

# CALIFORNIA END OF LIFE OPTION ACT 2017 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.<sup>1</sup> 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.*

This report presents data as reported to CDPH from the EOLA-mandated physician reporting forms received between January 1, 2017, and December 31, 2017, and reflects information on individuals who were prescribed aid-in-dying drugs and died in 2017. The information collected has been aggregated to protect the privacy of the individuals.

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<sup>1</sup> Assembly Bill x2 15 (Eggman), Chapter 1, Statutes of 2015.

For the year ending December 31, 2017, 577 individuals received prescriptions under the Act. 374 individuals died following their ingestion of the prescribed aid-in-dying drug(s). Of the 374 individuals, 90.4 percent were 60 years of age or older, 95.2 percent had health insurance and 83.4 percent were receiving hospice and/or palliative care.

## **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 contained in physicians' forms and California death certificates as of December 31, 2017.

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**

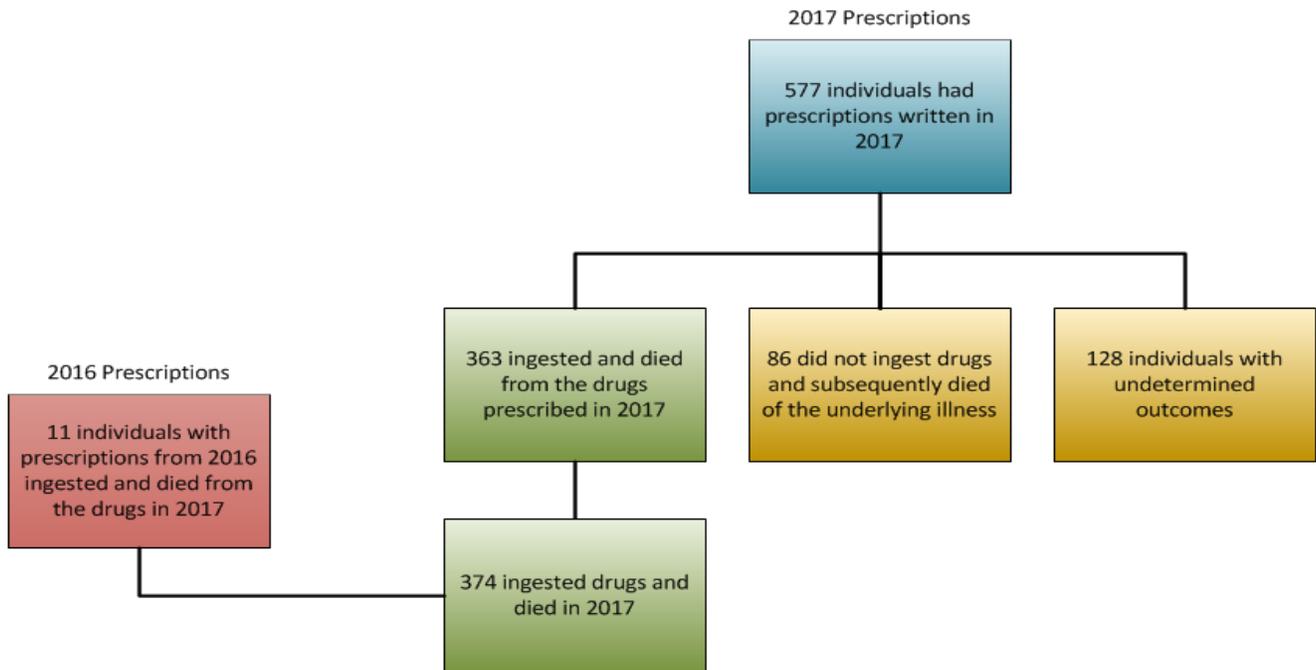
For the calendar year 2017, 632 individuals started the end-of-life option process, as set forth in the Act, by making two verbal requests to their physicians at least 15 days apart. 241 unique physicians prescribed 577 individuals aid-in-dying drugs. Of the 577 individuals who were prescribed such drugs, 363, or 62.9 percent, were reported by their physician to have died following ingestion of aid-in-dying drugs prescribed under EOLA; and 86 individuals, or 14.9 percent, died without ingestion of the prescribed aid-in-dying drug(s). The outcome of the remaining 128 individuals, or 22.2 percent, who have been prescribed aid-in-dying drugs is currently undetermined, as there has been no outcome reported for these individuals within the period covered by this report. 11 individuals prescribed medications in 2016, died from ingesting the drugs in 2017. As a result, the report demographics includes the 374 individuals who ingested and subsequently died from drugs prescribed by physicians during the 2017 calendar year. A chart illustrating the outcomes is provided on the next page as Figure 1.

The rate for those who died following ingestion of aid-in-dying drugs was 13.5 per 10,000 total deaths<sup>2</sup> based on 269,044 deaths in California for 2017.

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<sup>2</sup> This rate does not include any deaths following the ingestion of prescribed drugs after December 31, 2017 and is based on a preliminary total for all California deaths occurring in 2017.

**Figure 1: Summary of EOLA Prescriptions Written in 2017**



**Characteristics of Individuals**

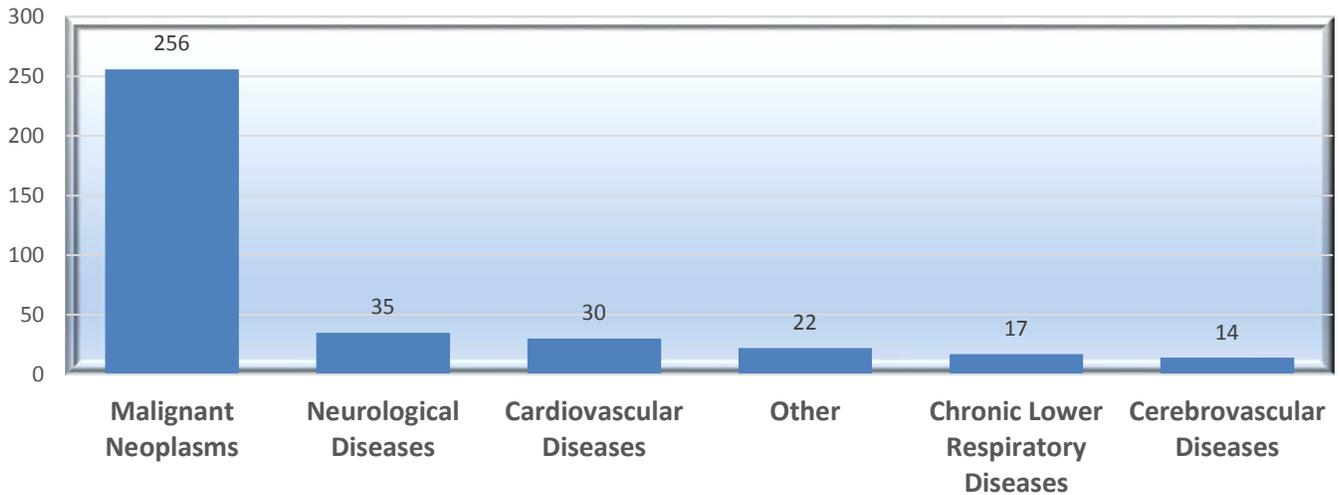
Of the 374 individuals who died pursuant to EOLA during 2017, 9.6 percent were under 60 years of age, 77.0 percent were 60-89 years of age, and 13.4 percent were 90 years of age and older. The median age was 74 years. At the time of death, the decedents were 88.9 percent white, 50.8 percent were female; 83.4 percent were receiving hospice and/or palliative care, and 72.7 percent had at least some level of college education. A summary of this information is set forth in Table 1.

Of the 374 individuals who died pursuant to EOLA during 2017, the majority, or 68.5 percent of their underlying illnesses, were identified as malignant neoplasms (cancer). Neurological disorders such as Amyotrophic Lateral Sclerosis and Parkinson’s accounted for the second largest underlying illness grouping, totaling 9.4 percent.

The remaining major categories of underlying illnesses were documented as: cardiovascular diseases (8.0 percent), chronic lower respiratory diseases (non-cancer; 4.5 percent), cerebrovascular diseases (3.7 percent), and other underlying illnesses (5.9 percent). The data are presented in Figure 2.

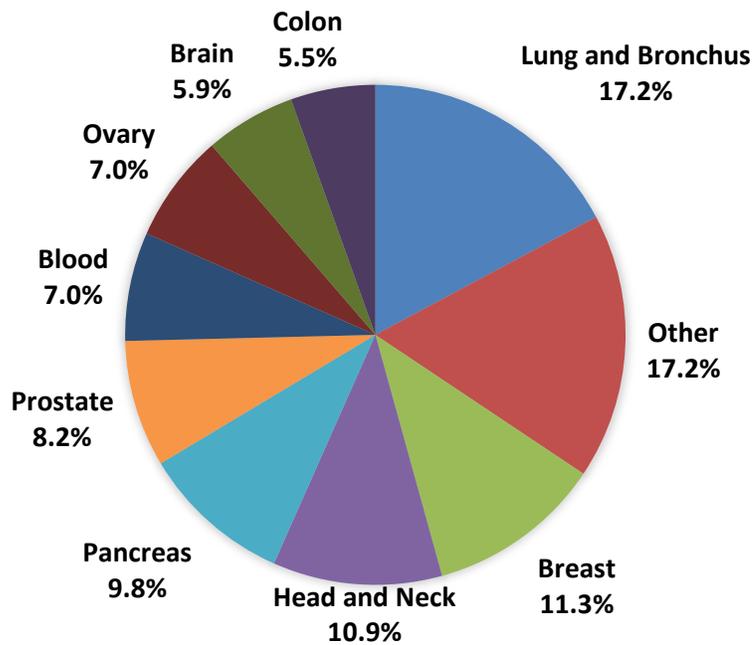
Certifiers (physicians, coroners, and medical examiners) report the underlying terminal disease as the cause of death on the death certificates. This approach complies with applicable law; best ensures the reliability and usefulness of data collected from the death certificate for state, national, and 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 2017**



Among those with malignant cancer as the underlying terminal disease – the largest group of individuals who utilized the Act – lung cancer accounted for 17.2 percent, breast cancer accounted for 11.3 percent, head and neck cancers made up 10.9 percent, pancreatic cancer comprised 9.8 percent, and 8.2 percent had prostate cancer. Other malignant neoplasms accounted for the remaining 42.6 percent, as shown in Figure 3.

**Figure 3: Percentage Summary of EOLA Individuals by Malignant Neoplasm Type**



Most of the individuals who participated in EOLA had some form of health insurance. Medicare and/or Medicaid accounted for 58.8 percent of individuals, followed by public/private insurance at 25.5 percent. 58 individuals, or 15.5 percent, had undetermined health insurance coverage.

**Table 1. Characteristics of the End of Life Option Act individuals who died following ingestion of aid-in-dying drug**

Characteristics	2017	
	(N=374)	
<b>Age</b>	<b>N (%)</b>	
Under 60	36	(9.6)
60-69	88	(23.5)
70-79	93	(24.9)
80-89	107	(28.6)
90 and Over	50	(13.4)
Median Year (range)	74	(31-106)
<b>Gender</b>	<b>N (%)</b>	
Female	190	(50.8)
Male	176	(47.1)
Unknown	8	(2.1)
<b>Education</b>	<b>N (%)</b>	
No High School Diploma	13	(3.5)
High School Diploma or General Educational Development	80	(21.4)
Some College no Degree	67	(17.9)
Associate, Bachelor or Master Degree	183	(48.9)
Doctorate or Professional Degree	22	(5.9)
Unknown	9	(2.4)
<b>Race/Ethnicity</b>	<b>N = 389<sup>3</sup> (%)</b>	
White	346	(88.9)
Asian/Native American/Pacific Islander	20	(5.1)
Hispanic	15	(3.9)
Unknown	8	(2.1)
Black	0	(0.0)
<b>End of Life Care</b>	<b>N (%)</b>	
Hospice and/or Palliative Care		
Enrolled	312	(83.4)
Not Enrolled	42	(11.2)
Unknown	20	(5.4)

<sup>3</sup> Numerator includes EOLA patients of multiple races and/or ethnicities.

<b>Insurance</b>	<b>N (%)</b>	
Medicare	198	(52.9)
Medi-Cal	11	(2.9)
Medicare/Medi-Cal (Dual Eligible)	11	(2.9)
Private Insurance	52	(13.9)
Medicare/Medi-Cal and Private Supplemental Insurance	43	(11.5)
Has Insurance but Unknown Type	41	(11.0)
Unknown	17	(4.5)
No Insurance	1	(0.3)
<b>Illness</b>	<b>N (%)</b>	
<b>Malignant Neoplasms</b>	<b>256</b>	<b>(68.5)</b>
Lung and Bronchus	44	(17.2)
Breast	29	(11.3)
Head and Neck	28	(10.9)
Pancreas	25	(9.8)
Prostate	21	(8.2)
Blood	18	(7.0)
Ovary	18	(7.0)
Brain	15	(5.9)
Colon	14	(5.5)
Other	44	(17.2)
<b>Neurological Disease</b>	<b>35</b>	<b>(9.4)</b>
<b>Cardiovascular Diseases</b>	<b>30</b>	<b>(8.0)</b>
<b>Chronic Lower Respiratory Diseases</b>	<b>17</b>	<b>(4.5)</b>
<b>Cerebrovascular Diseases</b>	<b>14</b>	<b>(3.7)</b>
<b>Other</b>	<b>22</b>	<b>(5.9)</b>

## 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 2016 or 2017, and subsequently died in 2017 of ingesting the prescribed drugs. The information collected by CDPH has been aggregated to protect the privacy of the participants.