TO THE HOUSE OF REPRESENTATIVES:

The Committee on Human Services to which was referred House Bill No. 293 entitled "An act relating to health equity data reporting and registry disclosure requirements" respectfully reports that it has considered the same and recommends that the bill be amended by striking out all after the enacting clause and inserting in lieu thereof the following:

* * * Health Equity Data Reporting * * *

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

§ 253. DATA RESPONSIVE TO HEALTH EQUITY INQUIRIES

* * *

(b)(1) The Department of Health shall systematically analyze such health equity data using the smallest appropriate units of analysis feasible to detect racial and ethnic disparities, as well as disparities along the lines of primary language, sex, disability status, sexual orientation, gender identity, and socioeconomic status, and report the results of such analysis on the Department's website periodically, but not less than biannually. The Department's analysis shall be used to measure over time the impact of actions taken to reduce health disparities in Vermont. The data informing the Department's analysis shall be made available to the public in accordance with State and federal law.

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

* * * Cancer Registry Disclosure Requirements * * *

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

§ 155. DISCLOSURE

* * *

(b) The Commissioner may furnish confidential information to the National Breast and Cervical Cancer Early Detection Program, other states' cancer registries, federal cancer control agencies, or health researchers in order to collaborate in a national cancer registry or to collaborate in cancer control and prevention research studies. However, before releasing confidential information, the Commissioner shall first obtain from such state registries, agencies, or researchers ~~an agreement in writing to keep~~ written assurances acceptable to the Commissioner that the identifying information shall be kept confidential and privileged as required by law. In the case of researchers, the Commissioner shall also first obtain written evidence of the approval of ~~their academic committee for the protection of human subjects established in~~

~~accordance with 45 C.F.R. part 46~~ an institutional review board or privacy board in accordance with 45 C.F.R. § 164.512(i)(1)(i)(A) and (B).

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

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

§ 174. CONFIDENTIALITY

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

(2) Notwithstanding subdivision (1) of this subsection, the Commissioner may enter into data sharing and protection agreements with researchers or state, regional, or national amyotrophic lateral sclerosis registries for bidirectional data exchange, provided access under such agreements is consistent with the privacy, security, and disclosure protections in this chapter. In the case of researchers, the Commissioner shall also first obtain written evidence of the approval of ~~their academic committee for the protection of human subjects established in accordance with 45 C.F.R. Part 46~~ an institutional review board or privacy board in accordance with 45 C.F.R. § 164.512(i)(1)(i)(A) and (B). The Commissioner shall disclose the minimum information necessary to accomplish a specified research purpose.

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* * * Effective Date * * *

Sec. 4. EFFECTIVE DATE

This act shall take effect on July 1, 2025.

(Committee vote: _____)

_____

Representative _____

FOR THE COMMITTEE