

CALIFORNIA END OF LIFE OPTION ACT 2019 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, 2019, and December 31, 2019, and reflects information on individuals who were prescribed aid-in-dying drugs and died in the calendar year of 2019, 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 year ending December 31, 2019, 618 individuals received prescriptions under the Act. In 2019, 405 individuals died following their ingestion of the prescribed aid-in-dying drug(s), which includes 27 individuals who received prescriptions prior to 2019. Of the 405 individuals, 88.6 percent were 60 years of age or older, 89.9 percent had health insurance and 85.4 percent were receiving hospice and/or palliative care.

Since the law came into effect June 9, 2016 through December 31, 2019, prescriptions have been written for a total of 1,985 people under the Act and 1,283 individuals, or 64.6 percent, have died from ingesting the medications. Of the 1,283 individuals who have died under the Act, 1,112, or 86.7 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.

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, and preparing an annual report. Data presented in this report are based on the information from physicians' forms and California death certificates for calendar year 2019.

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>.

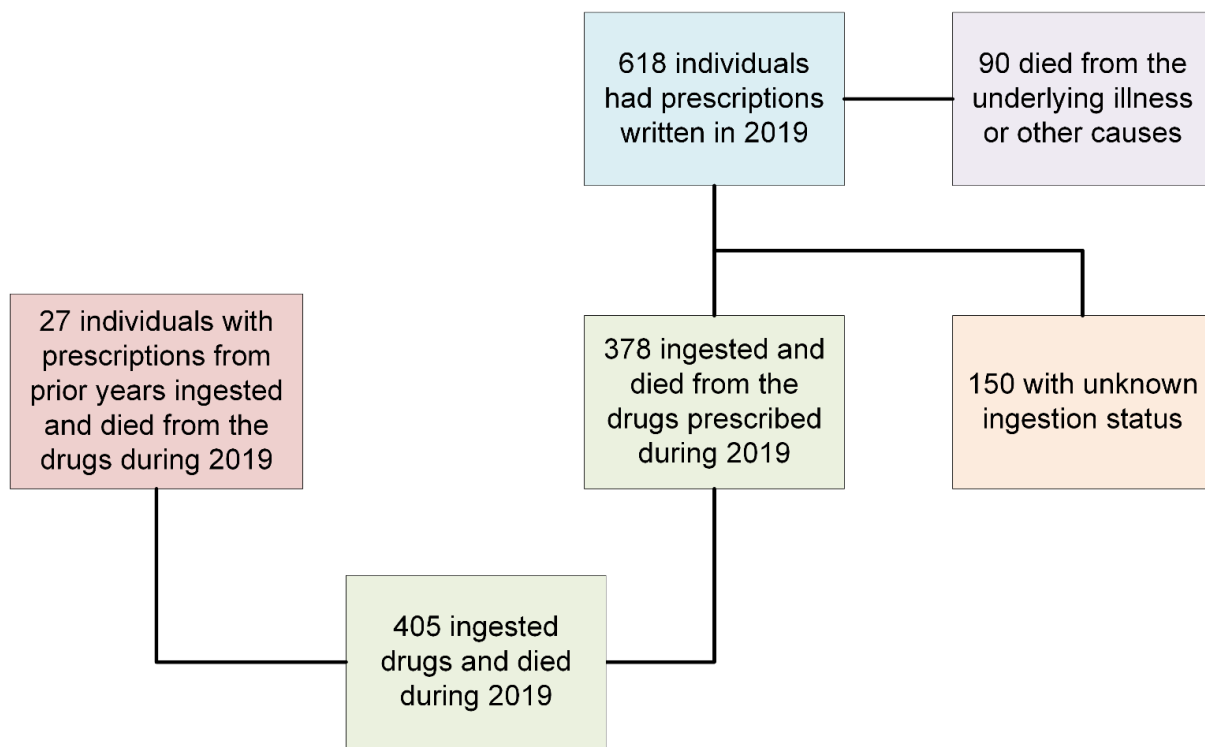
Participation in the End-of-Life Option Activities

For the calendar year 2019, 736 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 246 physicians prescribed 618 individuals aid-in-dying drugs. The two most common drug categories prescribed were a combination of a cardiotoxic, opioid, and sedative at 78.8 percent followed by individuals who were only prescribed a sedative at two percent. Of the 618 individuals who were prescribed such drugs, 378, or 61.2 percent, were reported by their physician to have died following ingestion of aid-in-dying drugs prescribed under the Act; and 90 individuals, or 14.6 percent, died from the underlying illness or other causes. The ingestion status of the remaining 150 individuals is unknown. Of the remaining 150 individuals, 82, or 13.3 percent, have died, but their ingestion status is unknown because

follow up information is not available yet. For the remaining 68 individuals, or 11.0 percent, both death and ingestion status are pending. Further, 27 individuals with prescriptions written in prior years ingested and died from the drugs during 2019. As a result, the report demographics include the 405 individuals who ingested and subsequently died during the 2019 calendar year from aid-in-dying drugs. A chart illustrating the outcomes is provided below as Figure 1.

In 2019, 405 individuals² died from ingestion of aid-in-dying drugs, a rate of 15.0 per 10,000 deaths based on 270,492^{3,4} deaths to California residents in 2019.

Figure 1: Summary of EOLA Prescriptions Written in Prior Years and Drugs Ingested in 2019⁵



Characteristics of Individuals

Of the 405 individuals who died pursuant to EOLA during 2019, 11.4 percent were under 60 years of age, 74.5 percent were 60-89 years of age, and 14.1 percent were 90 years of age and older. The median age was 76 years. The decedents were 87.2 percent white, 55.3 percent were male; 85.4 percent were receiving hospice and/or palliative care, and 74.4 percent had at least some level of college education. In addition, 84.0 percent informed their family of their decision to participate in EOLA. A summary of this information is set forth in Table 1 on page 7 and Table 3 on page 9.

² Total of individuals who received aid-in-dying prescriptions that died in 2019.

³ California Department of Public Health, California Comprehensive Death File, created in February 2020.

⁴ Does not include out-of-state California resident deaths as of February 2020.

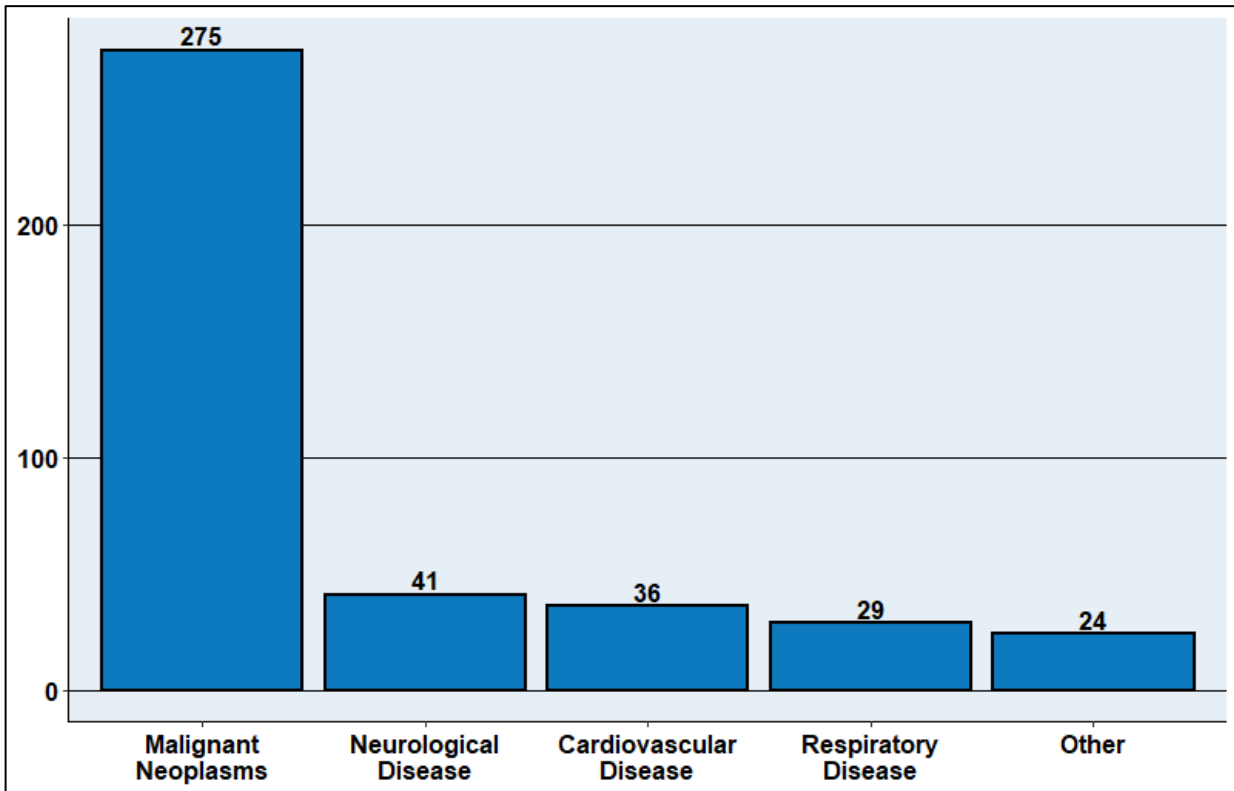
⁵ Based on forms received as of February 20, 2020.

Of the 405 individuals who died pursuant to EOLA during 2019, 67.9 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 10.1 percent.

The remaining major categories of underlying illnesses were documented as: cardiovascular diseases (8.9 percent), respiratory diseases (non-cancer; 7.2 percent) and other diseases (5.8 percent). The other diseases were documented as; cerebrovascular disease (1.7 percent), kidney disease (1.2 percent), endocrine, nutritional and metabolic disease (1.0 percent), immune mediated disease (0.7 percent) and other (1.2 percent). The data are presented in Figure 2 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.

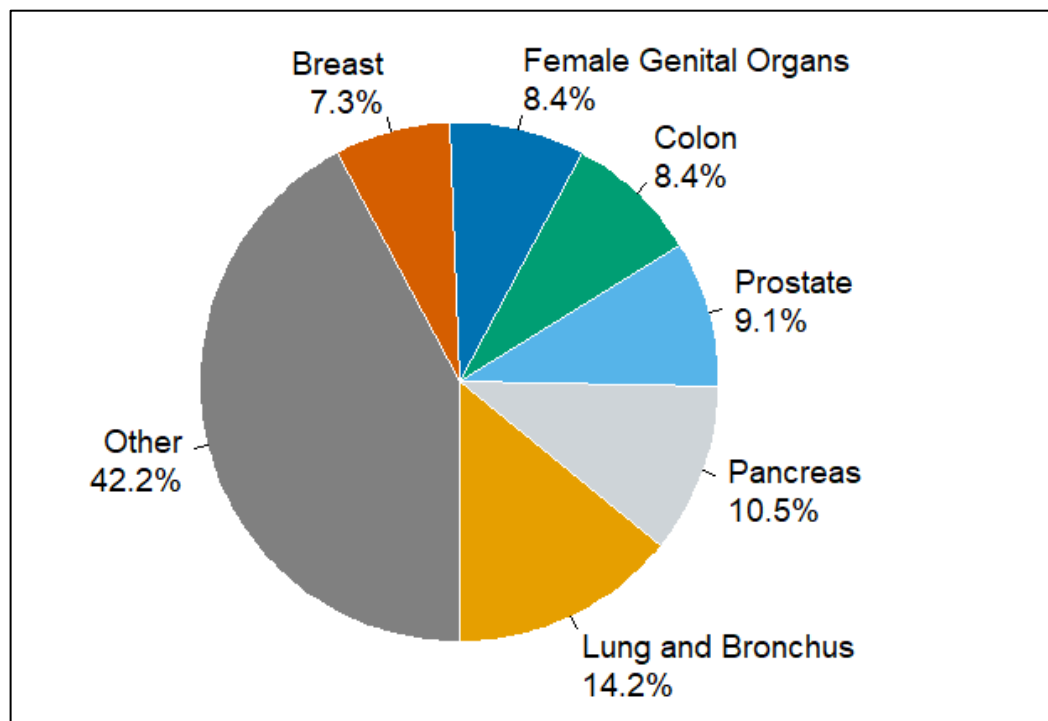
Figure 2: Major Illness Categories for EOLA Individuals in 2019



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

Among those with cancer as the underlying terminal disease – the largest group of individuals who utilized the Act– lung cancer accounted for 14.2 percent, pancreatic cancer accounted for 10.5 percent, prostate cancer constituted 9.1 percent, both colon cancer and cancer of the female genital organs constituted 8.4 percent each, and breast cancer accounted for 7.3 percent. Other malignant neoplasms accounted for the remaining 42.2 percent, as shown below in Figure 3. Additional information regarding the other types of malignant neoplasms can be found in Table 2 on page 8.

Figure 3: Major Malignant Neoplasm Types for EOLA Individuals in 2019⁷



In Table 3 on page 9, most (89.9 percent) of the individuals who participated in the Act had some form of health insurance. Medicare or Medicare combined with another type of insurance accounted for 65.7 percent of individuals followed by individuals with private insurance at 13.1 percent. Individuals who had an unspecified type of insurance comprised 8.6 percent of the Act participants followed by individuals with only Medi-Cal at 2.5 percent. 40 individuals, or 9.9 percent, had undetermined health insurance coverage, while one individual, or 0.2 percent, reported no health insurance coverage.

Table 3 on page 9 also shows that 47.9 percent of individuals had a physician or trained healthcare professional present at the time of ingestion of the aid-in-dying drug. Of the individuals who had a physician or trained healthcare professional present at the time of ingestion, the attending physician was present for 58.8 percent of patients. The majority, or 88.1 percent, of individuals were in a private home for ingestion.

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.

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 2019 or prior years, and subsequently died in 2019 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	2019	(N=405)
Age	N	(%)
Under 60	46	(11.4)
60-69	85	(21.0)
70-79	114	(28.1)
80-89	103	(25.4)
90 and Over	57	(14.1)
Median Age (Range)	76	(23-104)
Sex	N	(%)
Female	181	(44.7)
Male	224	(55.3)
Education	N	(%)
No High School Diploma	14	(3.5)
High School Diploma or GED	87	(21.5)
Some College	74	(18.3)
Associate's Degree	22	(5.4)
Bachelor's Degree	97	(24.0)
Master's Degree	64	(15.8)
Doctorate or Professional Degree	44	(10.9)
Unknown	3	(0.7)
Race/Ethnicity	N	(%)
White	353	(87.2)
Black	5	(1.2)
American Indian/Alaskan Native	0	(0.0)
Asian	26	(6.4)
Hawaiian/Pacific Islander	1	(0.2)
Other	1	(0.2)
Multi-Race	2	(0.5)
Hispanic	16	(4.0)
Unknown	1	(0.2)

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

EOLA Individuals	2019	(N=405)
Underlying Illness	N	(%)
Malignant Neoplasms (Cancer)	275	(67.9)
Lung and Bronchus	39	(14.2)
Pancreas	29	(10.5)
Prostate	25	(9.1)
Colon	23	(8.4)
Female Genital Organs	23	(8.4)
Breast	20	(7.3)
Other Digestive Organs [e.g., stomach, esophagus]	19	(6.9)
Blood	14	(5.1)
Liver	14	(5.1)
Eye, Brain and Other Parts of Central Nervous System	13	(4.7)
Ill-defined, Secondary and Unspecified Sites	12	(4.4)
Urinary tract	10	(3.6)
Lip, Oral Cavity and Pharynx	8	(2.9)
Skin	8	(2.9)
Bone	4	(1.5)
Mesothelial and Soft Tissue	4	(1.5)
Respiratory and Intrathoracic Organs	3	(1.1)
Thyroid and Other Endocrine Glands	1	(0.4)
Other Cancers	6	(2.2)
Neurological Disease	41	(10.1)
Amyotrophic lateral sclerosis	14	(34.1)
Parkinson's Disease	11	(26.8)
Polio	1	(2.4)
Other	15	(36.6)
Cardiovascular Disease	36	(8.9)
Respiratory Disease	29	(7.2)
Chronic Lower Respiratory Disease	19	(65.5)
Other	10	(34.5)
Cerebrovascular Disease	7	(1.7)
Kidney Disease	5	(1.2)
Endocrine, Nutritional and Metabolic Disease	4	(1.0)
Immune Mediated Disease [e.g., Multiple Sclerosis]	3	(0.7)
Other⁸	5	(1.2)

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

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

EOLA Individuals	2019	(N=405)
Insurance	N	(%)
Medicare or Medicare with another type of insurance	266	(65.7)
Private insurance	53	(13.1)
Medi-Cal	10	(2.5)
Other (including VA and Covered California)	0	(0.0)
Has Insurance, but unknown type	35	(8.6)
No Insurance	1	(0.2)
Unknown	40	(9.9)
Hospice and/or Palliative Care	N	(%)
Enrolled	346	(85.4)
Not Enrolled	31	(7.7)
Unknown	28	(6.9)
Aid-in-Dying Drugs	N	(%)
Cardiotonic, Opioid, Sedative	319	(78.8)
Sedative	8	(2.0)
Other	19	(4.7)
Unknown	59	(14.6)
Patient Informed Family of Decision	N	(%)
Yes	340	(84.0)
No	13	(3.2)
No Family to Inform	7	(1.7)
Unknown	45	(11.1)
Physician or Trained Healthcare Provider Present at Ingestion	N	(%)
Yes	194	(47.9)
Attending Physician	114	(58.8)
Other Physician	10	(5.2)
Other Healthcare Provider	70	(36.1)
No	58	(14.3)
Unknown	153	(37.8)
Location Where Aid-in-Dying Drugs were Ingested	N	(%)
Private Home	357	(88.1)
Assisted-Living Residence	29	(7.2)
Nursing Home	12	(3.0)
In-patient Hospice Residence	4	(1.0)
Acute Care Hospital	1	(0.2)
Other	2	(0.5)