



Report to the Vermont Legislature: Patient Choice at the End of Life

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In Accordance with Act 27 (2015), Section 1

Submitted to: House Committee on Human Services
House Committee on Health Care
Senate Committee on Health and Welfare

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Contents

Report to the Vermont Legislature: Patient Choice at the End of Life.....	1
Key Takeaways.....	3
Introduction	3
About the Data	4
Patient Choice Summary	5
Number of Individuals Who Utilized the Patient Choice Process	5
Residency of Individuals Who Utilized the Patient Choice Process.....	5
Underlying Diagnosis for Individuals Who Utilized the Patient Choice Process	6
Cause of Death for Individuals Who Utilized the Patient Choice Process.....	8
Number of Prescriptions Filled.....	9

Key Takeaways

The following are highlights from the reporting period July 1, 2023, to June 30, 2025:

- The use of Patient Choice increased substantially during this reporting period (July 1, 2023, to June 30, 2025). 190 individuals utilized the Patient Choice process over the last two years as compared to the 204 individuals who utilized the process in the ten years prior, from May 2013 to June 2023. This increase was influenced by changes in the law in 2023 that allowed out-of-state residents to utilize Patient Choice in Vermont.
- Out of the total 190 who utilized the Patient Choice process, 132 were Vermont residents, 56 were out-of-state residents, and 2 had an unknown state of residence.
- Out of the total 190 who utilized the Patient Choice process, the majority (125 individuals/66%) had an underlying diagnosis of cancer.
- Out of the 183 individuals who utilized the Patient Choice process and have a death recorded with the Vermont Vital Records Office, the vast majority of those died by Patient Choice (148 individuals/82%).

Introduction

In 2013, the General Assembly passed Act 39 that allowed Vermont physicians to prescribe medication to individuals with a terminal condition with the intent that the medication be self-administered for the purpose of hastening the patient's death. Act 39 (2013) set forth the required conditions for the patient and the physician to take this action lawfully.

Those conditions include the following requirements (see 18 V.S.A. § 5283):

- (1) an oral and written request by the patient to the physician;
- (2) that all steps in the process must be voluntary;
- (3) that the patient be capable of making such a decision;
- (4) confirmation of the diagnosis and prognosis by a second Vermont physician; and
- (5) an attestation by a non-interested witness to these steps.

Once the prescribing physician fulfills all the statutory requirements, the physician is required to report to the Department of Health (Department) that all steps have been taken. The filing of the report confers immunity from professional, criminal, or civil liability on health care providers associated with the treatment of the patient for this hastening of the patient's death.

In 2015, the General Assembly passed Act 27 that requires the Department to adopt rules to facilitate the collection of information regarding compliance (see 18 V.S.A. § 5293(a)).¹ Act 27 also requires the Department to generate and make available to the public this report: a biennial statistical overview of the information collected by the Department, as long as releasing the information complies with the federal Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104 - 191.1 (see 18 V.S.A. § 5293(b)).²

In May 2023, Act 10 (2023) was enacted, removing the requirement that only Vermont residents have access to Patient Choice and Control at the End of Life (Patient Choice).

About the Data

State law and regulation require the submission of four reporting forms to the Department.³ The purpose of the forms is to document the legal requirements of the Patient Choice process for an individual. The four forms capture the following information: the patient's request for the medication, the determinations from two physicians that the patient is eligible for Patient Choice, and the follow-up within 10 calendar days of the patient's death, if known, or 60 calendar days of the physician writing the prescription. As individuals and their physicians navigate through the Patient Choice process, the Department receives the required forms that document that the statutory requirements are being followed.

The terms "reportable event" and "individuals who utilized the Patient Choice process" used throughout this report mean that the patient met all the legal and regulatory requirements and the Department received all required reporting documents in accordance with State law and regulation.^{4,5} These terms do not mean that the patient has died or that the patient has died by using Patient Choice.

¹ The Rule Governing Compliance with Patient Choice at the End of Life adopted pursuant to 18 V.S.A. § 5293 is available here: <https://www.healthvermont.gov/sites/default/files/document/reg-patient-choice-end-of-life.pdf>.

² This means that this report will contain no information that could be used to potentially identify any patients or health care providers who have taken steps under 18 V.S.A Chapter 113.

³ The four forms – (1) Patient Request for Medication Form; (2) Physician Reporting Form; (3) Consulting Physician Reporting Form; and (4) Prescribing Physician Follow up Form are available here: <https://www.healthvermont.gov/systems/end-life-decisions/patient-choice-control-end-life>.

⁴ Not all Patient Choice deaths are necessarily accounted for in the proceeding figures. The data collected for this report is based on the data submitted to the Department by reporting physicians. It is possible that some physicians may fail to report all the information that is required in accordance with the law or report incorrect information to the Department. If the Department did not receive all four required reporting documents, the Department does not count the case as a "reportable event" and therefore the individual is not reflected in the reportable event counts listed below.

⁵ The Department defines a "case" as when the Department receives less than the four, but at least one, required reporting forms on behalf of an individual. A "case" does not become a "reportable event" until all four reporting forms are submitted to the Department. "Cases" are not included in this report.

To closely estimate the landscape of Patient Choice use in Vermont, the Department uses the following records:

- Data received from the four required forms submitted by reporting physicians.
- Death certificates on file with the Vermont Vital Records Office.
- Data from the Vermont Prescription Monitoring System.

Patient Choice Summary

Number of Individuals Who Utilized the Patient Choice Process

Since the passage of Act 39 (May 31, 2013, to June 30, 2025), there were 394 reportable events. During this report period (July 1, 2023, to June 30, 2025), there were 190 reportable events.

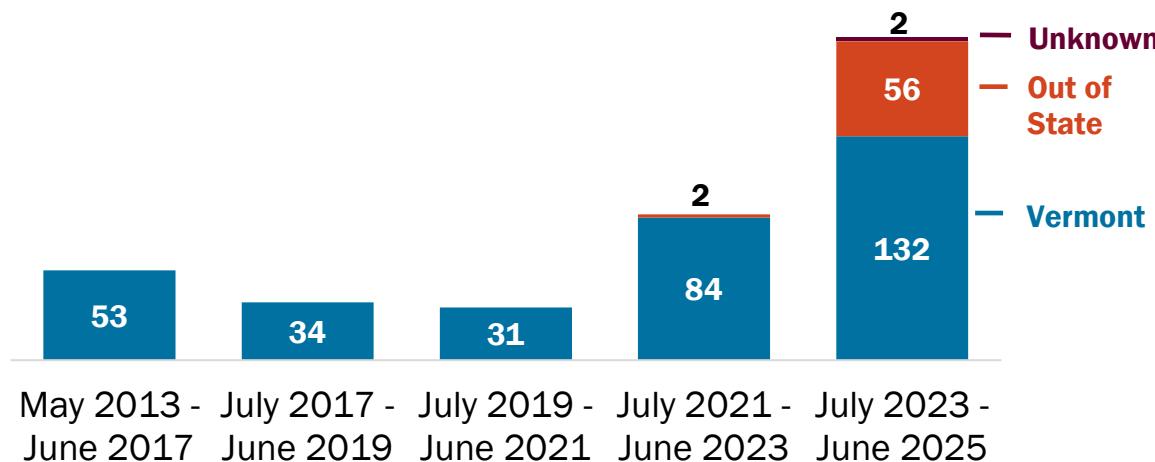
Residency of Individuals Who Utilized the Patient Choice Process

Prior to April 2023, only Vermont residents were eligible to use Patient Choice. Beginning in April 2023, the law was expanded to allow both out-of-state and Vermont residents to utilize Patient Choice.

Since the passage of Act 39, 334 Vermont residents, 58 out-of-state residents, and 2 individuals with an unknown state of residence utilized the program. During the report period, 132 Vermont residents, 56 out-of-state residents, and 2 individuals with an unknown state of residence utilized the program.

Figure 1 shows both the number and residency of individuals who utilized the patient choice process since the passage of Act 39 and highlights how the use of the patient choice process has increased over time. Changes in the law to allow for out-of-state residents to participate have contributed to this increase.

Figure 1. Patient Choice reportable events have increased over time.



Underlying Diagnosis for Individuals Who Utilized the Patient Choice Process

Since the passage of Act 39, the 394 reportable events fall into the following underlying diagnosis groups:

- 70% are due to cancer (277 reportable events).
- 12% are due to neurodegenerative conditions (47 reportable events).
- 5% are due to multiple conditions (24 reportable events).⁶
- 4% are due to end-stage lung disease (i.e., COPD, emphysema, idiopathic pulmonary fibrosis) (15 reportable events).
- 2% are due to end-stage heart disease (i.e., congestive heart failure, systolic heart failure, biventricular heart failure) (9 reportable events).
- 4% are due to another cause (16 reportable events).⁷
- 2% are due to an unknown cause (6 reportable events).⁸

⁶ “Multiple conditions” means that more than one disease was listed as an underlying diagnosis. For example, end-stage lung disease and cancer, two or more illnesses otherwise categorized as ‘another cause’, or a neurodegenerative condition and end-stage congestive heart failure.

⁷ “Another cause” means that the patient’s underlying condition is known but is not one of the listed underlying diagnosis groups (i.e., it is not a cancer, neurodegenerative disease, etc.)

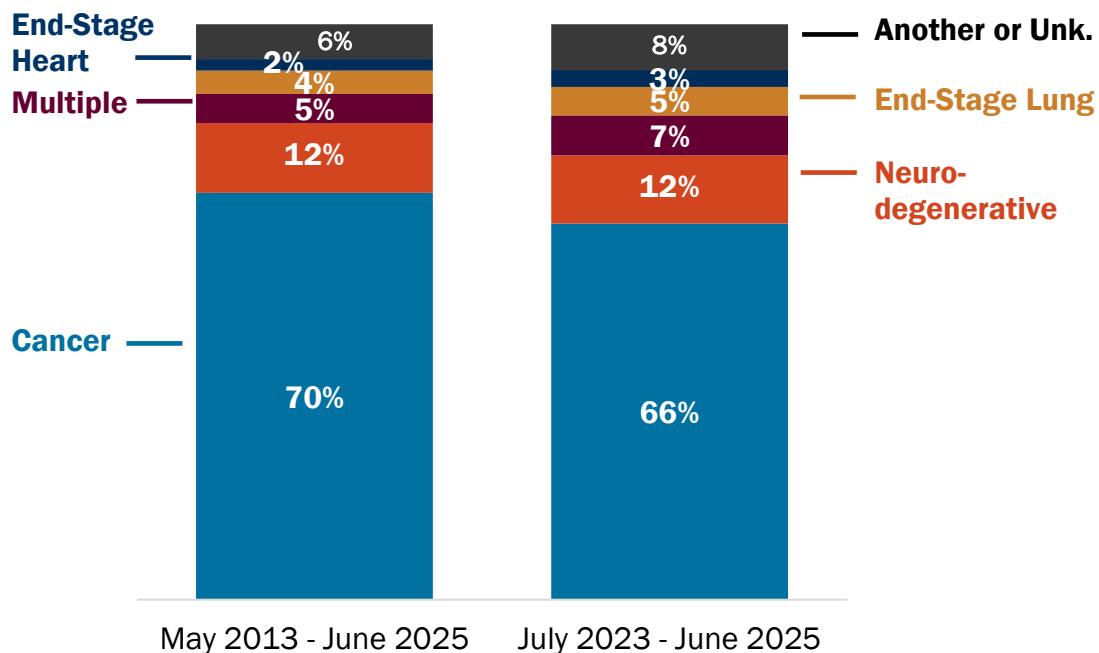
⁸ “Unknown cause” means the underlying diagnosis was not included on the patient choice form.

From July 1, 2023, to June 30, 2025, the 190 reportable events fall into the following underlying diagnoses groups:

- 66% are due to cancer (125 reportable events).
- 12% are due to neurodegenerative conditions (22 reportable events).
- 7% are due to multiple conditions (13 reportable events).⁶
- 5% are due to end-stage lung disease (i.e., COPD, emphysema, idiopathic pulmonary fibrosis) (10 reportable events).
- 3% are due to end-stage heart disease (i.e., congestive heart failure, systolic heart failure, biventricular heart failure) (6 reportable events).
- 5% are due to another cause (9 reportable events).⁷
- 3% are due to an unknown cause (5 reportable events).⁸

Figure 2 shows the underlying diagnosis for individuals who utilized the patient choice process since the passage of Act 39. It also highlights that cancer is the most common underlying diagnosis since the program was adopted (May 2013 – June 2025) and in the most recent reporting period (July 2023 – June 2025).

Figure 2. Cancer is the most common underlying diagnosis for individuals using the Patient Choice process.



Cause of Death for Individuals Who Utilized the Patient Choice Process

Since the passage of Act 39 (2013), 382 out of the 394 (97%) total reportable events had a death recorded with the Vermont Vital Records Office. All of the available death certificates list the appropriate cause (the underlying disease) and manner of death (natural), per Act 39 (2013) requirements.

Among these 382 reportable events, the deaths occurred in the following ways:

- 297 died by Patient Choice (78%).
- 64 died from the underlying disease (17%).
- 8 died from “other events” (2%).⁹
- 13 died from unknown mechanisms (3%).¹⁰

From July 1, 2023, to June 30, 2025, 183 out of the 190 (96%) total reportable events had a death recorded with the Vermont Vital Records Office.¹¹ All of the available death certificates list the appropriate cause (the underlying disease) and manner of death (natural), per Act 39 (2013) requirements.

Among these 183 reportable events, the deaths occurred in the following ways:

- 148 died by Patient Choice (82%).
- 24 died from the underlying disease (13%).
- 4 died from “other events” (2%).⁹
- 7 died from unknown mechanisms (4%).¹⁰

Figure 3 shows the cause of death for individuals who utilized the patient choice process since the passage of Act 39. It also highlights that most individuals who utilized the patient choice process and were confirmed to have died in Vermont died by using Patient Choice.

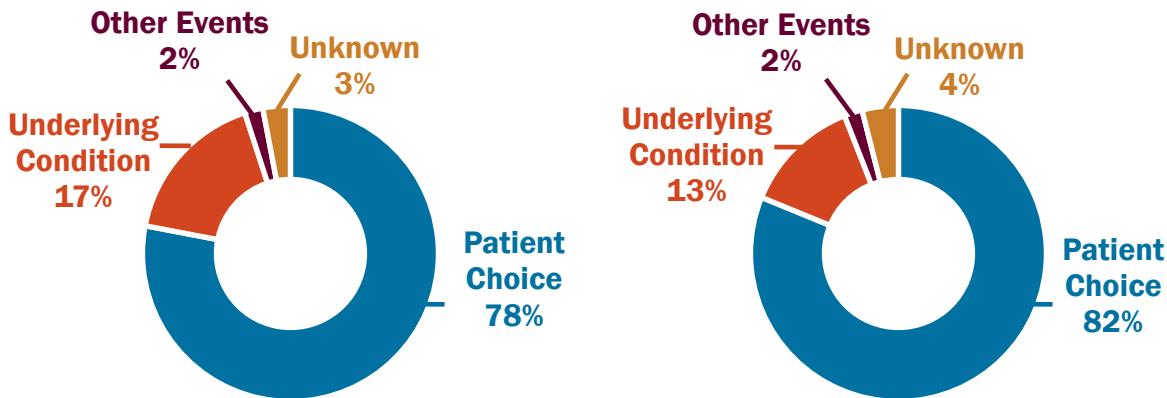
⁹ “Other events” may mean that (1) the prescribing physician indicated that the patient died but they died from something other than the Patient Choice prescription or the underlying disease or (2) the prescribing physician indicated that the patient was still alive 60 days after prescribing the Patient Choice medication, however the Department later confirmed the patient’s death through their death certificate, but their use of Patient Choice prescription is unknown.

¹⁰ “Unknown” means the patient died but the mechanism is unclear on the reporting form or it is unknown to the reporting physician if the patient died from the Patient Choice prescription, the underlying disease, or some other cause.

¹¹ Patients who died out of state may not have a death certificate on file with the Vermont Vital Records Office.

This is true both since the program was adopted (May 2013 – June 2025) and in the most recent reporting period (July 2023 – June 2025).

Figure 3. Most reportable events confirmed to have died in Vermont died by using Patient Choice.



Number of Prescriptions Filled

The Department used the Vermont Prescription Monitoring System (VPMS) to identify patients who have filled a prescription under the law. During the report period, the Department positively identified 175 out of the 190 reportable events as having filled a prescription under the law. There are a variety of reasons that might account for the remainder of the prescriptions not being present in VPMS, including those that were not filled, were filled out of state, or included a compound of medications that are not scheduled and therefore would not be logged in the VPMS.