

SENATE BILL REPORT

SB 5482

As Reported By Senate Committee On:
Health & Long-Term Care, March 1, 1999

Title: An act relating to the use of state data bases for institutionally reviewed medical and health research.

Brief Description: Regulating disclosure of medical and health research records.

Sponsors: Senators Thibaudeau, Deccio, Costa, Rasmussen and Winsley.

Brief History:

Committee Activity: Health & Long-Term Care: 2/4/99, 3/1/99 [DPS].

SENATE COMMITTEE ON HEALTH & LONG-TERM CARE

Majority Report: That Substitute Senate Bill No. 5482 be substituted therefor, and the substitute bill do pass.

Signed by Senators Thibaudeau, Chair; Wojahn, Vice Chair; Costa, Deccio, Franklin, Johnson and Winsley.

Staff: Joan K. Mell (786-7447)

Background: Nonprofit organizations performing health or medical research like the Fred Hutchinson Cancer Research Center are concerned about their access to vital statistic information given recent federal legislation such as the Driver's Privacy Protection Act, which may restrict access to personal identifying information. Researchers advocate the necessity of personal statistical information for research purposes. Apparently some studies require accurate tracking of an individual, which sometimes can only be accomplished with descriptive vital statistic information.

Currently, various laws protect against disclosure of private or confidential information from public agencies. Specific identifying information like vital statistics are often protected, particularly if attached to a name. For example, the Bureau of Statistics under the Secretary of State is exempt from state public disclosure requirements. The Bureau of Statistics may not reveal the names of individuals, firms, or corporations supplying information to it.

However, agencies like the Department of Social and Health Services and the Department of Health have internal procedures for providing research groups vital statistics records or other requested information subject to internal procedures and protocols that ensure confidentiality safeguards are followed. Under limited circumstances, identifying information may be provided with restrictions.

Summary of Substitute Bill: An exception is stated to the Driver's Privacy Protection Act for information currently available under the public disclosure laws. An exception to the federal law is required to protect the public health, safety, and welfare. Information

accessible under public disclosure may be released to health research organizations recognized by an institutional review board.

Health research organizations are nonprofit corporations authorized under federal or state law to conduct health or medical research.

Institutional review boards are any board, committee, or other group formally designated by an institution, or authorized under federal or state law, to review, approve the initiation of, or conduct periodic review of research programs to assure the protection of the rights and welfare of human research subjects.

Substitute Bill Compared to Original Bill: The original bill was not considered.

Appropriation: None.

Fiscal Note: Requested on January 29, 1999.

Effective Date: Ninety days after adjournment of session in which bill is passed.

Testimony For: Medical research requires access to records that can be utilized to access potential subjects. Notable cancer research opens doors to cures and other treatment regimens that would never be discovered absent access to individuals and information for research purposes.

Testimony Against: Consent to access records should be required. The scope of information requested is too broad.

Testified: Andrea Stepheson, MHC (concerns); Michael Garrick, DSHS (concerns); Mike Rybeck, Thomas Vaughn, Polly Newcomb, Fred Hutchinson Cancer Research (pro); CON: Gary Franklin, L&I ; Doug Klunder, Jerry Sheehan, ACLU of Washington; Janeane Dubuar, Computer Professionals for Social Responsibility. Mary Selecky, Acting Secretary of Department of Health.