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**SUBSTITUTE HOUSE BILL 1622**

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**State of Washington**

**58th Legislature**

**2003 Regular Session**

**By** House Committee on State Government (originally sponsored by Representatives Morrell, Pflug, Cody, Skinner and Clibborn; by request of Department of Social and Health Services)

READ FIRST TIME 03/05/03.

1 AN ACT Relating to research in the jurisdiction of a state agency;  
2 and amending RCW 42.48.010, 42.48.020, and 42.48.040.

3 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF WASHINGTON:

4 **Sec. 1.** RCW 42.48.010 and 1989 1st ex.s. c 9 s 207 are each  
5 amended to read as follows:

6 For the purposes of this chapter, the following definitions apply:

7 (1) "Individually identifiable" means that a record contains  
8 information which reveals or can likely be associated with the identity  
9 of the person or persons to whom the record pertains.

10 (2) "Legally authorized representative" means a person legally  
11 authorized to give consent for the disclosure of personal records on  
12 behalf of a minor or a legally incompetent adult.

13 (3) "Personal record" means any information obtained or maintained  
14 by a state agency which refers to a person and which is declared exempt  
15 from public disclosure, confidential, or privileged under state or  
16 federal law.

17 (4) "Research" means a ~~((planned and systematic sociological,~~  
18 ~~psychological, epidemiological, biomedical, or other scientific~~  
19 ~~investigation carried out by a state agency, by a scientific research~~

1 professional associated with a bona fide scientific research  
2 organization, or by a graduate student currently enrolled in an  
3 advanced academic degree curriculum, with an objective to contribute to  
4 scientific knowledge, the solution of social and health problems, or  
5 the evaluation of public benefit and service programs. This definition  
6 excludes methods of record analysis and data collection that are  
7 subjective, do not permit replication, and are not designed to yield  
8 reliable and valid results)) systematic investigation, including  
9 research development, testing, and evaluation, designed to develop or  
10 contribute to generalizable knowledge. Activities that meet this  
11 definition are research whether or not they are conducted or supported  
12 under a program that is considered research for other purposes. For  
13 example, some demonstration and service programs may include research  
14 activities. This definition excludes methods of record analysis and  
15 data collection that are subjective, do not permit replication, and are  
16 not designed to yield reliable and valid results.

17 (5) "Research in the jurisdiction of a state agency" means: (a)  
18 Research conducted by an employee or a contractor of a state agency;  
19 (b) research sponsored by a state agency; or (c) research that involves  
20 access to or disclosure of identifiable personal records obtained or  
21 maintained by a state agency.

22 (6) "Research record" means an item or grouping of information  
23 obtained for the purpose of research from or about a person or  
24 extracted for the purpose of research from a personal record.

25 ((+6)) (7) "State agency" means: (a) The department of social and  
26 health services; (b) the department of corrections; (c) an institution  
27 of higher education as defined in RCW 28B.10.016; ((or)) (d) the  
28 department of health; or (e) the department of labor and industries.

29 **Sec. 2.** RCW 42.48.020 and 1985 c 334 s 2 are each amended to read  
30 as follows:

31 (1) A state agency may authorize or provide access to or provide  
32 copies of an individually identifiable personal record for research  
33 purposes if informed written consent for the disclosure has been given  
34 to the appropriate department secretary, or the president of the  
35 institution, as applicable, or his or her designee, by the person to  
36 whom the record pertains or, in the case of minors and legally  
37 incompetent adults, the person's legally authorized representative.

1 (2) A state agency may authorize or provide access to or provide  
2 copies of an individually identifiable personal record for research  
3 purposes without the informed consent of the person to whom the record  
4 pertains or the person's legally authorized representative, only if:

5 (a) The state agency adopts research review and approval rules  
6 including, but not limited to, the requirement that the appropriate  
7 department secretary, or the president of the institution, as  
8 applicable, (~~appoint a standing human research~~) designate a  
9 registered institutional review board competent to review research  
10 proposals as to ethical and scientific soundness; and the review board  
11 determines that the disclosure request has scientific merit and is of  
12 importance in terms of the agency's program concerns, that the research  
13 purposes cannot be reasonably accomplished without disclosure of the  
14 information in individually identifiable form and without waiver of the  
15 informed consent of the person to whom the record pertains or the  
16 person's legally authorized representative, that disclosure risks have  
17 been minimized, and that remaining risks are outweighed by anticipated  
18 health, safety, or scientific benefits; and

19 (b) The disclosure does not violate federal law or regulations; and

20 (c) The state agency negotiates with the research professional  
21 receiving the records or record information a written and legally  
22 binding confidentiality agreement prior to disclosure. The agreement  
23 shall:

24 (i) Establish specific safeguards to assure the continued  
25 confidentiality and security of individually identifiable records or  
26 record information;

27 (ii) Ensure that the research professional will report or publish  
28 research findings and conclusions in a manner that does not permit  
29 identification of the person whose record was used for the research.  
30 Final research reports or publications shall not include photographs or  
31 other visual representations contained in personal records;

32 (iii) Establish that the research professional will destroy the  
33 individual identifiers associated with the records or record  
34 information as soon as the purposes of the research project have been  
35 accomplished and notify the agency to this effect in writing;

36 (iv) Prohibit any subsequent disclosure of the records or record  
37 information in individually identifiable form except as provided in RCW  
38 42.48.040; and

1 (v) Provide for the signature of the research professional, of any  
2 of the research professional's team members who require access to the  
3 information in identified form, and of the agency official authorized  
4 to approve disclosure of identifiable records or record information for  
5 research purposes.

6 **Sec. 3.** RCW 42.48.040 and 1985 c 334 s 4 are each amended to read  
7 as follows:

8 No research professional who conducts research in the jurisdiction  
9 of a state agency and who has established an individually identifiable  
10 research record from personal record information pursuant to RCW  
11 42.48.020(2), or who has established a research record from data or  
12 information voluntarily provided by ~~((an agency client or employee))~~ a  
13 research subject under ~~((a))~~ an oral or written confidentiality  
14 assurance for the explicit purpose of research, may disclose such a  
15 record in individually identifiable form unless:

16 (1) The person to whom the research record pertains or the person's  
17 legally authorized representative has given prior informed written  
18 consent for the disclosure; or

19 (2) The research professional reasonably believes that disclosure  
20 will prevent or minimize injury to a person and the disclosure is  
21 limited to information necessary to protect the person who has been or  
22 may be injured, and the research professional reports the disclosure  
23 only to the person involved or the person's guardian, the person's  
24 physician, and the agency; or

25 (3)(a) The research record is disclosed in individually  
26 identifiable form for the purposes of auditing or evaluating a research  
27 program; and

28 (b) The audit or evaluation is authorized or required by federal or  
29 state law or regulation or is based upon an explicit provision in a  
30 research contract, grant, or other written research agreement; and

31 (c) No subsequent disclosure of the research record in individually  
32 identifiable form will be made by the auditor or evaluator except as  
33 provided in this section; or

34 (4) The research record is furnished in compliance with a search  
35 warrant or court order: PROVIDED, That:

36 (a) The court issues the search warrant or judicial subpoena

1 concerning the research record solely for the purpose of facilitating  
2 inquiry into an alleged violation of law by the research professional  
3 using the record for a research purpose or by the agency; and

4 (b) Any research record obtained pursuant to (a) of this subsection  
5 and any information directly or indirectly derived from the research  
6 record shall remain confidential to the extent possible and shall not  
7 be used as evidence in an administrative, judicial, or legislative  
8 proceeding except against the research professional using the record  
9 for a research purpose or against the state agency.

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