

# HOUSE BILL REPORT

## SSB 5482

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### As Reported By House Committee On:

State Government

**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:** Senate Committee on Health & Long-Term Care (originally sponsored by Senators Thibaudeau, Deccio, Costa, Rasmussen and Winsley).

### Brief History:

#### Committee Activity:

State Government: 3/23/99, 4/2/99 [DPA].

#### Brief Summary of Substitute Bill (As Amended by House Committee)

- Allows personal information from driver's license or identicard records to be released to health research organizations for medical or health research projects.

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### HOUSE COMMITTEE ON STATE GOVERNMENT

**Majority Report:** Do pass as amended. Signed by 5 members: Representatives McMorris, Republican Co-Chair; Romero, Democratic Co-Chair; Miloscia, Democratic Vice Chair; Haigh and D. Schmidt.

**Minority Report:** Do not pass. Signed by 3 members: Representatives Campbell, Republican Vice Chair; Dunshee and Lambert.

**Staff:** Scott MacColl (786-7106).

### Background:

The U.S. Driver's Privacy Protection Act of 1994 prohibits the release and use of certain personal information from state motor vehicle records. There are specific

exceptions to the rule defined in statute, such as the information being used in research activities so long as the personal information is not published, redisclosed, or used to contact individuals.

Prior to the act, non-profit health research organizations had access and used driver's license information for research projects. The act, which went into effect in September of 1997, effectively made it illegal for non-profit health research organizations to obtain driver's license information from the Department of Licensing.

An institutional review board is a board or committee that is authorized by state law to approve and conduct periodic reviews of research programs to assure the protection of the rights and welfare of human research subjects. Members of an institutional review board are made up of industry professionals, the institution, and lay persons.

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**Summary of Amended Bill:**

Disclosure of Washington Department of Licensing driver's license and identicard records to health research organizations in connection with a qualified medical or health research project is considered a permissible use under the U.S. Driver's Privacy Protection Act. The information that may be disclosed as personal information is specifically defined as names, residential addresses, county of residence, date of birth, gender, eye color, height, weight, and date of last activity. The project must have been reviewed and approved by an institutional review board.

**Amended Bill Compared to Substitute Bill:** The information from the Department of Licensing that is allowed to be disclosed is defined to be personal information from driver's license and identicard records; the personal information from those records is defined as names, residential addresses, county of residence, date of birth, gender, eye color, height, weight, and date of last activity.

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**Appropriation:** None.

**Fiscal Note:** Requested on 3/23/99.

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

**Testimony For:** Fred Hutchinson Cancer Research Center can no longer access driver's license information from the Department of Licensing due to the federal Driver's Protection Privacy Act. The Center has a contract to study the downwind effects of the Hanford Nuclear Site, but they need access to that information to find

people for the study. There was considerable concern with the original bill, and the original fiscal note was considerable. However, with the amendments made in the Senate, the Department of Health has stated that the substitute bill has a zero affect.

Prior to the 1994 act, which went into effect in 1998, the center had access to driver's license information. This bill uses an exemption that was allowed in the federal act. The research center is looking for access to limited driver's license records, and not to any information that was not accessible in the past. Using population studies and long term studies allows the research center to better understand long term affects. This creates a need to locate people geographically based on their age and demographics. These records are paramount for these studies. They are very useful in helping with long term follow-up studies; as people move, the best way to reach them is to track them through driver's license files. The information is only used to contact people to give them the choice of participation in the study, although there are others who think that the research center should receive an agreement before even contacting someone.

**Testimony Against:** There is concern as to whether or not people have a choice to be contacted about being in the study. There is also a question as to whether social security numbers can be a part of the Department of Licensing information, and what other groups have access to this data.

**Testified:** (In favor) Senator Thibaudeau, prime sponsor; and Beth King, Karma Kruzinbeck, and Mike Ryherd, Fred Hutchinson Cancer Research Center.

(Opposed) Janeane Dubuar, Computer Professionals for Social Responsibility.