# CALIFORNIA END OF LIFE OPTION ACT 2023 DATA REPORT



For more information visit the <u>CDPH End of Life Option Act</u> website.

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#### **Executive Summary**

California's End of Life Option Act (EOLA) became effective on June 9, 2016, under AB 15 (Eggman, Chapter 1, Statutes of 2015). The EOLA allows terminally ill adults living in California to obtain and self-administer aid-in-dying drugs.<sup>1,2</sup> 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 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

<sup>&</sup>lt;sup>2</sup> Senate Bill 380 (Eggman), Chapter 542, Statues of 2021

This report presents the information on individuals who were prescribed aid-in-dying drugs and died in the calendar year of 2023, as well as cumulative counts from January 1, 2016 to December 31, 2023. The data is collected from the EOLA-mandated physician reporting forms received by CDPH through January 30, 2024. The information collected has been aggregated to protect the privacy of the individuals.

For the calendar year ending December 31, 2023:

- 1,281 individuals received prescriptions under the EOLA; and
- 884 individuals died following their ingestion of the prescribed aid- in-dying drug(s), which includes 49 individuals who received prescriptions prior to 2023.
  - $\circ$  Of the 884 individuals:
    - 92.8 percent<sup>3</sup> were 60 years of age or older;
    - 97.1 percent had health insurance; and
    - 93.8 percent were receiving hospice and/or palliative care.

Since the law came into effect June 9, 2016, through December 31, 2023:

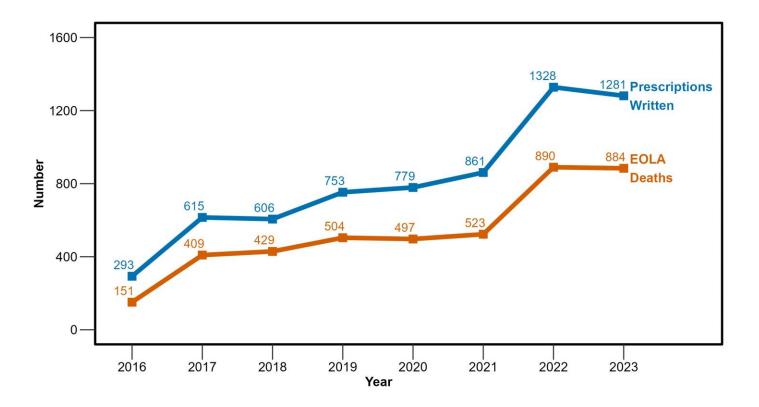
- 6,516 individuals have been written prescriptions under the EOLA;
- 4,287 individuals, or 65.8 percent, have died from ingesting the medications; and,
  - Of the 4,287 individuals, 3,911 or 91.2 percent, were receiving hospice and/or palliative care.

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.

Figure 1 illustrates the number of prescriptions written and the deaths under the EOLA from 2016 through 2023.

<sup>&</sup>lt;sup>3</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.



#### Figure 1: Summary of EOLA Prescriptions and Deaths 2016-2023

#### Introduction

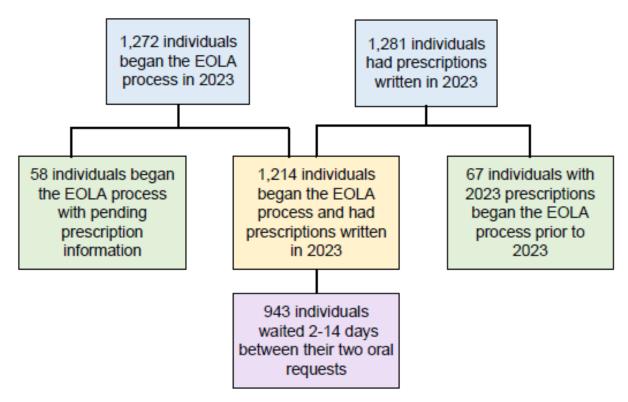
The EOLA allows an adult diagnosed with a terminal disease, who meets certain qualifications defined in Health and Safety Code Section 443.2, to request an aid-in-dying drug from a physician. The EOLA requires physicians to use forms specified in statute for submitting information to CDPH. CDPH is responsible 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 2023.

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

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

For the calendar year 2023, as presented in Figure 2:

- CDPH received forms from 1,272 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.
- Of the 1,272 individuals who started the end-of life process,1,214 individuals received a prescription in 2023 while the remaining 58 individuals have not yet received a prescription prior to the end of 2023.
- Out of the 1,214 individuals who started the end-of-life option process in 2023 and received a prescription during 2023, 943 individuals, or 77.7 percent, waited less than 15 days between the two verbal requests.
- An additional 67 individuals received a prescription during 2023 and began the request process prior to 2023.
- A total of 337 physicians prescribed 1,281 individuals aid-in-dying drugs.
- The most common drug category prescribed was a combination of a cardiotonic, opioid, and sedative at 98.4 percent.



#### Figure 2: Summary of EOLA Requests and Prescriptions Written in 2023

Of the 1,281 individuals who were prescribed such drugs in 2023:

- 835 individuals, or 65.2 percent, were reported by their physician to have died following ingestion of aid-in-dying drugs prescribed under the EOLA;
- 170 individuals, or 13.3 percent, died from the underlying illness or other causes; and,
- 276 remaining individuals, or 21.5 percent, have an unknown ingestion status.
  - Of the remaining 276 individuals with an unknown ingestion status:
    - 174 individuals, or 13.6 percent, have died, but their ingestion status is unknown because follow up information is not available yet; and,
    - 102 individuals, or 8.0 percent, both death and ingestion status are pending.

Furthermore, 49 individuals with prescriptions written in prior years ingested and died from the drugs during 2023. As a result, the report demographics include the 884 individuals who ingested and subsequently died during the 2023 calendar year from aid-in-dying drugs. A chart illustrating the outcomes is provided as Figure 3.

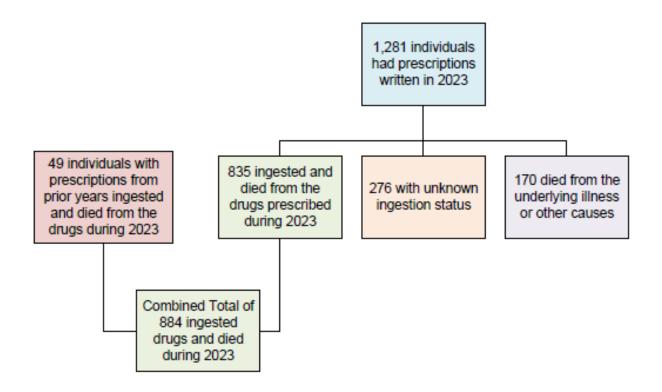
In 2023, 884 individuals<sup>4</sup> died from ingestion of aid-in-dying drugs, a rate of 30.4 per 10,000, or 0.30 percent, based on 290,511<sup>5,6</sup> deaths to California residents in 2023.

<sup>&</sup>lt;sup>4</sup> Total of individuals who received aid-in-dying prescriptions that died in 2023.

<sup>&</sup>lt;sup>5</sup> California Department of Public Health, California Comprehensive Death File, created in January 2024.

<sup>&</sup>lt;sup>6</sup> Does not include out-of-state California resident deaths as of January 2024.

### Figure 3: Outcome Summary of EOLA Prescriptions Written Including Prior Years and Drugs Ingested in 2023



#### **Characteristics of Individuals**

Of the 884 individuals who died pursuant to the EOLA during 2023:

- 7.2 percent were under 60 years of age;
- 76.6 percent were 60-89 years of age;
- 16.2 percent were 90 years of age and older;
- 78 years was the median age;
- 85.4 percent were white;
- 50.1 percent were male;
- 93.8 percent were receiving hospice and/or palliative care;
- 76.7 percent had at least some level of college education; and,
- 80.4 percent informed their family of their decision to participate in the EOLA.

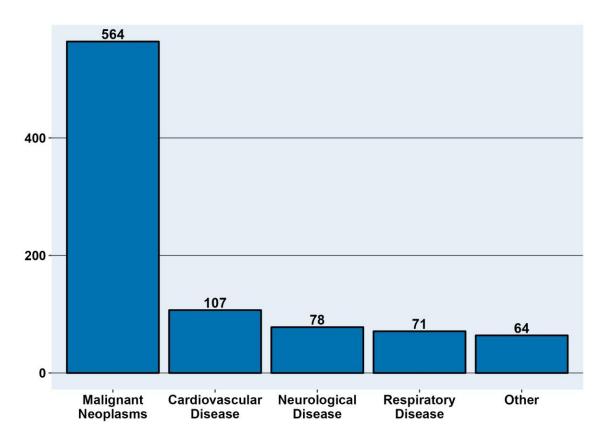
A summary of this information is set forth in Table 1 on pages 11-13 and Table 3 on pages 16-18.

Of the 884 individuals who died pursuant to the EOLA during 2023, as presented in Figure 4:

- 564 individuals, or 63.8 percent, had malignant neoplasms (cancer);
- 107 individuals, or 12.1 percent, had cardiovascular disease;
- 78 individuals, or 8.8 percent, had neurological disease;

- 71 individuals, or 8.0 percent, had respiratory diseases (non-cancer); and,
- 64 individuals, or 7.2 percent, had other underlying illnesses:
  - o 14 individuals, or 1.6 percent, had cerebrovascular disease;
  - o 13 individuals, or 1.5 percent, had kidney disease;
  - 11 individuals, or 1.2 percent, had endocrine, nutritional and metabolic disease;
  - o 8 individuals, or 0.9 percent, had immune mediated disease; and,
  - o 18 individuals, or 2.0 percent, had some other diseases.

Figure 4: Major Illness Categories for EOLA Individuals in 2023



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 EOLA.

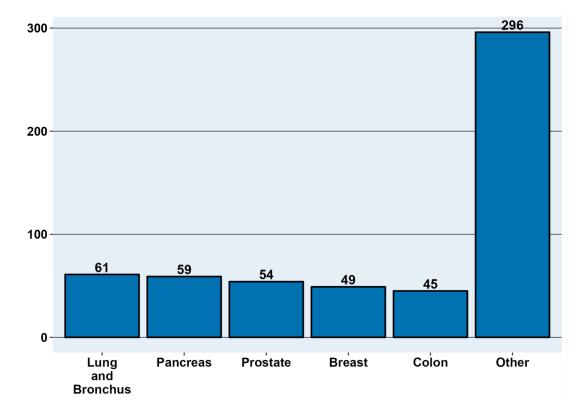
As presented in Figure 5, 564 individuals with malignant neoplasm as the underlying terminal disease represented the largest group who utilized the EOLA:

- 61 individuals, or 10.8 percent, had lung and bronchus cancer;
- 59 individuals, or 10.5 percent, had pancreatic cancer;

<sup>&</sup>lt;sup>7</sup> Health and Safety Code Section 102825(a) and Health and Safety Code Section 102860

- 54 individuals, or 9.6 percent, had prostate cancer;
- 49 individuals, or 8.7 percent, had breast cancer;
- 45 individuals, or 8.0 percent, had colon cancer; and,
- 296 individuals, or 52.5 percent, had other malignant neoplasms.

Additional information regarding the other types of malignant neoplasms can be found in Table 2 on pages 14-15.



#### Figure 5: Major Malignant Neoplasm Types for EOLA Individuals in 2023

Of the 884 individuals who died through participating in the EOLA in 2023, most of the individuals had some form of health insurance (97.1 percent):

- 504 individuals, or 57.0 percent, had Medicare or Medicare combined with another type of insurance;
- 90 individuals, or 10.2 percent, had private insurance;
- 15 individuals, or 1.7 percent, had only Medi-Cal;
- 4 individuals, or 0.5 percent, had another governmental insurance (e.g., Covered California or Veterans Affairs);
- 245 individuals, or 27.7 percent, had insurance but the type of insurance was unspecified;
- 7 individuals, or 0.8 percent, had no insurance; and
- 19 individuals, or 2.1 percent, no response was provided for health insurance coverage.

Out of the total of 884 individuals who died through participating in the EOLA:

- 776 individuals, or 87.8 percent, were in a private home for ingestion; and,
- 439 individuals, or 49.7 percent, had a physician or trained health care professional present at the time of ingestion.

Of the 439 individuals with a provider present at the time of ingestion of the aid-in-dying drug(s):

- 265 individuals, or 60.4 percent, had an attending physician provider present; and,
- 167 individuals, or 38.0 percent, had a trained healthcare professional present.
- 7 individuals, or 1.6 percent had a physician other than the attending present.

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 16-18.

#### 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 2023 or prior years, and subsequently died in 2023 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 anAid-in-Dying Drug

Age Groups	2023	2023 %	2022	2022 %	2016- 2021	2016- 2021 %	Total	Total %
Under 60	64	(7.2)	71	(8.0)	278	(11.1)	413	(9.6)
60-69	154	(17.4)	154	(17.3)	537	(21.4)	845	(19.7)
70-79	288	(32.6)	277	(31.1)	790	(31.4)	1355	(31.6)
80-89	235	(26.6)	239	(26.9)	585	(23.3)	1059	(24.7)
90 and Over	143	(16.2)	149	(16.7)	323	(12.9)	615	(14.3)

#### Age of the EOLA Individuals Who Died Following Ingestion of an Aid-in-Dying Drug

Age Summary	2023 Median	2023 Range	2022 Median	2022 Range	2016- 2021 Median	2016- 2021 Range	Total Median	Total Range
Median Age (Range)	78	(30-106)	77	(28-104)	75	(23-107)	76	(23-107)

# Gender of the EOLA Individuals Who Died Following Ingestion of an Aid-in-Dying Drug

EOLA Individuals	2023	2023 %	2022	2022 %	2016- 2021	2016- 2021 %	Total	Total %
Female	441	(49.9)	427	(48.0)	1240	(49.3)	2108	(49.2)
Male	443	(50.1)	463	(52.0)	1273	(50.7)	2179	(50.8)

Education of the EOLA Individuals Who Died Following Ingestion of an Aid-in-Dying Drug

Education Level	2023	2023 %	2022	2022 %	2016- 2021	2016- 2021 %	Total	Total %
No High School Diploma	29	(3.3)	28	(3.1)	78	(3.1)	135	(3.1)
HS Diploma or GED	168	(19.0)	174	(19.6)	508	(20.2)	850	(19.8)
Some College	165	(18.7)	149	(16.7)	437	(17.4)	751	(17.5)
Associate's Degree	59	(6.7)	71	(8.0)	189	(7.5)	319	(7.4)
Bachelor's Degree	211	(23.9)	222	(24.9)	640	(25.5)	1073	(25.0)
Master's Degree	162	(18.3)	156	(17.5)	392	(15.6)	710	(16.6)
Doctorate or Professional Degree	81	(9.2)	83	(9.3)	247	(9.8)	411	(9.6)
Unknown	9	(1.0)	7	(0.8)	22	(0.9)	38	(0.9)

Race/Ethnicity of the EOLA Individuals Who Died Following Ingestion of an Aid-in-Dying Drug

EOLA Individuals	2023	2023 %	2022	2022 %	2016- 2021	2016- 2021 %	Total	Total %
White	755	(85.4)	793	(89.1)	2208	(87.9)	3756	(87.6)
Black	8	(0.9)	4	(0.4)	24	(1.0)	36	(0.8)
American Indian/Alaska Native	1	(0.1)	4	(0.4)	2	(0.1)	7	(0.2)
Asian <sup>8,9</sup>	63	(7.1)	57	(6.4)	156	(6.2)	276	(6.4)
Asian Indian							24	(8.7)
Chinese							121	(43.8)
Filipino							11	(4.0)
Japanese							40	(14.5)
Korean							28	(10.1)
Vietnamese							15	(5.4)
Native Hawaiian/ Pacific Islander <sup>8,</sup> <sup>10</sup>	2	(0.2)	0	(0.0)	4	(0.2)	6	(0.1)
Other	2	(0.2)	0	(0.0)	3	(0.1)	5	(0.1)
Multi-race	6	(0.7)	5	(0.6)	18	(0.7)	29	(0.7)
Hispanic	43	(4.9)	24	(2.7)	96	(3.8)	163	(3.8)
Unknown	4	(0.5)	3	(0.3)	2	(0.1)	9	(0.2)

<sup>&</sup>lt;sup>8</sup> Disaggregated data on Asian and Pacific Islander groups pursuant to Government Code Section 8310.7.

<sup>&</sup>lt;sup>9</sup> To protect privacy and prevent reidentification of individuals, only selected data for disaggregated Asian groups are presented. In instances where there are small counts of specified race/ethnicity groups, the data has been masked and aggregated since presenting a combination of multiple groups with small race/ethnicity data 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, 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.
<sup>10</sup> To protect privacy and prevent reidentification of individuals, only selected data for disaggregated Native Hawaiian and Pacific Islander groups are 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 anAid-in-Dying Drug

Underlying Illness	2023	2023 %	2022	2022 %	2016- 2021	2016- 2021 %	Total	Total %
Malignant Neoplasms (Cancer)	564	(63.8)	592	(66.5)	1740	(69.2)	2896	(67.6)
Lung and Bronchus	61	(10.8)	70	(11.8)	276	(15.9)	407	(14.1)
Pancreas	59	(10.5)	66	(11.1)	174	(10.0)	299	(10.3)
Prostate	54	(9.6)	55	(9.3)	134	(7.7)	243	(8.4)
Other Digestive Organs	44	(7.8)	60	(10.1)	118	(6.8)	222	(7.7)
Breast	49	(8.7)	47	(7.9)	130	(7.5)	226	(7.8)
Female Genital Organs	32	(5.7)	45	(7.6)	119	(6.8)	196	(6.8)
Colon	45	(8.0)	38	(6.4)	120	(6.9)	203	(7.0)
Blood	39	(6.9)	40	(6.8)	108	(6.2)	187	(6.5)
Eye, Brain and Other Parts of Central Nervous System	35	(6.2)	21	(3.5)	101	(5.8)	157	(5.4)
III-defined, Secondary, and Unspecified Sites	30	(5.3)	33	(5.6)	77	(4.4)	140	(4.8)
Urinary Tract	21	(3.7)	26	(4.4)	84	(4.8)	131	(4.5)
Lip, Oral Cavity, and Pharynx	19	(3.4)	20	(3.4)	75	(4.3)	114	(3.9)
Liver	22	(3.9)	18	(3.0)	64	(3.7)	104	(3.6)
Skin	18	(3.2)	16	(2.7)	49	(2.8)	83	(2.9)
Mesothelial and Soft Tissue	10	(1.8)	10	(1.7)	41	(2.4)	61	(2.1)
Respiratory and Intrathoracic Organs	6	(1.1)	5	(0.8)	16	(0.9)	27	(0.9)
Thyroid and Other Endocrine Glands	5	(0.9)	5	(0.8)	13	(0.7)	23	(0.8)
Bone	1	(0.2)	4	(0.7)	9	(0.5)	14	(0.5)
Other Cancers	14	(2.5)	13	(2.2)	32	(1.8)	59	(2.0)

# Table 2 (continued): Underlying Illness of the EOLA Individuals Who DiedFollowing Ingestion of an Aid-in-Dying Drug

Underlying Illness	2023	2023 %	2022	2022 %	2016- 2021	2016- 2021 %	Total	Total %
Neurological Disease	78	(8.8)	76	(8.5)	279	(11.1)	433	(10.1)
Amyotrophic Lateral Sclerosis	45	(57.7)	48	(63.2)	158	(56.6)	251	(58.0)
Parkinson's Disease	24	(30.8)	13	(17.1)	48	(17.2)	85	(19.6)
Other	9	(11.5)	15	(19.7)	73	(26.2)	97	(22.4)
Cardiovascular Disease	107	(12.1)	104	(11.7)	186	(7.4)	397	(9.3)
Respiratory Disease	71	(8.0)	58	(6.5)	167	(6.6)	296	(6.9)
Chronic Lower Respiratory Disease	38	(53.5)	38	(65.5)	123	(73.7)	199	(67.2)
Interstitial Pulmonary Diseases	31	(43.7)	20	(34.5)	39	(23.4)	90	(30.4)
Other	2	(2.8)	0	(0.0)	5	(3.0)	7	(2.4)
Kidney Disease	13	(1.5)	17	(1.9)	38	(1.5)	68	(1.6)
Endocrine, Nutritional and Metabolic Disease	11	(1.2)	5	(0.6)	24	(1.0)	40	(0.9)
Immune Mediated Disease [e.g., Multiple Sclerosis]	8	(0.9)	7	(0.8)	14	(0.6)	29	(0.7)
Cerebrovascular Disease	14	(1.6)	16	(1.8)	26	(1.0)	56	(1.3)
Other <sup>11</sup>	18	(2.0)	15	(1.7)	39	(1.6)	72	(1.7)

<sup>&</sup>lt;sup>11</sup> 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 anAid-in-Dying Drug

Insurance of the EOLA Individuals Who Died Following Ingestion of an Aid-in-Dying Drug

Insurance	2023	2023 %	2022	2022 %	2016- 2021	2016- 2021 %	Total	Total %
Medicare or Medicare with another type of insurance	504	(57.0)	469	(52.7)	1480	(58.9)	2453	(57.2)
Private Insurance	90	(10.2)	100	(11.2)	375	(14.9)	565	(13.2)
Medi-Cal	15	(1.7)	22	(2.5)	48	(1.9)	85	(2.0)
Other Governmental Insurance	4	(0.5)	4	(0.4)	13	(0.5)	21	(0.5)
Has Insurance, but unknown type	245	(27.7)	279	(31.3)	423	(16.8)	947	(22.1)
No Insurance	7	(0.8)	5	(0.6)	20	(0.8)	32	(0.7)
Unknown	19	(2.1)	11	(1.2)	154	(6.1)	184	(4.3)

Hospice and/or Palliative Care of the EOLA Individuals Who Died Following Ingestion of an Aid-in-Dying Drug

Hospice and/or Palliative Care	2023	2023 %	2022	2022 %	2016- 2021	2016- 2021 %	Total	Total %
Enrolled	829	(93.8)	847	(95.2)	2235	(88.9)	3911	(91.2)
Not Enrolled	53	(6.0)	43	(4.8)	225	(9.0)	321	(7.5)
Unknown	2	(0.2)	0	(0.0)	53	(2.1)	55	(1.3)

Aid-in-Dying Drugs of the EOLA Individuals Who Died Following Ingestion of an Aid-in-Dying Drug

Aid in Dying Drugs	2023	2023 %	2022	2022 %	2016- 2021	2016- 2021 %	Total	Total %
Cardiotonic, Opioid, Sedative	781	(88.3)	798	(89.7)	1590	(63.3)	3169	(73.9)
Sedative	0	(0.0)	1	(0.1)	549	(21.8)	550	(12.8)
Other	13	(1.5)	10	(1.1)	153	(6.1)	176	(4.1)
Unknown	90	(10.2)	81	(9.1)	221	(8.8)	392	(9.1)

# Patient Informed Family of Decision of the EOLA Individuals Who Died Following Ingestion of an Aid-in-Dying Drug

EOLA Individuals	2023	2023 %	2022	2022 %	2016- 2021	2016- 2021 %	Total	Total %
Yes	711	(80.4)	762	(85.6)	2167	(86.2)	3640	(84.9)
No	16	(1.8)	12	(1.3)	51	(2.0)	79	(1.8)
No Family to Inform	12	(1.4)	5	(0.6)	47	(1.9)	64	(1.5)
Unknown	145	(16.4)	111	(12.5)	248	(9.9)	504	(11.8)

Physician or Trained Healthcare Provider Present at Ingestion of the EOLA Individuals Who Died Following Ingestion of an Aid-in-Dying Drug

Physicians/Trained Health Providers	2023	2023 %	2022	2022 %	2016- 2021	2016- 2021 %	Total	Total %
Yes	439	(49.7)	410	(46.1)	1001	(39.8)	1850	(43.2)
Attending Physician	265	(60.4)	194	(47.3)	565	(56.4)	1024	(55.4)
Other Physician	7	(1.6)	19	(4.6)	76	(7.6)	102	(5.5)
Other Healthcare Provider	167	(38.0)	197	(48.0)	360	(36.0)	724	(39.1)
No	44	(5.0)	54	(6.1)	224	(8.9)	322	(7.5)
Unknown	401	(45.4)	426	(47.9)	1288	(51.3)	2115	(49.3)

#### Location Where Aid-in-Dying Drugs were Ingested

Locations	2023	2023 %	2022	2022 %	2016- 2021	2016- 2021 %	Total	Total %
Private Home	776	(87.8)	788	(88.5)	2292	(91.2)	3856	(89.9)
Assisted-Living Residence	80	(9.0)	71	(8.0)	109	(4.3)	260	(6.1)
Nursing Home	10	(1.1)	11	(1.2)	64	(2.5)	85	(2.0)
In-patient Hospice Residence	12	(1.4)	12	(1.3)	34	(1.4)	58	(1.4)
Acute Care Hospital	0	(0.0)	3	(0.3)	4	(0.2)	7	(0.2)
Other	6	(0.7)	5	(0.6)	10	(0.4)	21	(0.5)