# CALIFORNIA END OF LIFE OPTION ACT 2021 DATA REPORT



# For more information:

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

## Contact:

EOLInfo@cdph.ca.gov

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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. 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.

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

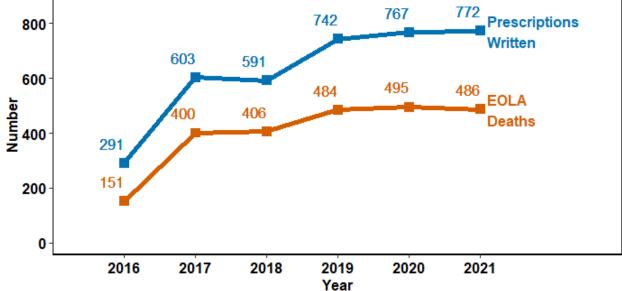
This report presents data as reported to CDPH from the EOLA-mandated physician reporting forms received between January 1, 2021 and December 31, 2021, and reflects information on individuals who were prescribed aid-in-dying drugs and died in the calendar year of 2021, as well as cumulative counts for 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, 2021, 772 individuals received prescriptions under the Act. In 2021, 486 individuals died following their ingestion of the prescribed aid-indying drug(s), which includes 38 individuals who received prescriptions prior to 2021. Of the 486 individuals, 88.5 percent<sup>2</sup> were 60 years of age or older, 98.6 percent had health insurance and 91.6 percent were receiving hospice and/or palliative care.

Since the law came into effect June 9, 2016 through December 31, 2021, prescriptions have been written for a total of 3,766 people under the Act and 2,422 individuals, or 64.3 percent. have died from ingesting the medications. Of the 2.422 individuals who have died under the Act, 2,148, or 88.7 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. A chart illustrating the number of prescriptions written and deaths under the Act from 2016 through 2021 is provided below in Figure 1.



Figure 1: Summary of EOLA Prescriptions and Deaths 2016-2021



<sup>&</sup>lt;sup>2</sup> Percentages presented in this Data Report are rounded to the nearest tenth. Due to rounding, percentages when totaled may not equal 100.0 percent.

#### 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 2021.

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

### Participation in the End-of-Life Option Activities

For the calendar year 2021, CDPH received forms from 767 individuals who 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 277 physicians prescribed 772 individuals aidin-dying drugs. The two most common drug categories prescribed were a combination of a cardiotonic, opioid, and sedative at 84.2 percent followed by individuals who were only prescribed a sedative at 0.2 percent. Of the 772 individuals who were prescribed such drugs, 448 individuals, or 58.0 percent, were reported by their physician to have died following ingestion of aid-in-dying drugs prescribed under the Act; and 130 individuals, or 16.8 percent, died from the underlying illness or other causes. The ingestion status of the remaining 194 individuals, or 25.1 percent is unknown. Of the remaining 194 individuals, 88 individuals, or 11.4 percent, have died, but their ingestion status is unknown because follow up information is not available yet. For the remaining 106 individuals, or 13.7 percent, both death and ingestion status are pending. Furthermore, 38 individuals with prescriptions written in prior years ingested and died from the drugs during 2021. As a result, the report demographics include the 486 individuals who ingested and subsequently died during the 2021 calendar year from aid-in-dying drugs. A chart illustrating the outcomes is provided below as Figure 2.

In 2021, 486 individuals<sup>3</sup> died from ingestion of aid-in-dying drugs, a rate of 14.8 per 10,000 deaths based on 327,855<sup>4,5</sup> deaths to California residents in 2021. Excluding COVID-19 deaths, the rate of individuals who died from ingestion of aid-in-dying drugs was 17.3 per 10,000 deaths based on 280,498 non-COVID-19 deaths to California residents in 2021.

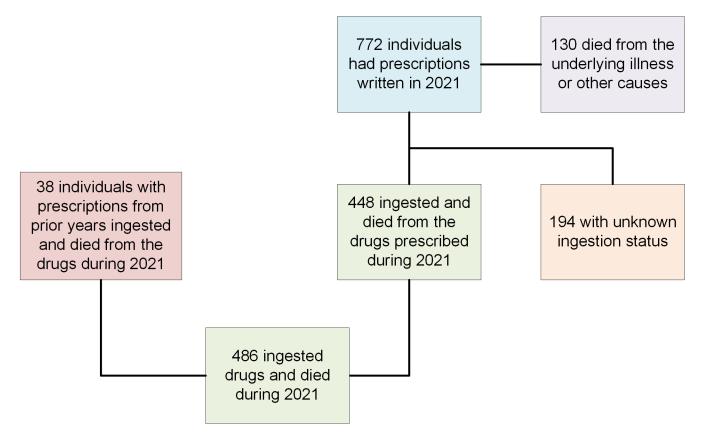
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<sup>&</sup>lt;sup>3</sup> Total of individuals who received aid-in-dying prescriptions that died in 2021.

<sup>&</sup>lt;sup>4</sup> California Department of Public Health, California Comprehensive Death File, created in February 2022.

<sup>&</sup>lt;sup>5</sup> Does not include out-of-state California resident deaths as of February 2022.

Figure 2: Summary of EOLA Prescriptions Written in Prior Years and Drugs Ingested in 2021<sup>6</sup>



#### **Characteristics of Individuals**

Of the 486 individuals who died pursuant to EOLA during 2021, 11.5 percent were under 60 years of age, 74.7 percent were 60-89 years of age, and 13.8 percent were 90 years of age and older. The median age was 76 years. The decedents were 85.6 percent white, 52.3 percent were male; 91.6 percent were receiving hospice and/or palliative care, and 76.7 percent had at least some level of college education. In addition, 87.0 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 486 individuals who died pursuant to EOLA during 2021, 66.0 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 13.2 percent.

The remaining major categories of underlying illnesses were documented as: cardiovascular diseases (8.4 percent), respiratory diseases (non-cancer; 6.6 percent), and other diseases (5.8 percent). The other diseases were documented as: kidney disease (2.1 percent); endocrine, nutritional and metabolic disease (1.4 percent); immune mediated disease (0.6

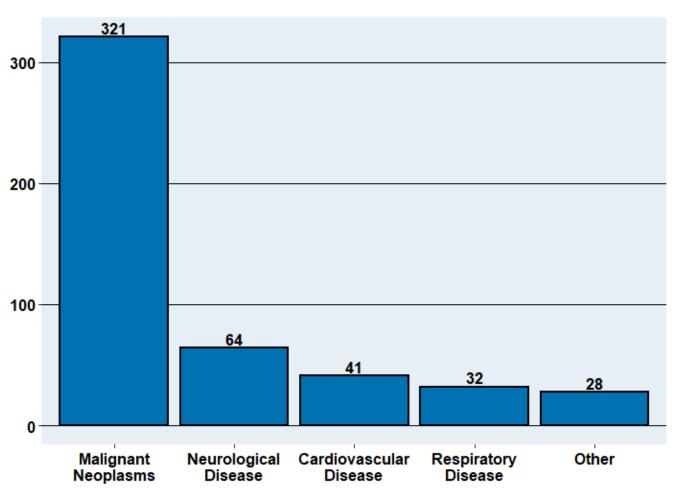
Page **5** of **14** 

<sup>&</sup>lt;sup>6</sup> Based on forms received as of February 1, 2022.

percent); cerebrovascular disease (0.4 percent); and other (1.2 percent). The data are presented in Figure 3 below.

Certifiers<sup>7</sup> (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>&</sup>lt;sup>7</sup> 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 and bronchus cancer accounted for 12.8 percent, pancreatic cancer accounted for 11.5 percent, colon cancer accounted for 7.8 percent, both cancer of the female genital organs and other digestive organs constituted 7.5 percent, respectively, and both blood and breast cancer comprised of 6.9 percent, respectively. Other malignant neoplasms accounted for the remaining 39.3 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.

126 100 -50 41 37 25 24 24 22 22 0 Blood Colon Female Other Breast Other Lung Pancreas and Genital Digestive Bronchus Organs Organs

Figure 4: Major Malignant Neoplasm Types for EOLA Individuals in 2021

Most of the individuals who participated in the Act had some form of health insurance (98.6 percent). Of those with health insurance, 52.3 percent of individuals had Medicare or Medicare combined with another type of insurance, while 16.0 percent of individuals had only private insurance. Individuals who had an unspecified type of insurance comprised 28.6 percent of the Act participants followed by individuals with only Medi-Cal at 1.0 percent, and individuals with other governmental insurance (e.g., Covered California or Veterans Affairs) at 0.6 percent. 7 individuals, or 1.4 percent, had undetermined health insurance coverage.

A physician or trained healthcare professional was present for 209 individuals, or 43.0 percent, at the time of ingestion of the aid-in-dying drug. Of the 209 individuals who had a physician or trained healthcare professional present at the time of ingestion, another healthcare provider was present for 46.4 percent of individuals, followed by an attending physician, who was present for 45.0 percent of individuals. Another physician was present for 8.6 percent of individuals. The majority, or 93.4 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 2021 or prior years, and subsequently died in 2021 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	2021	(N=486)	2020	(N=495)	2016- 2019	(N=1441)	Total	(N=2422)
Age	N	(%)	N	(%)	N	(%)	N	(%)
Under 60	56	(11.5)	44	(8.9)	171	(11.9)	271	(11.2)
60-69	91	(18.7)	111	(22.4)	317	(22.0)	519	(21.4)
70-79	159	(32.7)	168	(33.9)	427	(29.6)	754	(31.1)
80-89	113	(23.3)	110	(22.2)	346	(24.0)	569	(23.5)
90 and Over	67	(13.8)	62	(12.5)	180	(12.5)	309	(12.8)
Median Age (Range)	76	(30-105)	75	(27-107)	75	(23-106)	75	(23-107)
Gender	N	(%)	N	(%)	N	(%)	N	(%)
Female	232	(47.7)	252	(50.9)	710	(49.3)	1194	(49.3)
Male	254	(52.3)	243	(49.1)	731	(50.7)	1228	(50.7)
Education	N	(%)	N	(%)	N	(%)	N	(%)
No High School Diploma	15	(3.1)	10	(2.0)	49	(3.4)	74	(3.1)
HS Diploma or GED	92	(18.9)	104	(21.0)	291	(20.2)	487	(20.1)
Some College	68	(14.0)	88	(17.8)	264	(18.3)	420	(17.3)
Associate's Degree	37	(7.6)	49	(9.9)	93	(6.5)	179	(7.4)
Bachelor's Degree	134	(27.6)	131	(26.5)	355	(24.6)	620	(25.6)
Master's Degree	88	(18.1)	64	(12.9)	227	(15.8)	379	(15.6)
Doctorate or Professional Degree	46	(9.5)	46	(9.3)	151	(10.5)	243	(10.0)
Unknown	6	(1.2)	3	(0.6)	11	(8.0)	20	(0.8)

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

EOLA Individuals	2021	(N=486)	2020	(N=495)	2016- 2019	(N=1441)	Total	(N=2422)
Race/Ethnicity	N	(%)	N	(%)	N	(%)	N	(%)
White	416	(85.6)	430	(86.9)	1278	(88.7)	2124	(87.7)
Black	4	(8.0)	6	(1.2)	14	(1.0)	24	(1.0)
American Indian/Alaska Native	0	(0.0)	0	(0.0)	1	(0.1)	1	(0.0)
Asian	34	(7.0)	38	(7.7)	81	(5.6)	153	(6.3)
Hawaiian/Pacific Islander	0	(0.0)	1	(0.2)	3	(0.2)	4	(0.2)
Other	0	(0.0)	1	(0.2)	2	(0.1)	3	(0.1)
Multi-race	6	(1.2)	2	(0.4)	12	(0.8)	20	(8.0)
Hispanic	25	(5.1)	17	(3.4)	49	(3.4)	91	(3.8)
Unknown	1	(0.2)	0	(0.0)	1	(0.1)	2	(0.1)

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

EOLA Individuals	2021	(N=486)	2020	(N=495)	2016- 2019	(N=1441)	Total	(N=2422)
Underlying Illness	N	(%)	N	(%)	N	(%)	N	(%)
Malignant Neoplasms (Cancer)	321	(66.0)	344	69.5	1014	70.4	1679	69.3
Lung and Bronchus	41	(12.8)	58	(16.9)	163	(16.1)	262	(15.6)
Pancreas	37	(11.5)	38	(11.0)	94	(9.3)	169	(10.1)
Colon	25	(7.8)	24	(7.0)	71	(7.0)	120	(7.1)
Female Genital Organs	24	(7.5)	22	(6.4)	67	(6.6)	113	(6.7)
Other Digestive Organs	24	(7.5)	25	(7.3)	65	(6.4)	114	(6.8)
Blood	22	(6.9)	19	(5.5)	64	(6.3)	105	(6.3)
Breast	22	(6.9)	20	(5.8)	80	(7.9)	122	(7.3)
Prostate	21	(6.5)	24	(7.0)	84	(8.3)	129	(7.7)
Lip, Oral Cavity, and Pharynx	18	(5.6)	13	(3.8)	43	(4.2)	74	(4.4)
Eye, Brain and Other Parts of Central Nervous System	17	(5.3)	23	(6.7)	58	(5.7)	98	(5.8)
Mesothelial and Soft Tissue	16	(5.0)	7	(2.0)	17	(1.7)	40	(2.4)
Skin	13	(4.0)	7	(2.0)	29	(2.9)	49	(2.9)
Urinary Tract	13	(4.0)	19	(5.5)	47	(4.6)	79	(4.7)
Ill-defined, Secondary, and Unspecified Sites	11	(3.4)	18	(5.2)	45	(4.4)	74	(4.4)
Liver	7	(2.2)	16	(4.7)	39	(3.8)	62	(3.7)
Respiratory and Intrathoracic Organs	4	(1.2)	3	(0.9)	9	(0.9)	16	(1.0)
Thyroid and Other Endocrine Glands	2	(0.6)	2	(0.6)	9	(0.9)	13	(0.8)
Bone	1	(0.3)	1	(0.3)	7	(0.7)	9	(0.5)
Other Cancers	3	(0.9)	5	(1.5)	23	(2.3)	31	(1.8)

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

EOLA Individuals	2021	(N=486)	2020	(N=495)	2016- 2019	(N=1441)	Total	(N=2422)
Underlying Illness	N	(%)	N	(%)	N	(%)	N	(%)
Neurological Disease	64	(13.2)	56	(11.3)	152	(10.5)	272	(11.2)
Amyotrophic Lateral Sclerosis	31	(48.4)	32	(57.1)	89	(58.6)	152	(55.9)
Parkinson's Disease	13	(20.3)	8	(14.3)	26	(17.1)	47	(17.3)
Polio	0	(0.0)	0	(0.0)	2	(1.3)	2	(0.7)
Other	20	(31.3)	16	(28.6)	35	(23.0)	71	(26.1)
Cardiovascular Disease	41	(8.4)	27	(5.5)	107	(7.4)	175	(7.2)
Respiratory Disease	32	(6.6)	39	(7.9)	89	(6.2)	160	(6.6)
Chronic Lower Respiratory Disease	23	(71.9)	31	(79.5)	64	(71.9)	118	(73.8)
Other	9	(28.1)	8	(20.5)	25	(28.1)	42	(26.3)
Kidney Disease	10	(2.1)	7	(1.4)	18	(1.2)	35	(1.4)
Endocrine, Nutritional and Metabolic Disease	7	(1.4)	8	(1.6)	9	(0.6)	24	(1.0)
Immune Mediated Disease [e.g., Multiple Sclerosis]	3	(0.6)	2	(0.4)	9	(0.6)	14	(0.6)
Cerebrovascular Disease	2	(0.4)	5	(1.0)	19	(1.3)	26	(1.1)
Other <sup>8</sup>	6	(1.2)	7	(1.4)	24	(1.7)	37	(1.5)

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	2021	(N=486)	2020	(N=495)	2016- 2019	(N=1441)	Total	(N=2422)
Insurance	N	(%)	N	(%)	N	(%)	N	(%)
Medicare or Medicare with another type of insurance	254	(52.3)	301	(60.8)	903	(62.7)	1458	(60.2)
Private Insurance	78	(16.0)	70	(14.1)	214	(14.9)	362	(14.9)
Medi-Cal	5	(1.0)	9	(1.8)	35	(2.4)	49	(2.0)
Other Governmental Insurance	3	(0.6)	3	(0.6)	6	(0.4)	12	(0.5)
Has Insurance, but unknown type	139	(28.6)	57	(11.5)	185	(12.8)	381	(15.7)
No Insurance	0	(0.0)	0	(0.0)	6	(0.4)	6	(0.2)
Unknown	7	(1.4)	55	(11.1)	92	(6.4)	154	(6.4)
Hospice and/or Palliative Care	N	(%)	N	(%)	N	(%)	N	(%)
Enrolled	445	(91.6)	433	(87.5)	1270	(88.1)	2148	(88.7)
Not Enrolled	39	(8.0)	52	(10.5)	129	(9.0)	220	(9.1)
Unknown	2	(0.4)	10	(2.0)	42	(2.9)	54	(2.2)
Aid-in-Dying Drugs	N	(%)	N	(%)	N	(%)	N	(%)
Cardiotonic, Opioid, Sedative	409	(84.2)	419	(84.6)	687	(47.7)	1515	(62.6)
Sedative	1	(0.2)	3	(0.6)	518	(35.9)	522	(21.6)
Other	27	(5.6)	32	(6.5)	88	(6.1)	147	(6.1)
Unknown	49	(10.1)	41	(8.3)	148	(10.3)	238	(9.8)
Patient Informed Family of Decision	N	(%)	N	(%)	N	(%)	N	(%)
Yes	423	(87.0)	424	(85.7)	1242	(86.2)	2089	(86.3)
No	4	(8.0)	8	(1.6)	36	(2.5)	48	(2.0)
No Family to Inform	8	(1.6)	10	(2.0)	27	(1.9)	45	(1.9)
Unknown	51	(10.5)	53	(10.7)	136	(9.4)	240	(9.9)

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

EOLA Individuals	2021	(N=486)	2020	(N=495)	2016- 2019	(N=1441)	Total	(N=2422)
Physician or Trained Healthcare Provider Present at Ingestion	N	(%)	N	(%)	N	(%)	N	(%)
Yes	209	(43.0)	182	(36.8)	602	(41.8)	993	(41.0)
Attending Physician	94	(45.0)	81	(44.5)	385	(64.0)	560	(56.4)
Other Physician	18	(8.6)	18	(9.9)	39	(6.5)	75	(7.6)
Other Healthcare Provider	97	(46.4)	83	(45.6)	178	(29.6)	358	(36.1)
No	29	(6.0)	36	(7.3)	159	(11.0)	224	(9.2)
Unknown	248	(51.0)	277	(56.0)	680	(47.2)	1205	(49.8)
Location Where Aid-in-Dying Drugs were Ingested	N	(%)	N	(%)	N	(%)	N	(%)
Private Home	454	(93.4)	454	(91.7)	1299	(90.1)	2207	(91.1)
Assisted-Living Residence	16	(3.3)	15	(3.0)	75	(5.2)	106	(4.4)
Nursing Home	4	(0.8)	19	(3.8)	38	(2.6)	61	(2.5)
In-patient Hospice Residence	10	(2.1)	3	(0.6)	21	(1.5)	34	(1.4)
Acute Care Hospital	0	(0.0)	2	(0.4)	2	(0.1)	4	(0.2)
Other	2	(0.4)	2	(0.4)	6	(0.4)	10	(0.4)