CALIFORNIA END OF LIFE OPTION ACT 2022 DATA REPORT



For more information visit the CDPH End of Life Option Act page

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Executive Summary

California's End of Life Option Act (EOLA) became effective on June 9, 2016. The EOLA allows terminally ill adults living in California to obtain and self-administer aid-in-dying drugs. The EOLA 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 Website. 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

² Senate Bill 380 (Eggman), Chapter 542, Statues of 2021

This report presents data as reported to CDPH from the EOLA-mandated physician reporting forms received between January 1, 2022 and December 31, 2022, and reflects information on individuals who were prescribed aid-in-dying drugs and died in the calendar year of 2022, 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, 2022, 1,270 individuals received prescriptions under the EOLA. In 2022, 853 individuals died following their ingestion of the prescribed aidin-dying drug(s), which includes 50 individuals who received prescriptions prior to 2022. Of the 853 individuals, 91.9 percent³ were 60 years of age or older, 98.1 percent had health insurance and 95.4 percent were receiving hospice and/or palliative care.

Since the law came into effect June 9, 2016 through December 31, 2022, prescriptions have been written for a total of 5,168 people under the EOLA and 3,349 individuals, or 64.8 percent, have died from ingesting the medications. Of the 3,349 individuals who have died under the EOLA, 3,033, or 90.6 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 EOLA from 2016 through 2022 is provided below in Figure 1.

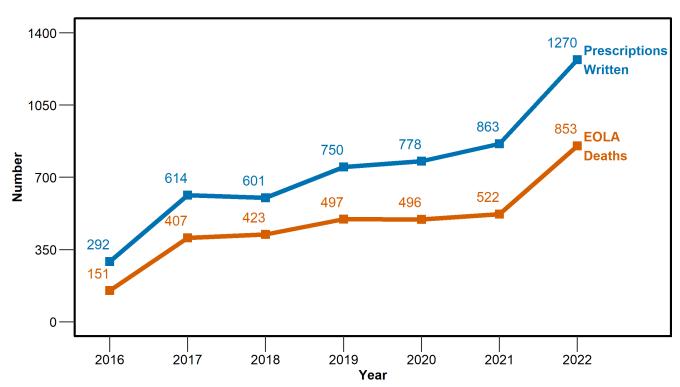


Figure 1: Summary of EOLA Prescriptions and Deaths 2016-2022

³ 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 EOLA 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 2022.

More information on the EOLA, reporting process, and required forms can be found on the CDPH End of Life Option Act page.

Participation in the End-of-Life Option Activities

For the calendar year 2022, CDPH received forms from 1,254 individuals who started the end-of-life option process, as set forth in the EOLA, by making two verbal requests to their physicians at least 48 hours apart. For 2022, as a result of Senate Bill 380 (Chapter 542, Statues of 2021), the duration between oral requests was reduced from 15 days to 48 hours. Of 1,254 individuals who started the end-of-life option process, 1,204 received a prescription in 2022 while the remaining 50 have not yet received a prescription prior to the end of 2022. Out of the 1,204 individuals who started the end-of-life option process in 2022 and received a prescription during 2022, 947 individuals, or 78.7 percent, waited less than 15 days between the two verbal requests. It is worth noting that there was an additional 66 individuals who received a prescription during 2022 but had begun the request process prior to 2022.

A total of 341 physicians prescribed 1,270 individuals aid-in-dying drugs. The most common drug category prescribed was a combination of a cardiotonic, opioid, and sedative at 89.0 percent. Of the 1,270 individuals who were prescribed such drugs, 803 individuals, or 63.2 percent, were reported by their physician to have died following ingestion of aid-in-dying drugs prescribed under the EOLA; and 173 individuals, or 13.6 percent, died from the underlying illness or other causes. The ingestion status of the remaining 294 individuals, or 23.1 percent is unknown. Of the remaining 294 individuals, 136 individuals, or 10.7 percent, have died, but their ingestion status is unknown because follow up information is not available yet. For the remaining 158 individuals, or 12.4 percent, both death and ingestion status are pending. Furthermore, 50 individuals with prescriptions written in prior years ingested and died from the drugs during 2022. As a result, the report demographics include the 853 individuals who ingested and subsequently died during the 2022 calendar year from aid-in-dying drugs. A chart illustrating the outcomes is provided below as Figure 2.

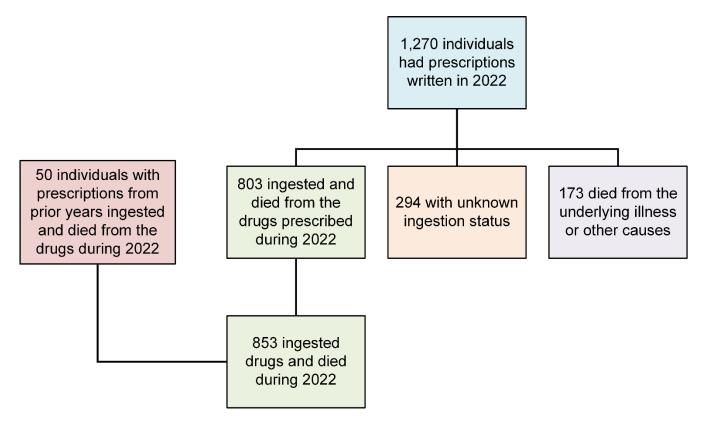
In 2022, 853 individuals⁴ died from ingestion of aid-in-dying drugs, a rate of 27.7 per 10,000 deaths based on 308,015^{5,6} deaths to California residents in 2022. Excluding COVID-19 deaths, the rate of individuals who died from ingestion of aid-in-dying drugs was 29.8 per 10,000 deaths based on 286,177 non-COVID-19 deaths to California residents in 2022.

⁴ Total of individuals who received aid-in-dying prescriptions that died in 2022.

⁵ California Department of Public Health, California Comprehensive Death File, created in January 2023.

⁶ Does not include out-of-state California resident deaths as of January 2023.

Figure 2: Summary of EOLA Prescriptions Written in Prior Years and Drugs Ingested in 2022



Characteristics of Individuals

Of the 853 individuals who died pursuant to the EOLA during 2022, 8.1 percent were under 60 years of age, 74.8 percent were 60-89 years of age, and 17.1 percent were 90 years of age and older. The median age was 78 years. The decedents were 89.0 percent white, 51.6 percent were male; 95.4 percent were receiving hospice and/or palliative care, and 76.4 percent had at least some level of college education. In addition, 84.5 percent informed their family of their decision to participate in the EOLA. A summary of this information is set forth in Table 1 on pages 10-11 and Table 3 on pages 14-15.

Of the 853 individuals who died pursuant to the EOLA during 2022, 66.0 percent were identified as having had malignant neoplasms (cancer). Cardiovascular disease accounted for the second largest underlying illness grouping, totaling 11.8 percent.

The remaining major categories of underlying illnesses were documented as: neurological disease (8.6 percent), and respiratory diseases (non-cancer; 6.8 percent). The other diseases were documented as: kidney disease (2.0 percent); other diseases (1.8 percent); cerebrovascular disease (1.6 percent); immune mediated disease (0.8 percent); endocrine, nutritional and metabolic disease (0.6 percent). The data are presented in Figure 3 below.

Certifiers⁷ (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 EOLA.

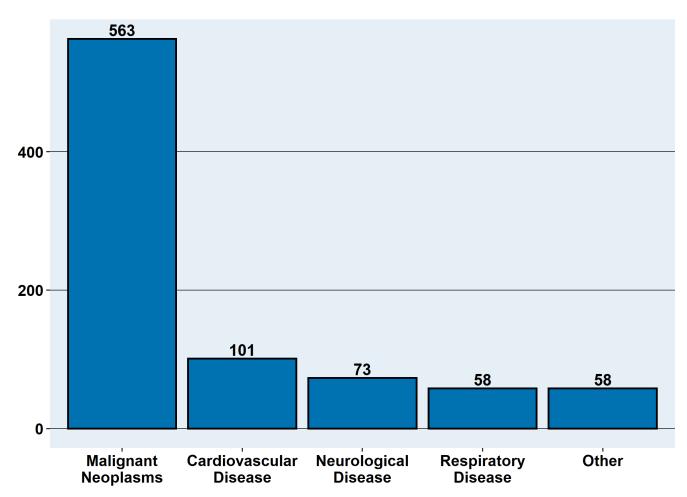


Figure 3: Major Illness Categories for EOLA Individuals in 2022

Among individuals with cancer as the underlying terminal disease – the largest group of individuals who utilized the EOLA – lung and bronchus cancer accounted for 11.2 percent, pancreatic cancer accounted for 11.0 percent, cancer of other digestive organs constituted 10.1 percent. Prostate cancer accounted for 9.2 percent and breast cancer counted for 7.8 percent. Other malignant neoplasms accounted for the remaining 50.6 percent, as shown below in Figure 4. Additional information regarding the other types of malignant neoplasms can be found in Table 2 on pages 12-13.

⁷ Health and Safety Code Section 102825(a) and Health and Safety Code Section 102860

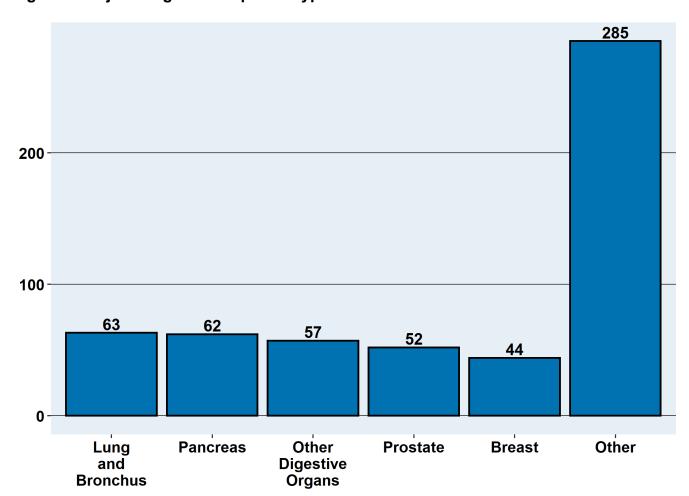


Figure 4: Major Malignant Neoplasm Types for EOLA Individuals in 2022

Most of the individuals who participated in the EOLA had some form of health insurance (98.1 percent). Of individuals participating in the EOLA, 52.5 percent individuals had Medicare or Medicare combined with another type of insurance, 10.7 percent had private insurance, 2.3 percent had only Medi-Cal, and 0.5 percent had another governmental insurance (e.g., Covered California or Veterans Affairs). The type of insurance was unspecified for 32.1 percent of individuals. Individuals with no insurance comprised 0.6 percent, and the remaining 1.3 percent of individuals had undetermined health insurance coverage.

A physician or trained healthcare professional was present for 406 individuals, or 47.6 percent, at the time of ingestion of the aid-in-dying drug. Of the 406 individuals who had a physician or trained healthcare professional present at the time of ingestion, another healthcare provider was present for 48.0 percent of individuals, followed by the attending physician, who was present for 47.3 percent of individuals. Another physician was present for 4.7 percent of individuals. The majority, or 88.3 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 14-15.

Conclusion

This Data Report presents data reported to CDPH from the EOLA-mandated physician reporting forms and reflects information on all patients who were prescribed aid-in-dying medications in 2022 or prior years, and subsequently died in 2022 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	2022	(N=853)	2021	(N=522)	2016- 2020	(N=1974)	Total	(N=3349)
Age	N	(%)	N	(%)	N	(%)	N	(%)
Under 60	69	(8.1)	58	(11.1)	218	(11.0)	345	(10.3)
60-69	142	(16.6)	96	(18.4)	435	(22.0)	673	(20.1)
70-79	261	(30.6)	175	(33.5)	612	(31.0)	1048	(31.3)
80-89	235	(27.5)	118	(22.6)	463	(23.5)	816	(24.4)
90 and Over	146	(17.1)	75	(14.4)	246	(12.5)	467	(13.9)
Median Age (Range)	78	(28-104)	76	(30-105)	75	(23-107)	76	(23-107)
Gender	N	(%)	N	(%)	N	(%)	N	(%)
Female	413	(48.4)	251	(48.1)	982	(49.7)	1646	(49.1)
Male	440	(51.6)	271	(51.9)	992	(50.3)	1703	(50.9)
Education	N	(%)	N	(%)	N	(%)	N	(%)
No High School Diploma	28	(3.3)	15	(2.9)	61	(3.1)	104	(3.1)
HS Diploma or GED	166	(19.5)	99	(19.0)	405	(20.5)	670	(20.0)
Some College	140	(16.4)	79	(15.1)	355	(18.0)	574	(17.1)
Associate's Degree	70	(8.2)	42	(8.0)	147	(7.4)	259	(7.7)
Bachelor's Degree	211	(24.7)	139	(26.6)	495	(25.1)	845	(25.2)
Master's Degree	150	(17.6)	92	(17.6)	299	(15.1)	541	(16.2)
Doctorate or Professional Degree	81	(9.5)	49	(9.4)	198	(10.0)	328	(9.8)
Unknown	7	(8.0)	7	(1.3)	14	(0.7)	28	(8.0)

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

EOLA Individuals	2022	(N=853)	2021	(N=522)	2016- 2020	(N=1974)	Total	(N=3349)
Race/Ethnicity	N	(%)	N	(%)	N	(%)	N	(%)
White	759	(89.0)	450	(86.2)	1742	(88.2)	2951	(88.1)
Black	4	(0.5)	4	(0.8)	20	(1.0)	28	(8.0)
American Indian/Alaska Native	4	(0.5)	0	(0.0)	2	(0.1)	6	(0.2)
Asian ^{8, 9}	54	(6.3)	36	(6.9)	120	(6.1)	210	(6.3)
Asian Indian							16	(7.6)
Chinese							90	(42.9)
Japanese							32	(15.2)
Korean							21	(10.0)
Vietnamese							12	(5.7)
Native Hawaiian /Pacific Islander ^{8, 10}	0	(0.0)	0	(0.0)	4	(0.2)	4	(0.1)
Other	0	(0.0)	0	(0.0)	3	(0.2)	3	(0.1)
Multi-race	5	(0.6)	6	(1.1)	15	(8.0)	26	(8.0)
Hispanic	24	(2.8)	25	(4.8)	67	(3.4)	116	(3.5)
Unknown	3	(0.4)	1	(0.2)	1	(0.1)	5	(0.1)

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⁸ Government Code Section 8310.7

⁹ To protect privacy and prevent reidentification of individuals, only selected information for disaggregated detailed race and ethnic groups is presented. Small counts of detailed groups have been masked and aggregated since presenting a combination of multiple small detailed groups along with race and ethnicity category totals increases the risk of reidentification of individuals. Notably, no counts for individual years are shown and only cumulative totals greater than 10 are shown. Of the disaggregated Asian groups, Bangladeshi, Cambodian, Filipino, Hmong, Indonesian, Laotian, Malaysian, Pakistani, Sri Lankan, Taiwanese, and Thai did not meet this threshold for cumulative counts and have not been included in the table.

¹⁰ To protect privacy and prevent reidentification of individuals, only selected information for disaggregated detailed race and ethnic groups is presented. Small counts of detailed groups have been masked and aggregated since presenting a combination of multiple small detailed groups along with race and ethnicity category totals, increases the risk of reidentification of individuals. Notably, no counts for individual years are shown and only cumulative totals greater than 10 are shown. Of the disaggregated Pacific Islander groups, Fijian, Guamanian, Native Hawaiian, Samoan, and Tongan did not meet this threshold.

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

EOLA Individuals	2022	(N=853)	2021	(N=522)	2016- 2020	(N=1974)	Total	(N=3349)
Underlying Illness	N	(%)	N	(%)	N	(%)	N	(%)
Malignant Neoplasms (Cancer)	563	(66.0)	342	(65.5)	1386	(70.2)	2291	(68.4)
Lung and Bronchus	63	(11.2)	45	(13.2)	226	(16.3)	334	(14.6)
Pancreas	62	(11.0)	39	(11.4)	134	(9.7)	235	(10.3)
Prostate	52	(9.2)	23	(6.7)	111	(8.0)	186	(8.1)
Other Digestive Organs	57	(10.1)	25	(7.3)	93	(6.7)	175	(7.6)
Breast	44	(7.8)	25	(7.3)	104	(7.5)	173	(7.6)
Female Genital Organs	43	(7.6)	27	(7.9)	91	(6.6)	161	(7.0)
Colon	35	(6.2)	25	(7.3)	95	(6.9)	155	(6.8)
Blood	40	(7.1)	24	(7.0)	83	(6.0)	147	(6.4)
Eye, Brain and Other Parts of Central Nervous System	19	(3.4)	17	(5.0)	83	(6.0)	119	(5.2)
Ill-defined, Secondary, and Unspecified Sites	32	(5.7)	12	(3.5)	65	(4.7)	109	(4.8)
Urinary Tract	26	(4.6)	15	(4.4)	68	(4.9)	109	(4.8)
Lip, Oral Cavity, and Pharynx	20	(3.6)	19	(5.6)	56	(4.0)	95	(4.1)
Liver	18	(3.2)	7	(2.0)	57	(4.1)	82	(3.6)
Skin	16	(2.8)	13	(3.8)	36	(2.6)	65	(2.8)
Mesothelial and Soft Tissue	9	(1.6)	16	(4.7)	24	(1.7)	49	(2.1)
Respiratory and Intrathoracic Organs	5	(0.9)	4	(1.2)	12	(0.9)	21	(0.9)
Thyroid and Other Endocrine Glands	5	(0.9)	2	(0.6)	11	(0.8)	18	(0.8)
Bone	4	(0.7)	1	(0.3)	8	(0.6)	13	(0.6)
Other Cancers	13	(2.3)	3	(0.9)	29	(2.1)	45	(2.0)

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

EOLA Individuals	2022	(N=853)	2021	(N=522)	2016- 2020	$I \cap K = I \cup I \cap I \cap I$	Total	(N=3349)
Underlying Illness	N	(%)	N	(%)	N	(%)	N	(%)
Neurological Disease	73	(8.6)	67	(12.8)	211	(10.7)	351	(10.5)
Amyotrophic Lateral Sclerosis	45	(61.6)	33	(49.3)	124	(58.8)	202	(57.5)
Parkinson's Disease	13	(17.8)	14	(20.9)	34	(16.1)	61	(17.4)
Other	15	(20.5)	20	(29.9)	53	(25.1)	88	(25.1)
Cardiovascular Disease	101	(11.8)	50	(9.6)	135	(6.8)	286	(8.5)
Respiratory Disease	58	(6.8)	32	(6.1)	132	(6.7)	222	(6.6)
Chronic Lower Respiratory Disease	38	(65.5)	23	(71.9)	97	(73.5)	158	(71.2)
Interstitial Pulmonary Diseases	20	(34.5)	8	(25.0)	31	(23.5)	59	(26.6)
Other	0	0.0	1	(3.1)	4	(3.0)	5	(2.3)
Kidney Disease	17	(2.0)	12	(2.3)	26	(1.3)	55	(1.6)
Endocrine, Nutritional and Metabolic Disease	5	(0.6)	7	(1.3)	17	(0.9)	29	(0.9)
Immune Mediated Disease [e.g., Multiple Sclerosis]	7	(0.8)	3	(0.6)	11	(0.6)	21	(0.6)
Cerebrovascular Disease	14	(1.6)	2	(0.4)	24	(1.2)	40	(1.2)
Other ¹¹	15	(1.8)	7	(1.3)	32	(1.6)	54	(1.6)

¹¹ 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	2022	(N=853)	2021	(N=522)	2016- 2020	(N=1974)	Total	(N=3349)
Insurance	N	(%)	N	(%)	N	(%)	N	(%)
Medicare or Medicare with another type of insurance	448	(52.5)	267	(51.1)	1205	(61.0)	1920	(57.3)
Private Insurance	91	(10.7)	83	(15.9)	290	(14.7)	464	(13.9)
Medi-Cal	20	(2.3)	4	(0.8)	43	(2.2)	67	(2.0)
Other Governmental Insurance	4	(0.5)	4	(0.8)	9	(0.5)	17	(0.5)
Has Insurance, but unknown type	274	(32.1)	156	(29.9)	266	(13.5)	696	(20.8)
No Insurance	5	(0.6)	1	(0.2)	16	(8.0)	22	(0.7)
Unknown	11	(1.3)	7	(1.3)	145	(7.3)	163	(4.9)
Hospice and/or Palliative Care	N	(%)	N	(%)	N	(%)	N	(%)
Enrolled	814	(95.4)	477	(91.4)	1742	(88.2)	3033	(90.6)
Not Enrolled	39	(4.6)	43	(8.2)	183	(9.3)	265	(7.9)
Unknown	0	(0.0)	2	(0.4)	49	(2.5)	51	(1.5)
Aid-in-Dying Drugs	N	(%)	N	(%)	N	(%)	N	(%)
Cardiotonic, Opioid, Sedative	759	(89.0)	453	(86.8)	1125	(57.0)	2337	(69.8)
Sedative	1	(0.1)	1	(0.2)	545	(27.6)	547	(16.3)
Other	8	(0.9)	27	(5.2)	119	(6.0)	154	(4.6)
Unknown	85	(10.0)	41	(7.9)	185	(9.4)	311	(9.3)
Patient Informed Family of Decision	N	(%)	N	(%)	N	(%)	N	(%)
Yes	721	(84.5)	465	(89.1)	1689	(85.6)	2875	(85.8)
No	12	(1.4)	4	(0.8)	45	(2.3)	61	(1.8)
No Family to Inform	5	(0.6)	8	(1.5)	38	(1.9)	51	(1.5)
Unknown	115	(13.5)	45	(8.6)	202	(10.2)	362	(10.8)

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

EOLA Individuals	2022	(N=853)	2021	(N=522)	2016- 2020	(N=1974)	Total	(N=3349)
Physician or Trained Healthcare Provider Present at Ingestion	N	(%)	N	(%)	N	(%)	N	(%)
Yes	406	(47.6)	216	(41.4)	785	(39.8)	1407	(42.0)
Attending Physician	192	(47.3)	98	(45.4)	467	(59.5)	757	(53.8)
Other Physician	19	(4.7)	19	(8.8)	57	(7.3)	95	(6.8)
Other Healthcare Provider	195	(48.0)	99	(45.8)	261	(33.2)	555	(39.4)
No	53	(6.2)	29	(5.6)	195	(9.9)	277	(8.3)
Unknown	394	(46.2)	277	(53.1)	994	(50.4)	1665	(49.7)
Location Where Aid-in-Dying Drugs were Ingested	N	(%)	N	(%)	N	(%)	N	(%)
Private Home	753	(88.3)	488	(93.5)	1787	(90.5)	3028	(90.4)
Assisted-Living Residence	71	(8.3)	18	(3.4)	91	(4.6)	180	(5.4)
Nursing Home	10	(1.2)	4	(8.0)	60	(3.0)	74	(2.2)
In-patient Hospice Residence	12	(1.4)	10	(1.9)	24	(1.2)	46	(1.4)
Acute Care Hospital	3	(0.4)	0	(0.0)	4	(0.2)	7	(0.2)
Other	4	(0.5)	2	(0.4)	8	(0.4)	14	(0.4)