

# CALIFORNIA END OF LIFE OPTION ACT 2016 DATA REPORT

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For more information:

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

Contact: [EOLInfo@cdph.ca.gov](mailto:EOLInfo@cdph.ca.gov)



## 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 followup 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 June 9, 2016, and December 31, 2016, and reflects information on individuals who were prescribed aid-in-dying drugs in 2016. The information collected has been aggregated to protect the privacy of the individuals. Subsequent annual reports will encompass 12 months of data.

For the partial year ending December 31, 2016, 191 individuals received prescriptions under EOLA. 111 individuals died following their ingestion of the prescribed aid-in-dying drug(s). Of the 111 individuals,

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

87.4 percent were 60 years of age or older, 96.4 percent had health insurance, and 83.8 percent were receiving hospice and/or palliative care. As this report covers only six-months of data, caution should be exercised in drawing conclusions based on the numbers reported.

## **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 is based on the information contained in physicians' forms and California death certificates as of December 31, 2016.

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**

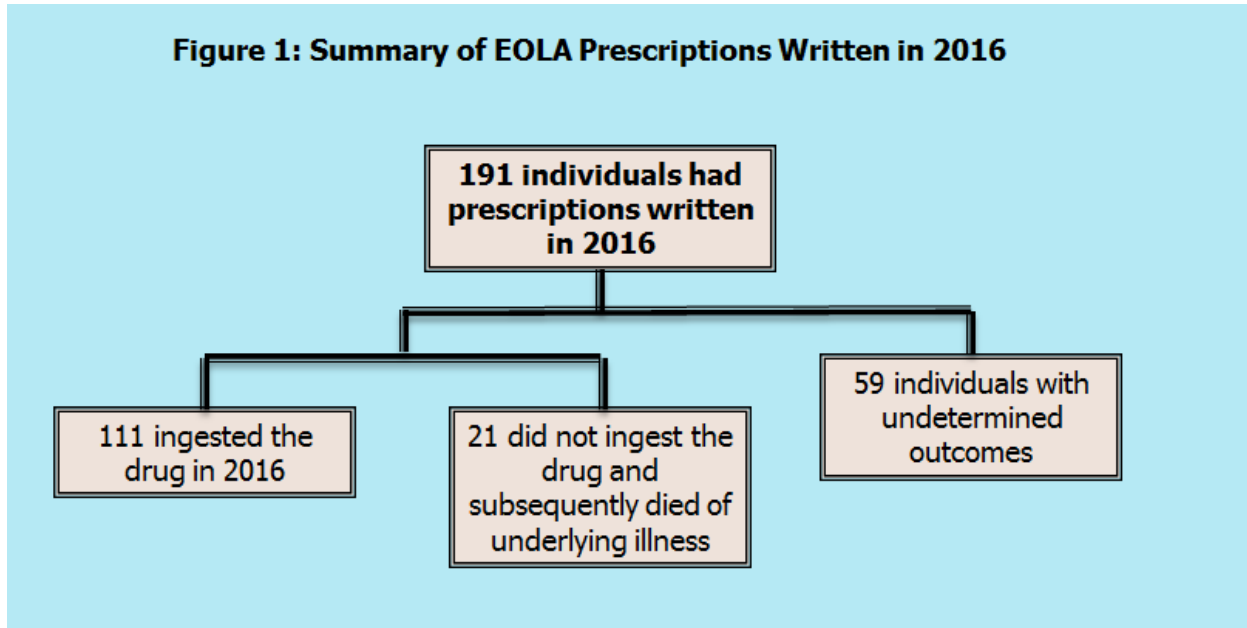
From June 9, 2016 through December 31, 2016, 258 individuals started the end-of-life option process, as set forth in the Act, by making two verbal requests to their physicians at least 15 days apart. 173 unique physicians prescribed 191 individuals aid-in-dying drugs. Of the 191 individuals who were prescribed such drugs, 111, or 58.1 percent, were reported by their physician to have died following ingestion of aid-in-dying drugs prescribed under EOLA; and 21 individuals, or 11.0 percent, died without ingestion of the prescribed aid-in-dying drug(s). The outcome of the remaining 59 individuals, or 30.9 percent, who have been prescribed aid-in-dying drugs, is currently undetermined as there has been no outcome reported for these individuals within the time period covered by this report. 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 6.06 per 10,000 total deaths<sup>2</sup> based on 183,265 deaths in California from June 9, 2016 to December 31, 2016.

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<sup>2</sup> This rate does not include any deaths following the ingestion of prescribed drugs after December 31, 2016. Total deaths in California include only those deaths that occurred from 00:00 hours June 9, 2016, to 23:59 December 31, 2016, and is not based on all deaths occurring in California in 2016.

**Figure 1: Summary of EOLA Prescriptions Written in 2016**



### **Characteristics of Individuals**

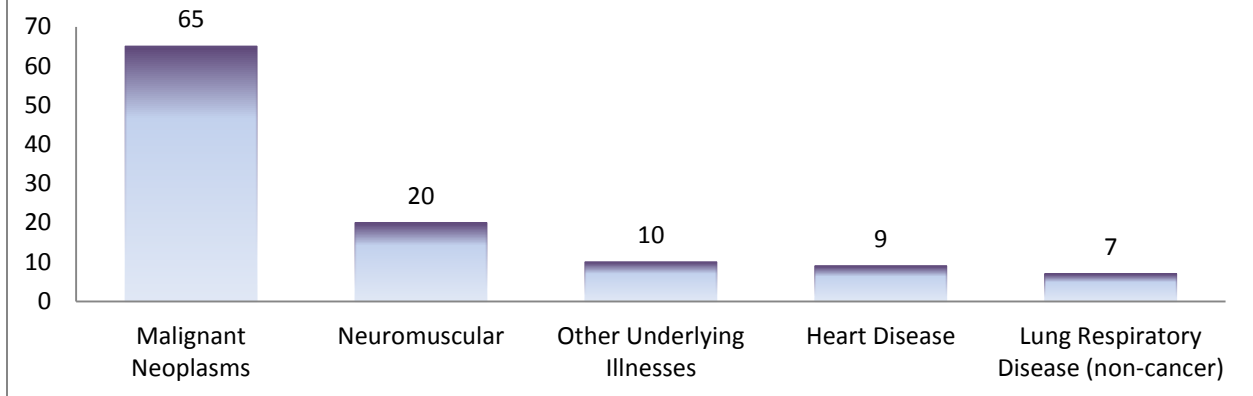
Of the 111 individuals who died pursuant to EOLA during 2016, 12.6 percent were under 60 years of age, 75.6 percent were 60-89 years of age, and 11.7 percent were 90 years of age and older. The median age was 73 years. At the time of death, the decedents were 89.5 percent white, 54.1 percent were female; 83.8 percent were receiving hospice and/or palliative care, and 72.1 percent had at least some level of college education. A summary of this information is set forth in Table 1.

Of the 111 individuals who died pursuant to EOLA during 2016, the majority, or 58.6 percent, of their underlying illnesses, were identified as malignant neoplasms (cancer). Neuromuscular disorders such as ALS<sup>3</sup> and Parkinson’s accounted for the second largest underlying illness grouping, totaling 18.0 percent. The remaining major categories of underlying illnesses were documented as: heart disease (8.1 percent), lung respiratory diseases (non-cancer) with 6.3 percent, and other underlying illnesses (9.0 percent). This data is presented below 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.

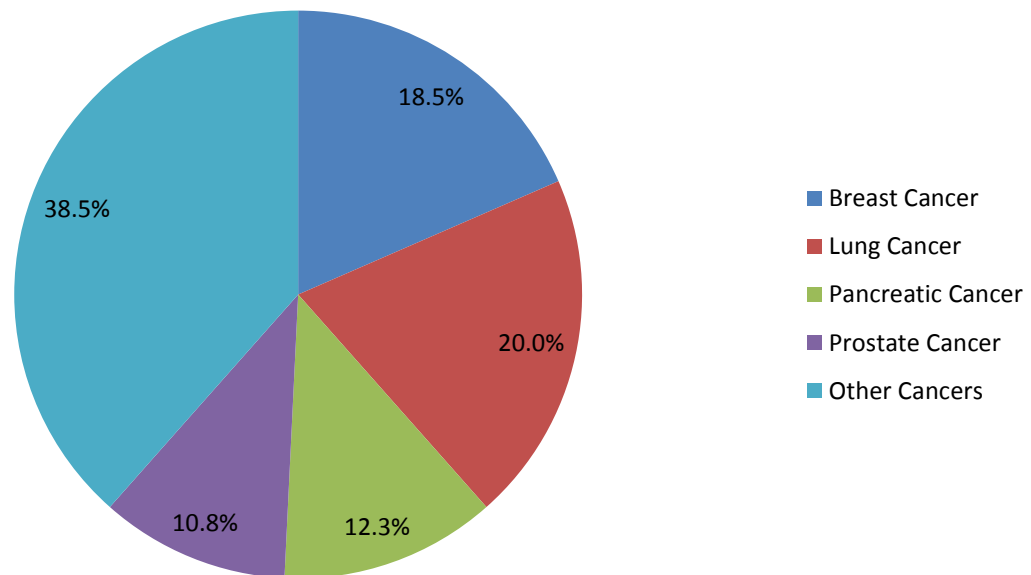
<sup>3</sup> Amyotrophic Lateral Sclerosis.

**Figure 2: Major Illness Categories for EOLA Individuals in 2016**



Among those with malignant cancer as the underlying terminal disease – the largest group of individuals who utilized the Act – lung cancer accounted for 20.0 percent, breast cancer accounted for 18.5 percent, pancreatic cancer comprised 12.3 percent, and 10.8 percent had prostate cancer. Other malignant neoplasms accounted for the remaining 38.5 percent, as shown below 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 Medi-Cal accounted for 56.8 percent of individuals, followed by public/private insurance at 30.6 percent. Ten individuals, or 9.0 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	2016	
	(N=111)	
<b>Age</b>	<b>N (%)</b>	
Under 60	14	(12.6)
60-69	25	(22.5)
70-79	30	(27.0)
80-89	29	(26.1)
90 and Over	13	(11.7)
Median Year (range)	73	(41-99)
<b>Gender</b>	<b>N (%)</b>	
Male	51	(45.9)
Female	60	(54.1)
<b>Education</b>	<b>N (%)</b>	
No High School Diploma	6	(5.4)
High School Diploma or General Educational Development	25	(22.5)
Some College no Degree	16	(14.4)
Associate, Bachelor or Master Degree	51	(45.9)
Doctorate or Professional Degree	13	(11.7)
<b>Race/Ethnicity</b>	<b>N = 114<sup>4</sup> (%)</b>	
White	102	(89.5)
Asian	6	(5.3)
Black	3	(2.6)
Hispanic	3	(2.6)
<b>End of Life Care</b>	<b>N (%)</b>	
Hospice and/or Palliative Care		
Enrolled	93	(83.8)
Not Enrolled	13	(11.7)
Unknown	5	(4.5)
<b>Insurance</b>	<b>N (%)</b>	
Medicare	49	(44.2)
Medi-Cal	4	(3.6)
Medicare/Medi-Cal (Dual Eligible)	10	(9.0)
Private Insurance	21	(18.9)
Medicare/Medi-Cal and Private Supplemental Insurance	13	(11.7)
Has Insurance but Unknown Type	10	(9.0)
No Insurance	4	(3.6)
<b>Illness</b>	<b>N (%)</b>	
<b>Malignant Neoplasms</b>	<b>65</b>	<b>(58.6)</b>
Breast	12	(18.5)
Lung	13	(20.0)
Prostate	7	(10.8)

<sup>4</sup> Numerator includes EOLA individuals of multiple races and/or ethnicities.

Pancreatic	8	(12.3)
Other	25	(38.5)
<b>Lung Respiratory Disease (non-cancer)</b>	<b>7</b>	<b>(6.3)</b>
<b>Heart Disease</b>	<b>9</b>	<b>(8.1)</b>
<b>Neuromuscular</b>	<b>20</b>	<b>(18.0)</b>
<b>Other</b>	<b>10</b>	<b>(9.0)</b>