
**Report to
The Vermont Legislature**

Report Concerning Patient Choice at the End of Life

In Accordance with Act 27 (2015), Section 1

An act relating to repealing the sunset on provisions pertaining to patient choice at end of life

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

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Report date: January 15, 2018



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Executive Summary

In accordance with Act 27 (2015), beginning in 2018, the Department of Health shall generate and make available to the public a biennial statistical report of the information collected by the Department, as long as releasing the information complies with the federal Health Insurance Portability and Accountability Act (HIPAA).

This report provides statistics concerning the utilization of Patient Choice at the End of Life, consistent with the HIPAA Privacy Rule that protects individually identifiable health information. Specifically, the report provides information on how many patients have met the requirements of the act, the underlying causes of death, and the number of prescriptions that have been filled by qualified patients.

Introduction

In 2013, the General Assembly passed Act 39 that allowed Vermont physicians to prescribe medication to a Vermont resident with a terminal condition with the intent that the medication be self-administered for the purpose of hastening the patient's death. Act 39 set forth conditions for the patient and the physician for this action to be taken lawfully. Those conditions include (but are not limited to) an oral and written request by the patient to the physician, a reminder that all steps in the process must be voluntary, that the patient be capable of making such a decision, confirmation of the diagnosis and prognosis by a second Vermont physician, and an attestation by a non-interested witness to these steps. See Appendix A for the complete requirement set forth in 18 V.S.A. § 5283.

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

In 2015, the General Assembly passed Act 27 (see Appendix B) that requires the Department of Health adopt rules to facilitate the collection of information regarding compliance. Act 27 also requires the Department to generate and make available to the public a biennial statistical report 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

The Department subsequently adopted the Rule Governing Compliance with Patient Choice at the End of Life (see Appendix C). The rule allows the Department to collect information that includes the number of prescriptions filled under the Act by pharmacists, the number of patients who are known to have died as a direct result of ingesting the prescription, the number of patients who died as a result of causes other than ingesting the prescription, the patient's underlying terminal disease, as well as some limited demographic information. The rule also requires the prescribing physician to file a simple follow-up form to assist the Department in confirming available data.

¹ 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 the Acts.

Summary of Underlying Causes of Death

The following summary is based on cases reported to the Vermont Department of Health and met the definition of a reportable event under Act 39 between the time period of May 31, 2013 and June 30th, 2017.

General Statistics

- There were 52 total events that met the definition of Act 39 for this reporting period.
 - The underlying diagnoses fall into the following general disease groups:
 - 83% of cases are Cancer (43 total cases);
 - 14% of cases are ALS (7 total cases); and
 - 3% are other causes.
- 48 out of 52 events have a death certificate on file with the Vital Records' Office. The remaining 4 cases are assumed to still be living since all deaths are reportable to the Health Department, and any Vermont resident dying in other states is reported and recorded by the Vital Records' Office.
- 100% of the death certificates listed the appropriate cause (the underlying disease) and manner of death (natural), per Act 39 requirements. Among the 48 confirmed deaths, the mechanism was:
 - 29 utilized the patient choice prescription (60%);
 - 17 died from the underlying disease (35%);
 - 1 died from other causes (2%); and
 - 1 unknown (2%).

Number of Prescriptions Filled

The Department of Health used the Vermont Prescription Monitoring System (VPMS) to identify patients that had filled a prescription under the Act. The Department positively identified 26 out of the 48 deceased cases that filled the prescription under the Act process. An additional 7 out of the remaining 22 decedents were likely prescribed a medication to hasten their deaths under the Act. 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 or were filled out of state.

Appendixes

Appendix A:

<http://legislature.vermont.gov/assets/Documents/2014/Docs/ACTS/ACT039/ACT039%20As%20Enacted.pdf>

Appendix B:

<http://legislature.vermont.gov/assets/Documents/2016/Docs/ACTS/ACT027/ACT027%20As%20Enacted.pdf>

Appendix C:

http://www.healthvermont.gov/sites/default/files/documents/2016/12/REG_patient-choice-at-end-of-life-compliance.pdf