H.98

An act relating to reportable disease registries and data

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

Sec. 1. 18 V.S.A. chapter 4 is amended to read:

CHAPTER 4. CANCER REGISTRY

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§ 153. PARTICIPATION IN PROGRAM

- (a) Any health care facility diagnosing or providing treatment to eancer patients with cancer shall report each case of cancer to the commissioner Commissioner or his or her authorized representative in a format prescribed by the commissioner Commissioner within 120 180 days of admission or diagnosis. If the facility fails to report in a format prescribed by the commissioner Commissioner, the commissioner's Commissioner's authorized representative may enter the facility, obtain the information, and report it in the appropriate format. In these cases, the facility shall reimburse the commissioner Commissioner or the authorized representative for the cost of obtaining and reporting the information.
- (b) Any health care provider diagnosing or providing treatment to eancer patients with cancer shall report each cancer case to the commissioner

 Commissioner or his or her authorized representative within 120 180 days of diagnosis. Those cases diagnosed or treated at a Vermont facility or previously

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admitted to a Vermont facility for diagnosis or treatment of that instance of cancer are exceptions and do not need to be reported by the health care provider.

(c) All health care facilities and health care providers who provide diagnostic or treatment services to patients with cancer shall report to the commissioner Commissioner any further demographic, diagnostic, or treatment information requested by the commissioner Commissioner concerning any person now or formerly receiving services, diagnosed as having or having had a malignant tumor. Additionally, the commissioner Commissioner or his or her authorized representative shall have physical access to all records which that would identify cases of cancer or would establish characteristics of the cancer, treatment of the cancer, or medical status of any identified cancer patient with cancer. Willful failure to grant access to such records shall be punishable by a fine of up to \$500.00 for each day access is refused. Any fines collected pursuant to this subsection shall be deposited in the general fund.

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§ 155. DISCLOSURE

(a) The <u>commissioner Commissioner</u> may enter into agreements to exchange confidential information with other cancer registries in order to obtain complete reports of Vermont residents diagnosed or treated in other

states and to provide information to other states regarding their residents diagnosed or treated in Vermont.

(b) The commissioner 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 Commissioner shall first obtain from such state registries, agencies, or researchers an agreement in writing to keep the identifying information confidential and privileged. In the case of researchers, the commissioner Commissioner shall also first obtain evidence of the approval of their academic committee for the protection of human subjects established in accordance with part 46 of Title 45 of the Code of Federal Regulations 45 C.F.R. part 46.

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Sec. 2. 18 V.S.A. § 1001 is amended to read:

§ 1001. REPORTS TO COMMISSIONER OF HEALTH

(a) When a physician, health care provider, nurse practitioner, nurse, physician assistant, or school health official has reason to believe that a person is sick or has died of a diagnosed or suspected disease, identified by the Department of Health as a reportable disease and dangerous to the public

health, or if a laboratory director has evidence of such sickness or disease, he or she shall transmit within 24 hours a report thereof and identify the name and address of the patient and the name of the patient's physician to the Commissioner of Health or designee. In the case of the human immunodeficiency virus (HIV), "reason to believe" shall mean personal knowledge of a positive HIV test result. The Commissioner, with the approval of the Secretary of Human Services, shall by rule establish a list of those diseases dangerous to the public health that shall be reportable. Nonmedical community-based organizations shall be exempt from this reporting requirement. All information collected pursuant to this section and in support of investigations and studies undertaken by the commissioner Commissioner for the purpose of determining the nature or cause of any disease outbreak shall be privileged and confidential. The Health Department of Health shall, by rule, require that any person required to report under this section has in place a procedure that ensures confidentiality. In addition, in relation to the reporting of HIV and the acquired immune deficiency syndrome (AIDS), the Health Department shall, by rule:

(1) develop procedures, in collaboration with individuals living with
HIV or AIDS and with representatives of the Vermont AIDS service
organizations, to ensure confidentiality of all information collected pursuant to
this section: and

- (2) develop procedures for backing up encrypted, individually identifying information, including procedures for storage, location, and transfer of data.
- (b)(1) Public health records that relate to HIV or AIDS that contain any personally identifying information, or any information that may indirectly identify a person and was developed or acquired by state or local public health agencies, shall be confidential and shall only be disclosed following notice to the individual subject of the public health record or the individual's legal representative and pursuant to a written authorization voluntarily executed by the individual or the individual's legal representative. Except as provided in subdivision (2) of this subsection, notice and authorization is required prior to all disclosures, including disclosures to other states, the federal government, and other programs, departments, or agencies of state government.
- (2) Notwithstanding the provisions of subdivision (1) of this subsection, disclosure without notification shall be permitted to other states' infectious disease surveillance programs for the sole purpose of comparing the details of ease reports identified as possibly duplicative, provided such Public health records developed or acquired by State or local public health agencies that relate to HIV or AIDS and that contain either personally identifying information or information that may indirectly identify a person shall be confidential and only disclosed following notice to and written authorization

from the individual subject of the public health record or the individual's legal representative. Notice otherwise required pursuant to this section shall not be required for disclosures to the federal government; other departments, agencies, or programs of the State; or other states' infectious disease surveillance programs if the disclosure is for the purpose of comparing the details of potentially duplicative case reports, provided the information shall be shared using the least identifying information first so that the individual's name shall be used only as a last resort.

- (c) A disclosure made pursuant to subsection (b) of this section shall include only the information necessary for the purpose for which the disclosure is made. The disclosure shall be made only on agreement that the information shall remain confidential and shall not be further disclosed without additional notice to the individual and written authorization by the individual subject as required by subsection (b) of this section. [Repealed.]
- (d) A confidential public health record, including any information obtained pursuant to this section, shall not be:
- (1) disclosed or discoverable in any civil, criminal, administrative, or other proceeding;
- (2) used to determine issues relating to employment or insurance for any individual;

- (3) used for any purpose other than public health surveillance, and epidemiological follow-up.
 - (e) Any person who:
- (1) Willfully or maliciously discloses the content of any confidential public health record without written authorization or other than as authorized by law or in violation of subsection (b), (c), or (d) of this section shall be subject to a civil penalty of not less than \$10,000.00 and not more than \$25,000.00, costs and attorney's fees as determined by the court, compensatory and punitive damages, or equitable relief, including restraint of prohibited acts, costs, reasonable attorney's fees, and other appropriate relief.
- (2) Negligently discloses the content of any confidential public health record without written authorization or other than as authorized by law or in violation of subsection (b), (c), or (d) of this section shall be subject to a civil penalty in an amount not to exceed \$2,500.00 plus court costs, as determined by the court, which penalty and costs shall be paid to the subject of the confidential information.
- (3) Willfully, maliciously, or negligently discloses the results of an HIV test to a third party in a manner that identifies or provides identifying characteristics of the person to whom the test results apply without written authorization or other than as authorized by law or in violation of subsection (b), (c), or (d) of this section and that results in economic, bodily, or

psychological harm to the subject of the test is guilty of a misdemeanor, punishable by imprisonment for a period not to exceed one year or a fine not to exceed \$25,000.00, or both.

- (4) Commits any act described in subdivision (1), (2), or (3) of this subsection shall be liable to the subject for all actual damages, including damages for any economic, bodily, or psychological harm that is a proximate result of the act. Each disclosure made in violation of this chapter is a separate and actionable offense. Nothing in this section shall limit or expand the right of an injured subject to recover damages under any other applicable law.
- (f) Except as provided in subdivision (a)(2) of this section, the Health
 Department is prohibited from collecting, processing, or storing any
 individually identifying information concerning HIV/AIDS on any networked
 computer or server, or any laptop computer or other portable electronic device.
 On rare occasion, not as common practice, the Department may accept
 HIV/AIDS individually identifying information electronically. Once that
 information is collected, the Department shall, in a timely manner, transfer the
 information in compliance with this subsection. [Repealed.]
- (g) Health care providers must, prior to performing an HIV test, inform the individual to be tested that a positive result will require reporting of the result and the individual's name to the Department, and that there are testing sites that provide anonymous testing that are not required to report positive results.

The Department shall develop and make widely available a model notification form.

- (h) Nothing in this section shall affect the ongoing availability of anonymous testing for HIV. Anonymous HIV testing results shall not be required to be reported under this section.
- (i) No later than November 1, 2007, the Health Department shall conduct an information and security audit in relation to the information collected pursuant to this section, including evaluation of the systems and procedures it developed to implement this section and an examination of the adequacy of penalties for disclosure by state personnel. No later than January 15, 2008, the Department shall report to the Senate Committee on Health and Welfare and the House Committee on Human Services concerning options available, and the costs those options would be expected to entail, for maximizing protection of the information collected pursuant to this section. That report shall also include the Department's recommendations on whether the General Assembly should impose or enhance criminal penalties on health care providers for unauthorized disclosures of medical information. The Department shall solicit input from AIDS service organizations and the community advisory group regarding the success of the Department's security measures and their examination of the adequacy of penalties as they apply to HIV/AIDS and include this input in the report to the Legislature. The Department shall

annually evaluate the systems and confidentiality procedures developed to implement networked and non-networked electronic reporting, including system breaches and penalties for disclosure to State personnel. The Department shall provide the results of this evaluation to and solicit input from the Vermont HIV/AIDS Community Advisory Group.

- (j) No later than January 1, 2008, the Department shall plan and commence a public campaign designed to educate the general public about the value of obtaining an HIV test. The Department shall collaborate with community-based organizations to educate the public and health care providers about the benefits of HIV testing and the use of current testing technologies.
- (k) The Commissioner shall maintain a separate database of reports received pursuant to subsection 1141(i) of this title for the purpose of tracking the number of tests performed pursuant to subchapter 5 of chapter 21, subchapter 5 of this title and such other information as the Department of Health determines to be finds necessary and appropriate. The database shall not include any information that personally identifies a patient.
- Sec. 3. 18 V.S.A. § 1129 is amended to read:

§ 1129. IMMUNIZATION REGISTRY

(a) A health care provider shall report to the department Department all
 data regarding immunizations of adults and of children under the age of
 18 years of age within seven days of the immunization, provided that required

reporting of immunizations of adults shall commence within one month after the health care provider has established an electronic health records system and data interface pursuant to the e-health standards developed by the Vermont information technology leaders Information Technology Leaders. A health insurer shall report to the department Department all data regarding immunizations of adults and of children under the age of 18 years of age at least quarterly. All data required pursuant to this subsection shall be reported in a form format required by the department Department.

(b) The department Department may use the data to create a registry of immunizations. Registry information shall remain confidential and privileged, except as provided in subsections (c) and (d) of this section. Registry information regarding a particular adult shall be provided, upon request, to the adult, the adult's health care provider, and the adult's health insurer. A minor child's record also Registry information regarding a particular minor child may be provided, upon request, to school nurses, or in the absence of a nurse on staff, administrators as defined in 16 V.S.A. § 1691a, and upon request and with written parental consent, to licensed day care providers, to document compliance with Vermont immunization laws. Registry information regarding a particular child shall be provided, upon request, to the child after the child reaches the age of majority and to the minor child's parent, or guardian, health insurer, and health care provider, or to the child after the child reaches the age

of majority. Registry information shall be kept confidential and privileged and may be shared only in summary, statistical, or other form in which particular individuals are not identified.

- (c) The Department may exchange confidential registry information with the immunization registries of other states in order to obtain comprehensive immunization records.
- (d) The Department may provide confidential registry information to health care provider networks serving Vermont patients and, with the approval of the Commissioner, to researchers who present evidence of approval from an institutional review board in accordance with 45 C.F.R. § 164.512.
- (e) Prior to releasing confidential information pursuant to subsections (c) and (d) of this section, the Commissioner shall obtain from state registries, health care provider networks, and researchers a written agreement to keep any identifying information confidential and privileged.
- (f) The Department may share registry information for public health purposes in summary, statistical, or other form in which particular individuals are not identified, except as provided in subsections (c) and (d) of this section.

This act shall take effect on July 1, 2015.

Sec. 4. EFFECTIVE DATE