H.98 Cancer Registry Provisions

"The goal is to turn data into information, and information into insight."
Carly Fiorina, Chairwoman of Good360, Breast cancer survivor

"I never guess. It is a capital mistake to theorize before one has data. Insensibly one begins to twist facts to suit theories, instead of theories to suit facts."
Sir Arthur Conan Doyle, Author of Sherlock Holmes stories

This bill would strengthen Vermont's Cancer Registry law by standardizing cancer data collection and supporting confidentiality agreements in order to assist in cancer prevention programs on the state and federal level. More accurate data collection can serve to identify gaps in care, better inform treatment protocols and save lives.

Chapter 4 - Participation Provision

The change from 120 to 180 days would allow more time for accurate recording of cancer stage and treatment data. The current statute mandates reporting of cancer cases after four months of diagnosis, while many treatments are decided upon or administered after that time. The change would also make Vermont's law more consistent with other states' cancer registry reporting laws, as 180 days is the general standard amongst states. The change would help standardize Vermont's data and simplify the quality indicator reports, making it easier for health care facilities to determine whether they are in compliance with the Vermont Cancer Registry law.

Disclosure Provision

The Disclosure provision of the Cancer Registry Law is used as reference for every determination whether to share confidential information with a requestor and for every data use agreement protecting the shared data. A change to the Disclosure provision would make the determination to share data with the Ladies First program more consistent with other data requestors and would strengthen the justification to be able to share data with the Ladies First program.

In discussing this provision with Ali Johnson, the Vermont Cancer Registry Chief, she said the reason they need to exchange confidential data with the Ladies First program (Vermont's National Breast and Cervical Cancer Early Detection Program) is twofold:

(1) it provides the Ladies First program detailed diagnosis and staging information on their members;
(2) and it identifies potentially unreported cancer diagnoses for the Cancer Registry.

Higher quality Ladies First data could, in turn, identify gaps in care and problems with health care access by identifying whether Ladies First members are being diagnosed at earlier or later stages.

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ACS CAN, the nonprofit, nonpartisan advocacy affiliate of the American Cancer Society, supports evidence-based policy and legislative solutions designed to eliminate cancer as a major health problem. ACS CAN works to encourage elected officials and candidates to make cancer a top priority. ACS CAN gives ordinary people extraordinary power to fight cancer with the training and tools they need to make their voices heard.

The American Cancer Society Cancer Action Network • www.acscan.org/vermont