

CALIFORNIA END OF LIFE OPTION ACT 2020 DATA REPORT



For more information:

<https://www.cdph.ca.gov/Programs/CHSI/Pages/End-of-Life-Option-Act-.aspx>

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Executive Summary

California's End of Life Option Act (EOLA) became effective on June 9, 2016. The Act allows terminally ill adults living in California to obtain and self-administer aid-in-dying drugs.¹ The Act requires the California Department of Public Health (CDPH) to provide annual reports under strict privacy requirements. CDPH's reporting requirements are outlined in Health and Safety Code section 443.19 (b), which reads:

(b) On or before July 1, 2017, and each year thereafter, based on the information collected in the previous year, the department shall create a report with the information collected from the attending physician follow up form and post that report to its Internet Web site. The report shall include, but not be limited to, all of the following based on the information that is provided to the department and on the department's access to vital statistics:

(1) The number of people for whom an aid-in-dying prescription was written.

(2) The number of known individuals who died each year for whom aid-in-dying prescriptions were written, and the cause of death of those individuals.

(3) For the period commencing January 1, 2016, to and including the previous year, cumulatively, the total number of aid-in-dying prescriptions written, the number of people who died due to use of aid-in-dying drugs, and the number of those people who died who were enrolled in hospice or other palliative care programs at the time of death.

(4) The number of known deaths in California from using aid-in-dying drugs per 10,000 deaths in California.

(5) The number of physicians who wrote prescriptions for aid-in-dying drugs.

(6) Of people who died due to using an aid-in-dying drug, demographic percentages organized by the following characteristics:

(A) Age at death.

(B) Education level.

(C) Race.

(D) Sex.

(E) Type of insurance, including whether or not they had insurance.

(F) Underlying illness.

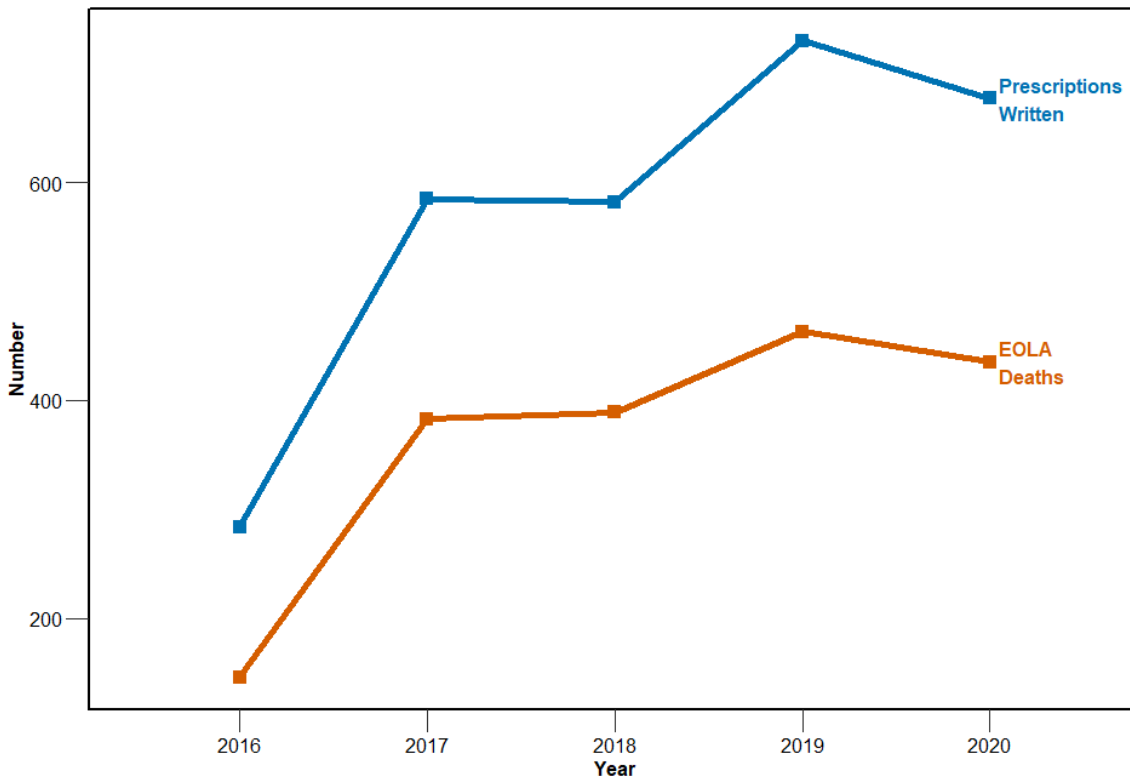
¹ Assembly Bill x2 15 (Eggman), Chapter 1, Statutes of 2015.

This report presents data as reported to CDPH from the EOLA-mandated physician reporting forms received between January 1, 2020 and December 31, 2020, and reflects information on individuals who were prescribed aid-in-dying drugs and died in the calendar year of 2020, as well as cumulative counts for the period commencing January 1, 2016. The information collected has been aggregated to protect the privacy of the individuals.

For the calendar year ending December 31, 2020, 677 individuals received prescriptions under the Act. In 2020, 435 individuals died following their ingestion of the prescribed aid-in-dying drug(s), which includes 34 individuals who received prescriptions prior to 2020. Of the 435 individuals, 90.8 percent were 60 years of age or older, 89.2 percent had health insurance and 86.7 percent were receiving hospice and/or palliative care.

Since the law came into effect June 9, 2016 through December 31, 2020, prescriptions have been written for a total of 2,858 people under the Act and 1,816 individuals, or 63.5 percent, have died from ingesting the medications. Of the 2,858 individuals who have died under the Act, 1,587, or 87.4 percent, were receiving hospice and/or palliative care. Note that cumulative counts reported above do not match prior reports. These differences arise from a number of factors including the timing of forms received, the registration of deaths, and the inclusion of duplicate records in prior reports, which have been removed. A chart illustrating the number of prescriptions written and deaths under the Act from 2016 through 2020 is provided below in Figure 1.

Figure 1: Summary of EOLA Prescriptions and Deaths 2016-2020



Introduction

The EOLA allows an adult diagnosed with a terminal disease, who meets certain qualifications, to request an aid-in-dying drug from a physician. The Act requires physicians to use forms specified in statute for submitting information to CDPH. CDPH is responsible for collecting data from these forms to prepare an annual report. Data presented in this report are based on the information from physicians' forms and California death certificates for calendar year 2020.

More information on the Act, reporting process, and required forms can be found here: <https://www.cdph.ca.gov/Programs/CHSI/Pages/End-of-Life-Option-Act-.aspx>.

Participation in the End-of-Life Option Activities

For the calendar year 2020, 662 individuals started the end-of-life option process, as set forth in the Act, by making two verbal requests to their physicians at least 15 days apart. A total of 262 physicians prescribed 677 individuals aid-in-dying drugs. The two most common drug categories prescribed were a combination of a cardiotoxic, opioid, and sedative at 82.3 percent followed by individuals who were only prescribed a sedative at 0.7 percent. Of the 677 individuals who were prescribed such drugs, 401, or 59.2 percent, were reported by their physician to have died following ingestion of aid-in-dying drugs prescribed under the Act; and 112 individuals, or 16.5 percent, died from the underlying illness or other causes. The ingestion status of the remaining 164 individuals is unknown. Of the remaining 164 individuals, 83, or 12.3 percent, have died, but their ingestion status is unknown because follow up information is not available yet. For the remaining 81 individuals, or 12 percent, both death and ingestion status are pending. Furthermore, 34 individuals with prescriptions written in prior years ingested and died from the drugs during 2020. As a result, the report demographics include the 435 individuals who ingested and subsequently died during the 2020 calendar year from aid-in-dying drugs. A chart illustrating the outcomes is provided below as Figure 2.

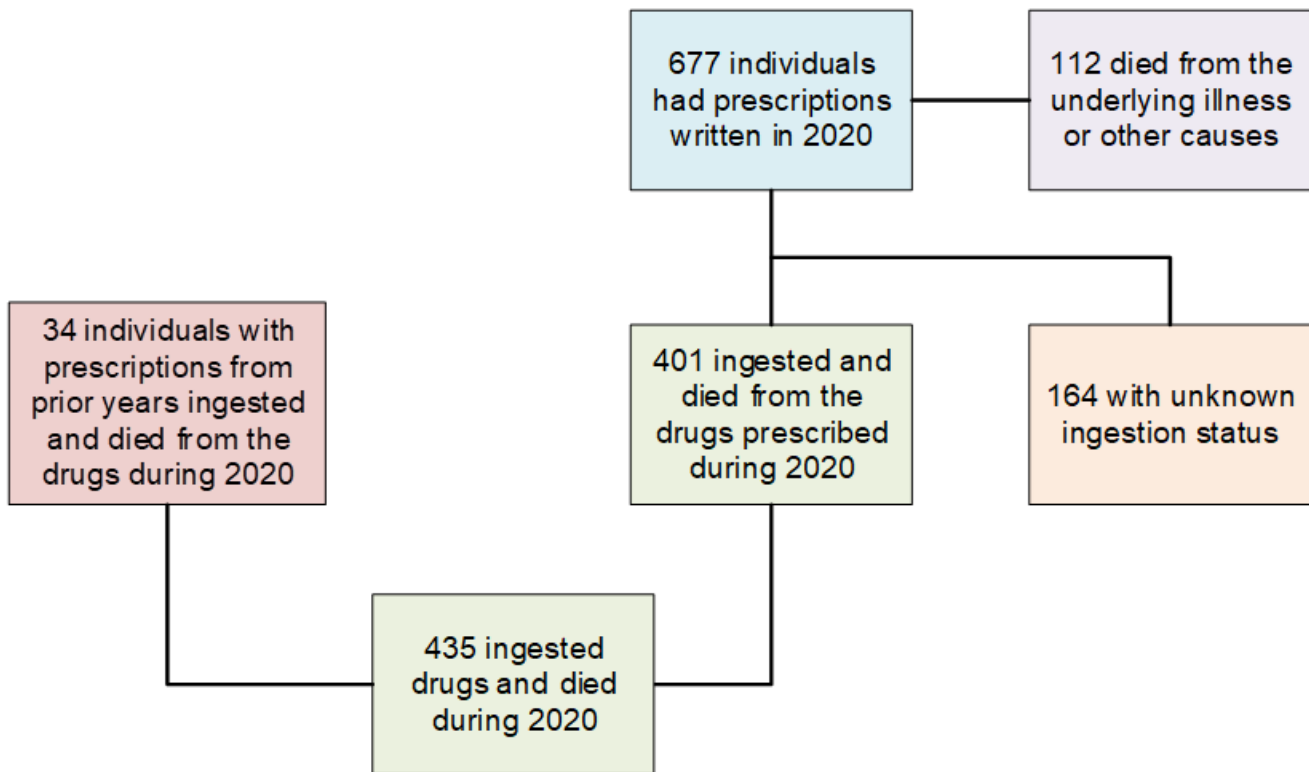
In 2020, 435 individuals² died from ingestion of aid-in-dying drugs, a rate of 13.8 per 10,000 deaths based on 314,982^{3,4} deaths to California residents in 2020. Excluding COVID-19 deaths, the rate of individuals who died from ingestion of aid-in-dying drugs was 15.4 per 10,000 deaths based on 282,559 non-COVID-19 deaths to California residents in 2020.

² Total of individuals who received aid-in-dying prescriptions that died in 2020.

³ California Department of Public Health, California Comprehensive Death File, created in February 2021.

⁴ Does not include out-of-state California resident deaths as of February 2021.

Figure 2: Summary of EOLA Prescriptions Written in Prior Years and Drugs Ingested in 2020⁵



Characteristics of Individuals

Of the 435 individuals who died pursuant to EOLA during 2020, 9.2 percent were under 60 years of age, 77.9 percent were 60-89 years of age, and 12.9 percent were 90 years of age and older. The median age was 74 years. The decedents were 87.4 percent white, 50.8 percent were female; 86.7 percent were receiving hospice and/or palliative care, and 76.1 percent had at least some level of college education. In addition, 83.4 percent informed their family of their decision to participate in EOLA. A summary of this information is set forth in Table 1 on pages 9-10 and Table 3 on pages 13-14.

Of the 435 individuals who died pursuant to EOLA during 2020, 70.8 percent were identified as having had malignant neoplasms (cancer). Neurological diseases such as amyotrophic lateral sclerosis and Parkinson’s accounted for the second largest underlying illness grouping, totaling 10.8 percent.

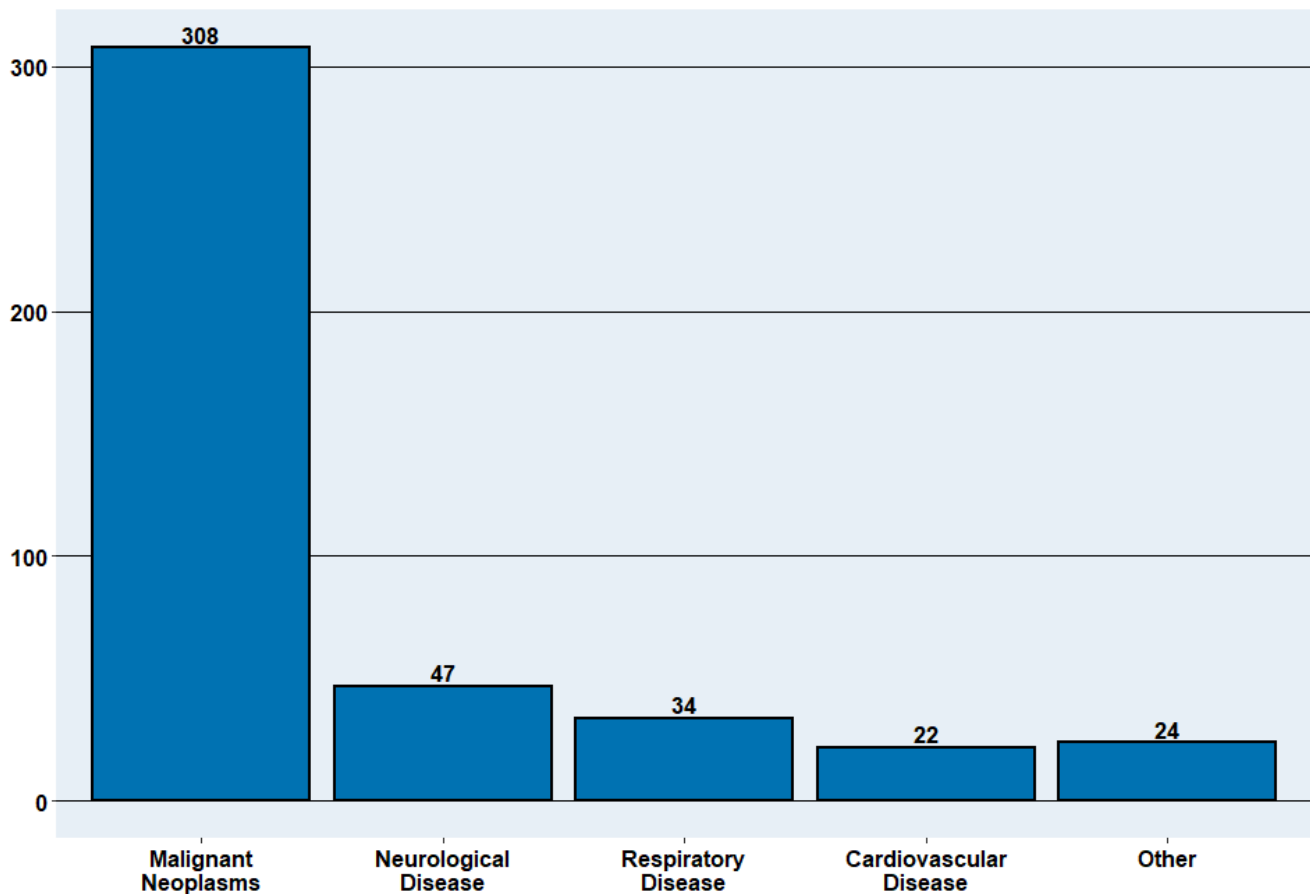
The remaining major categories of underlying illnesses were documented as: respiratory diseases (non-cancer; 7.8 percent), cardiovascular diseases (5.1 percent), and other

⁵ Based on forms received as of February 8, 2021.

diseases (5.5 percent). The other diseases were documented as; kidney disease (1.4 percent), cerebrovascular disease (1.1 percent), endocrine, nutritional and metabolic disease (1.1 percent), immune mediated disease (0.2 percent) and other (1.6 percent). The data are presented in Figure 3 below.

Certifiers⁶ (physicians, coroners, and medical examiners) report the underlying terminal disease as the cause of death on the death certificates. This approach complies with applicable law; best ensures the reliability and usefulness of data collected from the death certificate for state, national, and international surveillance purposes; and effectuates the California Legislature’s intent to maintain the confidentiality of individuals’ participation in the Act.

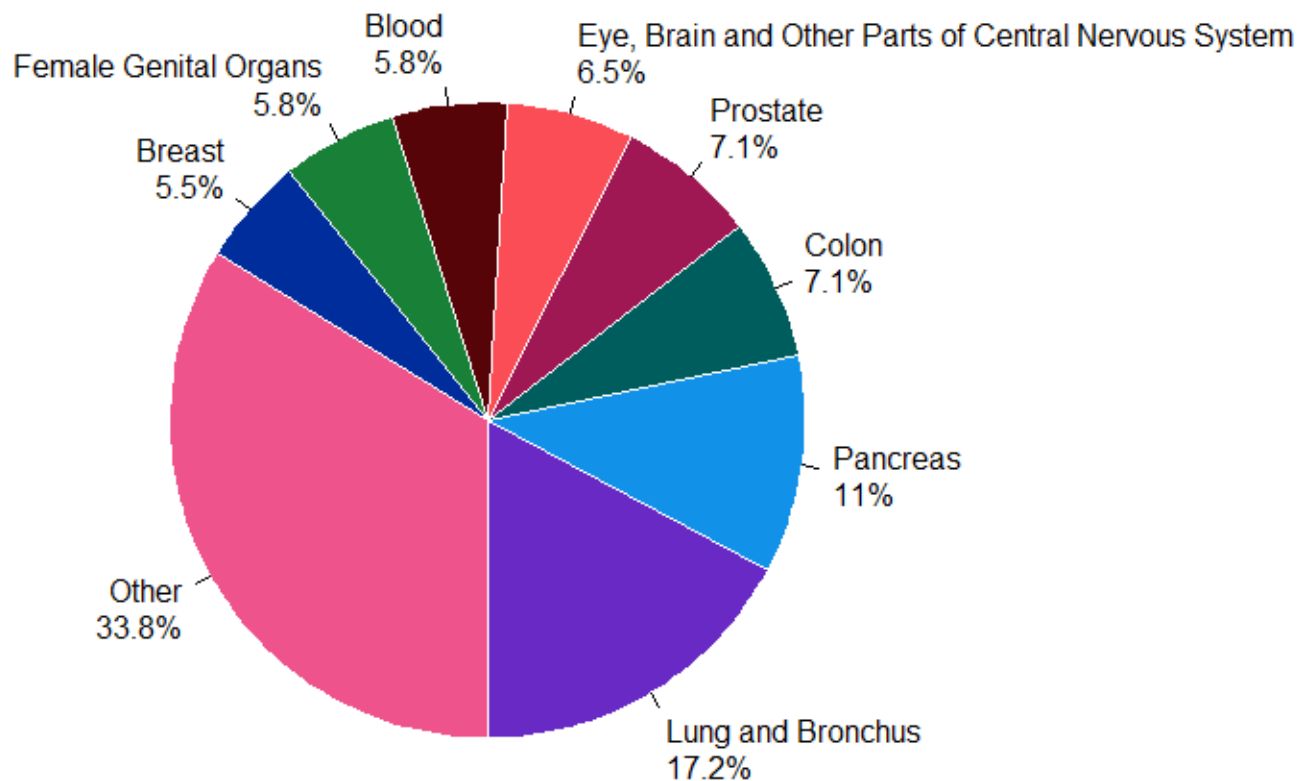
Figure 3: Major Illness Categories for EOLA Individuals in 2020



⁶ Health and Safety Code 102825(a) and Health and Safety code 102860

Among individuals with cancer as the underlying terminal disease – the largest group of individuals who utilized the Act—lung cancer accounted for 17.2 percent, pancreatic cancer accounted for 11.0 percent, both colon cancer and prostate cancer constituted 7.1 percent, cancer of the eye, brain, and other parts of central nervous system constituted 6.5 percent, blood cancer and cancer of the female genital organs both comprised 5.8 percent, and breast cancer accounted for 5.5 percent. Other malignant neoplasms accounted for the remaining 33.8 percent, as shown below in Figure 4. Additional information regarding the other types of malignant neoplasms can be found in Table 2 on pages 11-12.

Figure 4: Major Malignant Neoplasm Types for EOLA Individuals in 2020⁷



Most of the individuals who participated in the Act had some form of health insurance (89.2 percent). Of those with health insurance, 62.5 percent of individuals had Medicare or Medicare combined with another type of insurance, while 13.3 percent of individuals had only private insurance. Individuals who had an unspecified type of insurance comprised 10.6 percent of the Act participants followed by individuals with only Medi-Cal at 2.1 percent, and individuals with other governmental insurance (e.g., Covered California or

⁷ Percentages presented in this Data Report are rounded to the nearest tenth. Due to rounding, percentages when totaled may not equal 100.0 percent.

Veterans Affairs) at 0.7 percent. 47 individuals, or 10.8 percent, had undetermined health insurance coverage.

A physician or trained healthcare professional was present for 179 individuals, or 41.1 percent, at the time of ingestion of the aid-in-dying drug. Of the 179 individuals who had a physician or trained healthcare professional present at the time of ingestion, another healthcare provider was present for 45.8 percent of individuals, followed by an attending physician, who was present for 44.1 percent of individuals. The majority, or 92.0 percent, of all individuals were in a private home for ingestion.

Additional information regarding insurance status and other characteristics of individuals who died following ingestion of an aid-in-dying drug can be found in Table 3 on pages 13-14.

Conclusion

This Data Report presents data reported to CDPH from EOLA-mandated physician reporting forms and reflects information on all patients who were prescribed aid-in-dying medications in 2020 or prior years, and subsequently died in 2020 of ingesting the prescribed drugs. The information collected by CDPH has been aggregated to protect the privacy of the participants.

Table 1: Demographics of the EOLA Individuals Who Died Following Ingestion of an Aid-in-Dying Drug

EOLA Individuals	2020	(N=435)	2019	(N=463)	2016-2018	(N=918)	Total	(N=1816)
Age	N	(%)	N	(%)	N	(%)	N	(%)
Under 60	40	(9.2)	55	(11.9)	110	(12.0)	205	(11.3)
60-69	98	(22.5)	98	(21.2)	206	(22.4)	402	(22.1)
70-79	147	(33.8)	131	(28.3)	275	(30.0)	553	(30.5)
80-89	94	(21.6)	117	(25.3)	218	(23.7)	429	(23.6)
90 and Over	56	(12.9)	62	(13.4)	109	(11.9)	227	(12.5)
Median Age (Range)	74	(27-107)	76	(23-104)	74	(27-106)	75	(23-107)
Gender	N	(%)	N	(%)	N	(%)	N	(%)
Female	221	(50.8)	217	(46.9)	466	(50.8)	904	(49.8)
Male	214	(49.2)	246	(53.1)	452	(49.2)	912	(50.2)
Education	N	(%)	N	(%)	N	(%)	N	(%)
No High School Diploma	8	(1.8)	16	(3.5)	30	(3.3)	54	(3.0)
HS Diploma or GED	93	(21.4)	96	(20.7)	176	(19.2)	365	(20.1)
Some College	78	(17.9)	83	(17.9)	168	(18.3)	329	(18.1)
Associate's Degree	40	(9.2)	28	(6.0)	62	(6.8)	130	(7.2)
Bachelor's Degree	120	(27.6)	116	(25.1)	228	(24.8)	464	(25.6)
Master's Degree	53	(12.2)	70	(15.1)	151	(16.4)	274	(15.1)
Doctorate or Professional Degree	40	(9.2)	49	(10.6)	98	(10.7)	187	(10.3)
Unknown	3	(0.7)	5	(1.1)	5	(0.5)	13	(0.7)

Table 1: Demographics of the EOLA Individuals Who Died Following Ingestion of an Aid-in-Dying Drug, continued

EOLA Individuals	2020	(N=435)	2019	(N=463)	2016-2018	(N=918)	Total	(N=1816)
Race/Ethnicity	N	(%)	N	(%)	N	(%)	N	(%)
White	380	(87.4)	400	(86.4)	823	(89.7)	1603	(88.3)
Black	4	(0.9)	6	(1.3)	7	(0.8)	17	(0.9)
American Indian/Alaskan Native	0	(0.0)	0	(0.0)	1	(0.1)	1	(0.1)
Asian	33	(7.6)	30	(6.5)	50	(5.4)	113	(6.2)
Hawaiian/Pacific Islander	1	(0.2)	2	(0.4)	1	(0.1)	4	(0.2)
Other	1	(0.2)	1	(0.2)	1	(0.1)	3	(0.2)
Multi-race	1	(0.2)	4	(0.9)	6	(0.7)	11	(0.6)
Hispanic	15	(3.4)	19	(4.1)	29	(3.2)	63	(3.5)
Unknown	0	(0.0)	1	(0.2)	0	(0.0)	1	(0.1)

Table 2: Underlying Illness of the EOLA Individuals Who Died Following Ingestion of an Aid-in-Dying Drug

EOLA Individuals	2020	(N=435)	2019	(N=463)	2016-2018	(N=918)	Total	(N=1816)
Underlying Illness	N	(%)	N	(%)	N	(%)	N	(%)
Malignant Neoplasms (Cancer)	308	(70.8)	320	69.1	645	70.3	1273	70.1
Lung and Bronchus	53	(17.2)	51	(15.9)	105	(16.8)	209	(16.4)
Pancreas	34	(11.0)	33	(10.3)	56	(8.7)	123	(9.7)
Prostate	22	(7.1)	27	(8.4)	51	(7.9)	100	(7.9)
Colon	22	(7.1)	27	(8.4)	43	(6.7)	92	(7.2)
Female Genital Organs	18	(5.8)	26	(8.1)	39	(6.0)	83	(6.5)
Breast	17	(5.5)	28	(8.8)	51	(7.9)	96	(7.5)
Other Digestive Organs [e.g., stomach, esophagus]	21	(6.8)	19	(5.9)	45	(7.0)	85	(6.7)
Blood	18	(5.8)	18	(5.6)	43	(6.7)	79	(6.2)
Liver	14	(4.5)	15	(4.7)	22	(3.4)	51	(4.0)
Eye, Brain and Other Parts of Central Nervous System	20	(6.5)	16	(5.0)	38	(5.9)	74	(5.8)
Ill-defined, Secondary, and Unspecified Sites	15	(4.9)	13	(4.1)	30	(4.7)	58	(4.6)
Urinary Tract	18	(5.8)	11	(3.4)	30	(4.7)	59	(4.6)
Lip, Oral Cavity, and Pharynx	13	(4.2)	9	(2.8)	31	(4.8)	53	(4.2)
Skin	6	(1.9)	8	(2.5)	21	(3.3)	35	(2.7)
Bone	1	(0.3)	4	(1.3)	2	(0.3)	7	(.5)
Mesothelial and Soft Tissue	7	(2.3)	4	(1.3)	13	(2.0)	24	(1.9)
Respiratory and Intrathoracic Organs	3	(1.0)	3	(0.9)	5	(0.8)	11	(0.9)
Thyroid and Other Endocrine Glands	1	(0.3)	1	(0.3)	6	(0.9)	8	(0.6)
Other Cancers	5	(1.6)	7	(2.2)	14	(2.2)	26	(2.0)

Table 2: Underlying Illness of the EOLA Individuals Who Died Following Ingestion of an Aid-in-Dying Drug, continued

EOLA Individuals	2020	(N=435)	2019	(N=463)	2016-2018	(N=918)	Total	(N=1816)
Underlying Illness	N	(%)	N	(%)	N	(%)	N	(%)
Neurological Disease	47	(10.8)	45	(9.7)	106	(11.5)	198	(10.9)
Amyotrophic Lateral Sclerosis	27	(57.4)	16	(35.6)	73	(68.9)	116	(58.6)
Parkinson's Disease	8	(17.0)	12	(26.7)	14	(13.2)	34	(17.2)
Polio	0	(0)	1	(2.2)	1	(0.9)	2	(1.0)
Other	12	(25.5)	16	(35.6)	18	(17.0)	46	(23.2)
Cardiovascular Disease	22	(5.1)	39	(8.4)	66	(7.2)	127	(7.0)
Respiratory Disease	34	(7.8)	33	(7.1)	50	(5.4)	117	(6.4)
Chronic Lower Respiratory Disease	28	(82.4)	21	(63.7)	40	(80)	89	(76.1)
Other	6	(17.6)	12	(36.4)	10	(20)	28	(24.0)
Cerebrovascular Disease	5	(1.1)	7	(1.5)	11	(1.2)	23	(1.3)
Kidney Disease	6	(1.4)	5	(1.1)	13	(1.4)	24	(1.3)
Endocrine, Nutritional and Metabolic Disease	5	(1.1)	5	(1.1)	4	(0.4)	14	(0.8)
Immune Mediated Disease [e.g., Multiple Sclerosis]	1	(0.2)	4	(0.9)	5	(0.5)	10	(0.6)
Other⁸	7	(1.6)	5	(1.1)	18	(2.0)	30	(1.6)

⁸ Includes Gastrointestinal Disease; Liver Disease; Infectious and Parasitic Disease; Musculoskeletal and Connective Tissue Diseases; Blood Disease

Table 3: Characteristics of the EOLA Individuals Who Died Following Ingestion of an Aid-in-Dying Drug

EOLA Individuals	2020	(N=435)	2019	(N=463)	2016-2018	(N=918)	Total	(N=1816)
Insurance	N	(%)	N	(%)	N	(%)	N	(%)
Medicare or Medicare with another type of insurance	272	(62.5)	292	(63.1)	593	(64.6)	1157	(63.7)
Private Insurance	58	(13.3)	71	(15.3)	131	(14.3)	260	(14.3)
Medi-Cal	9	(2.1)	10	(2.2)	24	(2.6)	43	(2.4)
Other Governmental Insurance	3	(0.7)	0	(0)	5	(0.5)	8	(0.4)
Has Insurance, but unknown type	46	(10.6)	38	(8.2)	124	(13.5)	208	(11.5)
No Insurance	0	(0.0)	1	(0.2)	4	(0.4)	5	(.28)
Unknown	47	(10.8)	51	(11.0)	37	(4.0)	135	(7.4)
Hospice and/or Palliative care	N	(%)	N	(%)	N	(%)	N	(%)
Enrolled	377	(86.7)	400	(86.4)	810	(88.2)	1587	(87.4)
Not Enrolled	48	(11.0)	33	(7.1)	96	(10.5)	177	(9.7)
Unknown	10	(2.3)	30	(6.5)	12	(1.3)	52	(2.9)
Aid-in-Dying Drugs	N	(%)	N	(%)	N	(%)	N	(%)
Cardiotonic, Opioid, Sedative	358	(82.3)	372	(80.3)	290	(31.6)	1020	(56.2)
Sedative	3	(0.7)	10	(2.2)	472	(51.4)	485	(26.7)
Other	32	(7.4)	21	(4.5)	67	(7.3)	120	(6.6)
Unknown	42	(9.7)	60	(13.0)	89	(9.7)	191	(10.5)
Patient Informed Family of Decision	N	(%)	N	(%)	N	(%)	N	(%)
Yes	363	(83.4)	400	(86.4)	794	(86.5)	1557	(85.7)
No	6	(1.4)	15	(3.2)	21	(2.3)	42	(2.3)
No Family to Inform	9	(2.1)	8	(1.7)	16	(1.7)	33	(1.8)
Unknown	57	(13.1)	40	(8.6)	87	(9.5)	184	(10.1)

Table 3: Characteristics of the EOLA Individuals Who Died Following Ingestion of an Aid-in-Dying Drug, continued

EOLA Individuals	2020	(N=435)	2019	(N=463)	2016-2018	(N=918)	Total	(N=1816)
Physician or Trained Healthcare Provider Present at Ingestion	N	(%)	N	(%)	N	(%)	N	(%)
Yes	179	(41.1)	196	(42.3)	406	(44.2)	781	(43.0)
Attending Physician	79	(44.1)	115	(58.7)	270	(66.5)	464	(59.4)
Other Physician	18	(10.1)	10	(5.1)	29	(7.1)	57	(7.3)
Other Healthcare Provider	82	(45.8)	71	(36.2)	107	(26.4)	260	(33.3)
No	34	(7.8)	48	(10.4)	111	(12.1)	193	(10.6)
Unknown	222	(51.0)	219	(47.3)	401	(44.0)	842	(46.4)
Location Where Aid-in-Dying Drugs were Ingested	N	(%)	N	(%)	N	(%)	N	(%)
Private Home	400	(92.0)	408	(88.1)	835	(91.0)	1643	(90.5)
Assisted-Living Residence	14	(3.2)	30	(6.5)	42	(4.6)	86	(4.7)
Nursing Home	17	(3.9)	15	(3.2)	22	(2.4)	54	(3.0)
In-patient Hospice Residence	2	(0.5)	5	(1.1)	16	(1.7)	23	(1.3)
Acute Care Hospital	1	(0.2)	2	(0.4)	0	(0)	3	(0.2)
Other	1	(0.2)	3	(0.6)	3	(0.3)	7	(0.4)