

HOUSE BILL REPORT

HB 1622

As Reported by House Committee On:
State Government

Title: An act relating to research in the jurisdiction of a state agency.

Brief Description: Clarifying the definition of "research."

Sponsors: Representatives Morrell, Pflug, Cody, Skinner and Clibborn; by request of Department of Social and Health Services.

Brief History:

Committee Activity:

State Government: 2/27/03, 3/4/03 [DPS].

Brief Summary of Substitute Bill

- The definition of "research" in the context of releasing personal records for research purposes is broadened.
- The Department of Labor and Industries is added to the list of agencies eligible to release personal records for research purposes.

HOUSE COMMITTEE ON STATE GOVERNMENT

Majority Report: The substitute bill be substituted therefor and the substitute bill do pass. Signed by 9 members: Representatives Haigh, Chair; Miloscia, Vice Chair; Armstrong, Ranking Minority Member; Shabro, Assistant Ranking Minority Member; Hunt, McDermott, Nixon, Tom and Wallace.

Staff: Katie Blinn (786-7114).

Background:

The Department of Social and Health Services, the Department of Corrections, the Department of Health, or a state college or university may authorize the release of a personal record for research purposes if consent is provided by the person to whom the record pertains or, in the case of a minor or legally incompetent person, by the person's legal representative. The agency may authorize the release of a personal record without consent if:

1. The agency adopts research review and approval rules, including the requirement that a research review board be appointed to:
 - a. review research proposals for ethical and scientific soundness;
 - b. determine that release of the record has scientific merit and is important to the agency's program;
 - c. determine that the research cannot be accomplished without the personal record; and
 - d. minimize the risks of releasing the record, and determine that the remaining risks are outweighed by the anticipated health, safety, or scientific benefits of the research.
2. Disclosure does not violate federal law or regulations.
3. The research professional receiving the personal record agrees to abide by a legally binding confidentiality agreement.

A research professional who has developed an individually identifiable research record based on information in a personal record that was provided by a state agency may not disclose information in the research record unless:

1. consent is provided by the person to whom the record pertains or the person's legal representative;
2. the research professional reasonably believes that disclosure will prevent or minimize injury, and disclosure is limited to the information necessary;
3. the research record is disclosed in individually identifiable form for the purposes of auditing or evaluating the research program; or
4. the research record is furnished in response to a search warrant or court order.

"Research" is defined as a planned and systematic sociological, psychological, epidemiological, biomedical, or other scientific investigation carried out by a state agency, by a scientific research professional associated with a bona fide research organization, or by a graduate student. The objective of the investigation must be to contribute to scientific knowledge, the solution of social and health problems, or the evaluation of public benefit and service programs. The definition specifically excludes methods of analysis and data collection that are subjective, do not permit replication, or are not designed to yield reliable and valid results.

Summary of Substitute Bill:

"Research" is defined as a systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge. Activities that meet this definition are considered "research" whether or not they are conducted or supported under a program that is considered "research" for other purposes. For example, some demonstration and service programs may include research activities. The definition specifically excludes methods of analysis and data collection that are

subjective, do not permit replication, or are not designed to yield reliable and valid results.

The Department of Labor and Industries is added to the list of agencies eligible to release personal records for research purposes. Agencies are no longer required to appoint a research review board, but instead must designate a "registered institutional review board" to review and approve the release of personal records.

The prohibition on research professionals disclosing information developed in a research record applies only to research professionals who conduct research in the jurisdiction of a state agency. "Research in the jurisdiction of a state agency" is defined as:

1. Research conducted by an employee or contractor of a state agency;
2. Research sponsored by a state agency; or
3. Research that involves access to or disclosure of identifiable personal records obtained or maintained by a state agency.

Substitute Bill Compared to Original Bill:

The substitute bill reinstates language in the definition of research that excludes methods of record analysis and data collection that are subjective, do not permit replication, or are not designed to yield reliable and valid results.

Appropriation: None.

Fiscal Note: Not Requested.

Effective Date of Substitute Bill: The bill takes effect 90 days after adjournment of session in which bill is passed.

Testimony For: This is an agency request bill, requested by the Department of Social and Health Services. Agencies are able to provide greater protections to personal records because of this law. The bill would extend these protections to the Department of Labor and Industries. Agencies could designate the review board of another agency to review research proposals, rather than have to reinvent the wheel by creating their own review board. The bill will harmonize state law with federal standards regarding research. The bill improves the definition of research to be consistent with federal regulations. The bill holds researchers more accountable and reduces duplication of efforts among agencies.

Testimony Against: The Association of Washington Business (AWB) supports legitimate reasons for sharing information, as long as the practices are implemented carefully. However, AWB has concerns about the proposed change in the definition of research, based on a pending lawsuit regarding the ergonomics rules.

Testified: (In support) Representative Morrell, prime sponsor; and Barbara Silverstein, Department of Labor and Industries.

(With concerns) Amber Balch, Association of Washington Business.