REPORT TO THE THIRTY-FOURTH LEGISLATURE STATE OF HAWAII

2024

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

July 1, 2024



Executive Summary

The information compiled in this report covers the collection period from January 1, 2023, through end of December 31, 2023. All data in this report come from the Attending Provider, Consulting Provider, and Counseling Provider forms required by law and received by the Department of Health (DOH) during the collection period. This report will discuss the utilization of 2023 and an update to the amendments to the law, Chapter 327L.

During this reporting period, there were a total of ninety-one (91) qualified patients who received aid-in-dying prescriptions. Seventy-six (76) qualified patients died; of these 76 patients, fifty-one (51) 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.

The eligibility process from the first oral request to the date of receipt of the written prescription was an average of <u>38 days</u>. The average waiting period between the first and second oral request was <u>24 days</u>.

Amendments to the Our Care, Our Choice Act (OCOCA) went into effect on June 1, 2023, resulting in the following changes to the law:

- Qualified Advanced Practice Registered Nurses can now act as Attending, Consulting or Mental Health Provider
- Licensed Marriage & Family Therapists (LMFTs) are now qualified Mental Health Providers
- The waiting period between a patient's first and second oral requests is now five days and can be waived if the provider determines that the patient won't survive it.

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 provider, and ensure your Attending Provider documents the date of your first oral request in your medical record. If the initial Attending Provider opts-out from participating, patients can continue the process with another Attending Provider.

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 "<u>Timeline Eligibility Process</u>." The Department also has a website with the required <u>Health Care Provider and Patient Forms</u>.



Attending Providers: An Attending Provider (physician or APRN) is a Hawaii licensed provider who is qualified by specialty or experience to make a professional diagnosis and prognosis regarding the patient's illness. There was a total of fourteen (14) Attending Providers who wrote prescriptions during this reporting period. The largest number of participating attending providers were based on Oahu with nine (9), followed by four (4) on Hawaii Island, one (1) on Kauai, zero (0) on Maui, Molokai, and Lanai.

Consulting Providers: A Consulting Provider (physician or APRN) is a Hawaii licensed provider who is qualified by specialty or experience to make a professional diagnosis and prognosis regarding the patient's illness. There was a total of fifty-six (56) Consulting Providers during this reporting period. The largest number of participating Consulting Providers were based on Oahu with thirty-seven (37), followed by nine (9) on Hawaii Island, six (6) on Kauai, four (4) on Maui, and zero (0) on Molokai and Lanai.

Counseling Providers: Counseling Providers are either a Psychiatrist, Psychologist, Licensed Clinical Social Worker (LCSW), Licensed Marriage and Family Therapist (LMFT), or Advanced Practice Registered Nurse (APRN) with a psychiatric or clinical nurse specialization. There was a total of eleven (11) Counseling Providers who conducted mental capacity evaluations during this reporting period. The largest number of participating Consulting Providers were based on Oahu with eight (8), followed by two (2) on Hawaii Island, and one (1) Hawaii-licensed provider island is undermined, and zero (0) on Kauai, Maui, Molokai, and Lanai.

Introduction

Chapter 327L authorizes Hawaii residents with a terminal illness and six (6) months or less to live to 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:

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

Details of the eligibility process may be accessed on the DOH OCOCA website.

Reportable Information

The DOH collected the following reportable information during the period January 1, 2023, through December 31, 2023 (envelopes post-dated not later than December 31, 2023).

The number of qualified patients for whom a prescription was written in 2023: 91

The number of known qualified patients who died from 2019 - 2023: **242**

2019	2020	2021	2022	2023
28	34	49	55	76

The total number of prescriptions written for all years from 2019 - 2023: **288**

2019	2020	2021	2022	2023
30	37	70	60	91

The total number of qualified patients who died while enrolled in hospice or other similar palliative care program for 2023: <u>73</u>

The number of known deaths in Hawaii from a prescription written pursuant to this chapter per five-thousand deaths in Hawaii in 2023: **20**

The number and location of Attending Providers who wrote prescriptions in 2023: 14

Oahu	Hawaii Island	Kauai
9	4	1

The underlying illness for seventy-six (76) qualified patients who died in 2023:

#	Underlying Illness	#	Underlying Illness
1	Rectal Cancer	39	Lung Cancer
2	Pancreatic Cancer	40	Severe R CVA & Resultant L Hemiplegia
3	MAI infection with progressive fibrotic interstitial lung disease	41	Metastatic Malignant Melanoma
4	Parkinson's Disease	42	Metastatic Lung Cancer
5	Liver Cancer	43	Lung Cancer
6	Head and Neck Cancer	44	Lung Cancer
7	Glioblastoma Multiforme	45	Anal Cancer
8	Breast Cancer	46	Head and Neck Cancer
9	Metastatic Melanoma	48	Recurrent Atypical Meningioma
10	Esophageal Cancer	49	Kidney Cancer
11	Lung Cancer	50	Liver Cancer
12	Pancreatic Cancer	51	Pulmonary Fibrosis, COPD



#	Underlying Illness	#	Underlying Illness
13	Lung Cancer	52	End Stage Heart Failure - Severe Aortic
	_		Stenosis
14	Pancreatic Cancer	53	Metastatic Merkel Cell Carcinoma
15	End-Stage Liver Disease	54	Severe Diabetes with end stage renal and
			vascular disease
	Pancreatic Cancer	55	Pancreatic Cancer
17	Metastatic Breast Cancer	56	Pancreatic Cancer
18	Metastatic Adenoma of the Lung	57	Cervical Carcinoma, Portal Vein
			Thrombosis
	Multiple Myeloma	58	Thyroid Cancer
21	Renal Cancer	59	Cirrhosis with End-Stage Liver Disease
			with worsening ascites
	Pancreatic Cancer	60	Metastatic Breast Cancer
23	Breast Cancer	61	Metastatic Ovarian Cancer
24	Prostate Cancer	62	Creutzfeldt-Jacob Disease
25	Pancreatic Cancer	63	Renal Cell Cancer
26	Ovarian Cancer	64	Pancreatic Cancer
27	ALS	65	Metastatic Bladder Cancer
28	DISH producing End Stage	66	Hepatocellular Carcinoma
	Cardiorespiratory Failure		
29	Multiple Myeloma	67	Metastatic Gallbladder Cancer
30	Severe Neurologic Deterioration	68	Metastatic Breast Cancer
31	Progressive Interstitial Pulmonary	69	Metastatic Breast Cancer
	Fibrosis		
	Myelodysplastic Syndrome	70	Breast Cancer
33	Breast Cancer	71	Lung Cancer
34	Breast Cancer	72	End Stage Heart Failure
35	Pulmonary Fibrosis & Emphysema	73	Stage IV Angiosarcoma
36	B-Cell Lymphoma Leukemia	74	Metastatic Ovarian Cancer
37	Breast Cancer	75	Prostate Cancer
38	ALS	76	Gastroesophageal Junction Carcinoma

Qualified patients who died because of self-administering the aid-in-dying prescription: 51

	Underlying Illness	Type of Insurance	Age	Education	Race	Sex
	MAI infection w/ progressive fibrotic interstitial lung disease	Medicare		Bachelor's Degree	Caucasian	Female
2	Parkinson's Disease	Medicare + Private	85	No Info	Caucasian	Male



	Underlying Illness	Type of Insurance	Age	Education	Race	Sex
3	Head and Neck Cancer	Medicare + Private	101	Bachelor's Degree	Caucasian	Male
4	Metastatic Melanoma	Medicare + Private	72	No Info	Caucasian	Male
5	Lung Cancer	Medicare + Private	77	Master's Degree	Caucasian	Female
6	Lung Cancer	Medicare + Private	70	No Info	Caucasian	Female
7	End-Stage Liver Disease	Don't know type; had insurance	66	High School Diploma	Caucasian	Male
8	Pancreatic Cancer	Medicare + Private	83	No info	Caucasian	Male
9	Metastatic Breast Cancer	Military/ TRICARE	44	Bachelor's Degree	Caucasian	Female
10	Metastatic Adenoma of the Lung	Don't know type; had insurance	77	Doctoral	Caucasian	Female
11	Multiple Myeloma	Medicare + Private	76	Some College, No Degree	Caucasian	Male
12	Renal Cancer	Medicare + Private	71	No info	Caucasian	Female
13	Breast Cancer	Private	60	No info	No Info	Female
14	Prostate Cancer	Hawaii Quest/ Medicaid	65	Master's Degree	Caucasian	Male
15	ALS	Private	61	Bachelor's Degree	Asian	Male
16	DISH producing End Stage Cardiorespiratory Failure	Medicare + Private	75	No info	Caucasian	Male
17	Severe Neurologic Deterioration from a stroke	Medicare + Private	85	High School Diploma	Hispanic/ Latino	Female
18	Progressive Interstitial Pulmonary Fibrosis	Private	76	Bachelor's Degree	Caucasian	Male
19	Myelodysplastic Syndrome	Medicare	88	Doctoral	Caucasian	Male
20	Breast Cancer	Private	38	No info	Asian	Female
21	Breast Cancer	Medicare + Private	92	No info	Caucasian	Female
22	Pulmonary Fibrosis & Emphysema	Medicare	73	Associate's Degree	Asian	Male
23	B-Cell Lymphoma Leukemia	Private	76	Bachelor's Degree	Caucasian	Male



	Underlying Illness	Type of Insurance	Age	Education	Race	Sex
24	ALS	Medicare	61	Some College, No Degree	Caucasian	Male
25	Breast Cancer	Private	73	Bachelor's Degree	Caucasian	Female
26	Lung Cancer	Medicare + Private	72	No info	No Info	Male
27	Severe R CVA & Resultant L Hemiplegia	Don't know type; had insurance	92	Some College, No Degree	Asian	Female
28	Metastatic Malignant Melanoma	Medicare	83	High School Diploma	Caucasian	Male
29	Metastatic Lung Cancer	Medicare + Private + MDX Hawaii Humana	70	No info		Female
30	Lung Cancer	Medicare + Private	83	Master's Degree	Native Hawaiian	Male
31	Lung Cancer	Medicare + Private	74	Master's Degree	Caucasian	Male
32	Anal Cancer	Medicare + Private	80	No Info	Caucasian	Female
33	Head and Neck Cancer	Medicare + Private	78	No Info	Asian	Male
34	Recurrent Atypical Meningioma	Medicare + Private	81	Master's Degree	Asian	Male
35	Liver Cancer	Medicare + Private	69	Master's Degree	Caucasian	Female
36	End Stage Heart Failure - Severe Aortic Stenosis	Medicare + Private	91	No Info	Caucasian	Male
37	Metastatic Merkel Cell Carcinoma	Medicare + Private	88	No Info	Caucasian	Female
38	Severe Diabetes with end stage renal and vascular disease	Medicare + Private	71	No Info	Caucasian	Male
39	Pancreatic Cancer	Medicare + Private	84	Bachelor's Degree	Caucasian	Female
40	Cervical Carcinoma, Portal Vein Thrombosis	Medicare + Private	83	No info	Caucasian	Female
41	Thyroid Cancer	Medicare + Private	73	No Info	Caucasian	Male
42	Cirrhosis with End-Stage Liver Disease	Medicare	77	Bachelor's Degree	Asian	Male



	Underlying Illness	Type of Insurance	Age	Education	Race	Sex
43	Metastatic Ovarian Cancer	Medicare	75	No Info	Caucasian	Female
44	Creutzfeldt-Jacob Disease	Medicare	74	Doctoral Degree	Caucasian	Male
45	Hepatocellular Carcinoma	Medicare	68	Associate's Degree	Asian	Male
46	Metastatic Gallbladder Cancer	Don't know type; had insurance	83	No info	Caucasian	Male
47	Breast Cancer	Medicare + Private	77	No Info	Caucasian	Female
48	End Stage Heart Failure	Medicare + Private	81	No Info	Pacific Islander	Female
49	Metastatic Ovarian Cancer	Private	65	Bachelor's Degree	Asian	Female
50	Prostate Cancer	Medicare + Private	89	Doctoral Degree	Caucasian	Male
51	Gastroesophageal Junction Carcinoma	Medicare + Private	74	No info	Caucasian	Male

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.