

1 H.293

2 Introduced by Representative Maguire of Rutland City

3 Referred to Committee on

4 Date:

5 Subject: Health; health equity reporting; cancer registry; amyotrophic lateral
6 sclerosis registry; disclosure of identifying information

7 Statement of purpose of bill as introduced: This bill proposes to reduce from
8 annually to every three years the submission of a report by the Department of
9 Health analyzing health equity data. It further proposes to amend the
10 disclosure provisions pertaining to the cancer and amyotrophic lateral sclerosis
11 registries.

12 An act relating to health equity data reporting and registry disclosure
13 requirements

14 It is hereby enacted by the General Assembly of the State of Vermont:

15 * * * Health Equity Data Reporting * * *

16 Sec. 1. 18 V.S.A. § 253 is amended to read:

17 § 253. DATA RESPONSIVE TO HEALTH EQUITY INQUIRIES

18 * * *

19 (b)(1) The Department of Health shall systematically analyze such health
20 equity data using the smallest appropriate units of analysis feasible to detect

1 racial and ethnic disparities, as well as disparities along the lines of primary
2 language, sex, disability status, sexual orientation, gender identity, and
3 socioeconomic status, and report the results of such analysis on the
4 Department's website periodically, but not less than biannually. The
5 Department's analysis shall be used to measure over time the impact of actions
6 taken to reduce health disparities in Vermont. The data informing the
7 Department's analysis shall be made available to the public in accordance with
8 State and federal law.

9 (2) ~~Annually~~ Every three years beginning in 2028, on or before January
10 15, the Department shall submit a report containing the results of the analysis
11 conducted pursuant to subdivision (1) of this subsection to the Senate
12 Committee on Health and Welfare and to the House Committees on Health
13 Care and on Human Services.

14 * * * Cancer Registry Disclosure Requirements * * *

15 Sec. 2. 18 V.S.A. § 155 is amended to read:

16 § 155. DISCLOSURE

17 * * *

18 (b) The Commissioner may furnish confidential information to the National
19 Breast and Cervical Cancer Early Detection Program, other states' cancer
20 registries, federal cancer control agencies, or health researchers in order to
21 collaborate in a national cancer registry or to collaborate in cancer control and

1 prevention research studies. However, before releasing confidential
2 information, the Commissioner shall first obtain from such state registries,
3 agencies, or researchers ~~an agreement in writing to keep~~ assurances acceptable
4 to the Commissioner that the identifying information shall be kept confidential
5 and privileged as required by law. In the case of researchers, the
6 Commissioner shall also first obtain evidence of the approval of ~~their academic~~
7 ~~committee for the protection of human subjects established in accordance with~~
8 ~~45 C.F.R. part 46~~ an institutional review board or privacy board in accordance
9 with 45 C.F.R. § 164.512(i)(1)(i)(A) and (B).

10 * * * Amyotrophic Lateral Sclerosis Registry Disclosure Requirements * * *

11 Sec. 3. 18 V.S.A. § 174 is amended to read:

12 § 174. CONFIDENTIALITY

13 (a)(1) All identifying information regarding an individual patient or health
14 care provider is exempt from public inspection and copying under the Public
15 Records Act and shall be kept confidential.

16 (2) Notwithstanding subdivision (1) of this subsection, the
17 Commissioner may enter into data sharing and protection agreements with
18 researchers or state, regional, or national amyotrophic lateral sclerosis
19 registries for bidirectional data exchange, provided access under such
20 agreements is consistent with the privacy, security, and disclosure protections
21 in this chapter. In the case of researchers, the Commissioner shall also first

1 obtain evidence of the approval of ~~their academic committee for the protection~~
2 ~~of human subjects established in accordance with 45 C.F.R. Part 46 an~~
3 institutional review board or privacy board in accordance with 45 C.F.R.
4 § 164.512(i)(1)(i)(A) and (B). The Commissioner shall disclose the minimum
5 information necessary to accomplish a specified research purpose.

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7 * * * Effective Date * * *

8 Sec. 4. EFFECTIVE DATE

9 This act shall take effect on July 1, 2025.