Mental Health Care Professional Shortage Area.

### **Participating Providers**

New providers are highly encouraged to seek guidance from the Department or participating providers on the process, in particular the "Timeline Eligibility Process" accessible <u>here</u>. The Department also has a website on the OCOCA with the required provider forms and information here.

Attending Physicians: There was a total of seventeen (17) attending physicians who wrote prescriptions during this reporting period. The largest number of participating attending physicians were based on Oahu with eleven (11), followed by three (3) on Hawaii island, two (2) on Maui, one (1) on Lanai and zero (0) on Kauai and Molokai.



Consulting Physicians: There was a total of thirty-nine (39) consulting physicians. The largest number of consulting physicians were based on Oahu with twenty-six (26), followed by nine (9) on Hawaii island, four (4) on Maui, and zero (0) on Lanai, Molokai, and Kauai.

Counseling Providers: Counseling providers are either a psychiatrist, psychologist, or licensed clinical social worker. There was a total of eighteen (18) counseling providers who conducted mental capacity evaluations. Oahu had the largest number of counseling providers with fifteen (15), followed by one (1) on Hawaii island, one (1) on Lanai, one (1) on Maui, and zero (0) on Molokai and Kauai.

#### Introduction

Chapter 327L 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 and 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: <a href="http://health.hawaii.gov/opppd/ococ/">http://health.hawaii.gov/opppd/ococ/</a>

#### **Reportable Information**

The DOH collected the following reportable information during the period January 1, 2022, through December 31, 2022 (envelopes post-dated not later than December 31, 2022).

- The number of qualified patients for whom a prescription was written: <u>60</u>
- The number of known qualified patients who died from 2019-2022: **166**

2019	2020	2021	2022
28	34	49	55



• The underlying illness for fifty-five (55) qualified patients who died in 2022:

#	<b>Underlying Illness</b>	#	Underlying Illness
1	Metastatic Breast Cancer	29	Lung Cancer
2	End-Stage Renal Disease	30	Thyroid Cancer
3	Severe Infected Decubitus Ulcer	31	ALS
4	Non-Hodgkin's Lymphoma	32	Prostate Metastatic Cancer
			Cerebral Hemorrhage;
5	Multiple Myeloma	33	R side hemiplegia & aphasia
6	Colon Cancer	34	Colon Cancer
	End-stage heart disease; Recurrence		
7	of Melanoma Face/Neck	35	End-Stage COPD
8	Appendiceal Carcinoma	36	Glioblastoma Multiforme
9	Progressive Supranuclear Palsy	37	Acute Chronic Systolic Heart Failure
10	End Stage Heart Disease	38	Metastatic Lung Cancer
	Metastatic Neuroendocrine		
11	Carcinoma	39	Heart Failure & COPD
12	Amyotrophic Lateral Sclerosis	40	Adult Polyglucosan Body Disease
13	Peritoneal Carcinomatosis	41	Metastatic Prostate Cancer
			End-Stage Heart Disease/Pulmonary
14	Lung Malignancy	42	Hypertension
15	Multiple Myeloma	43	ALS
16	Idiopathic Pulmonary Fibrosis	44	Carcinosarcoma of Endometrium Metastases
17	Lung Cancer w/ Meta	45	Spinocerebellar Ataxia
18	Gallbladder Cancer	46	Prostate Cancer
20	Hypopharyngeal Cancer	48	Small Cell Lung Cancer
			Idiopathic Pulmonary Fibrosis/Non-Specific
21	Pancreatic Cancer	49	Interstitial Lung Disease
22	Brain Tumor	50	Metastatic Breast Cancer
23	Brain Cancer	51	Invasive Adenocarcinoma of the Rectum
	Metastatic Breast Cancer		
24	w/Symptomatic Brain Metastases	52	Anal Cancer
			Colon Cancer Metastasis to Liver, Lungs,
25	Renal Carcinoma	53	Peritoneum
26	ALS	54	Pancreatic Cancer
27	Gastric Carcinoma	55	Multiple System Atrophy
28	Breast Cancer		

- The total number of prescriptions written in 2022: <u>60</u>
- The total number of prescriptions written for all years from 2019 2022: **197**

2019	2020	2021	2022
30	37	70	60



- The total number of qualified patients who died while enrolled in hospice or other similar palliative care program for 2022: <u>47</u>
- The number of known deaths in Hawaii from a prescription written pursuant to this chapter per five-thousand deaths in Hawaii in 2022: 14
- The number and location of attending providers who wrote prescriptions in 2022: 17

Oahu	Hawaii Island	Maui	Lanai
11	3	2	1

• Qualified patients who died because of self-administering the aid-in-dying prescription:

	<b>Underlying Illness</b>	Type of	Age	Education	Race	Sex
		Insurance				(M/F)
1	Appendiceal Carcinoma	Medicare + Private	68	No info	Hispanic/ Latino	М
2	Metastatic Breast Cancer	Don't know type; had insurance	82	High School Diploma	White	F
3	Severe Infected Decubitus Ulcer	Medicare + Private	74	Master's Degree	White	M
4	End-stage heart disease; Recurrence of Melanoma Face/Neck	Medicare	72	No info	White	M
5	Idiopathic Pulmonary Fibrosis	Medicare + Private	65	Bachelor's Degree	White	M
6	Lung Malignancy	Medicare + Private	86	No info	White	F
7	Progressive Supranuclear Palsy	Don't know type; had insurance	70	Master's Degree	White	M
8	End Stage Heart Disease	Medicare	97	High School (9th grade only)	White	M
9	Amyotrophic Lateral Sclerosis	Don't know type; had insurance	78	Doctoral Degree	White	F
10	Multiple Myeloma	Medicare + Private + Tricare	89	Bachelor's Degree	Asian	M



11	Pancreatic Cancer	Medicare + Private	60	No info	White	M
12	End-Stage Renal Disease	Medicare	74	Bachelor's Degree	Asian	F
13	Lung Cancer	Medicare + Private	65	No info	Asian	F
14	Metastatic cancer involving lung, bone, spleen; malignant spindle cell carcinoma	Medicare	79	Bachelor's Degree	White	M
15	Lung Cancer w/ Meta	Don't know type; had insurance	79	Bachelor's Degree	Hispanic/ Latino	M
16	ALS	No Insurance	48	Bachelor's Degree	White	M
17	Peritoneal Carcinomatosis	Kaiser	75	No info	White	F
18	Brain Tumor	Medicare + Private	84	No info	Asian	M
19	ALS	Medicare + Private	65	Some College, No Degree	Pacific Islander	M
20	Prostate Metastatic Cancer	MDX Hawaii AARP	70	High School Diploma	White	M
21	Glioblastoma Multiforme	Medicare	78	No info	White	M
22	Acute Chronic Systolic Heart Failure	Hawaii Quest/Medicaid	53	High School Diploma	White	F
23	End-Stage COPD	Medicare	87	Master's Degree	Asian	M
24	Metastatic Lung Cancer	Medicare + Private	72	Associate degree	White + Native American	M
25	Metastatic Prostate Cancer	Private	63	Bachelor's Degree	Asian	M



26	Spinocerebellar Ataxia	Private	65	High School Diploma	Asian	F
27	Cerebral Hemorrhage; R side hemiplegia & aphasia	Medicare	70	Some College, No Degree	White	M
28	Metastatic Breast Cancer	Kaiser + Medicare	79	Master's Degree	White	F
29	Adult Polyglucosan Body Disease	Don't know type; had insurance	48	Bachelor's Degree	Asian; Native Hawaiian ; Pacific Islander	M
30	Prostate Cancer	Kaiser + Medicare	86	Master's Degree	White	M
31	End-Stage Heart Disease/Pulmonary Hypertension	Kaiser + Medicare	99	Master's Degree	White	М
32	Lung Cancer	Kaiser + Medicare	87	No info	No info	F
33	Multiple system atrophy	Hawaii Quest/Medicaid	58	No info	Asian	M
34	Invasive Adenocarcinoma of the Rectum	Medicare	76	Bachelor's Degree	White	F
35	ALS	Don't know type; had insurance	73	High School Diploma	White	F
36	Colon Cancer	Medicare + Private	59	High School Diploma	White	М
37	Anal Cancer	Medicare + Private	76	High School Diploma	Native Hawaiian	F



#### **Legislative Recommendations**

The Department of Health recommends the repeal of the reporting requirement under section 327L-14(d)(5), "the number of known deaths in Hawaii from a prescription written pursuant to this chapter per five-thousand deaths in Hawaii." This metric is unnecessary and reveals no substantive additional information since deaths-per-5,000 is an arbitrary rate, and since not all deaths by ingestion of medication dispensed pursuant to Chapter 327L are documented.