

SUMMARY ANALYSIS OF AMENDED BILL

Author: Bowen Analyst: Gail Hall Bill Number: SB 13
 Related Bills: See Prior Analysis Telephone: 845-6111 Amended Date: 4/13/2005 and 4/21/2005
 Attorney: Patrick Kusiak Sponsor: _____

SUBJECT: Personal Information Disclosure For Research Purposes

DEPARTMENT AMENDMENTS ACCEPTED. Amendments reflect suggestions of previous analysis of bill as introduced/amended _____.

AMENDMENTS IMPACT REVENUE. A new revenue estimate is provided.

AMENDMENTS DID NOT RESOLVE THE DEPARTMENTS CONCERNS stated in the previous analysis of bill as introduced/amended _____.

FURTHER AMENDMENTS NECESSARY.

DEPARTMENT POSITION CHANGED TO _____.

REMAINDER OF PREVIOUS ANALYSIS OF BILL AS INTRODUCED
December 6, 2004 STILL APPLIES.

OTHER – See comments below.

SUMMARY

This bill would amend the Civil Code and the Welfare and Institutions Code to provide strict limitations on the personal information a state agency may disclose for statistical research and reporting.

SUMMARY OF AMENDMENTS

The April 21st amendments give the Committee for the Protection of Human Subjects (CPHS) for the California Health and Human Services Agency (CHHSA) the authority to enter into written agreements with other boards to approve research projects.

The April 13th amendments restored the provisions that allowed state agencies to disclose personal information to public and private sector researchers. This item is discussed further in the THIS BILL discussion below. The remainder of the department’s analysis of the bill as introduced on December 6, 2004, still applies.

POSITION

Pending.

Board Position:	Department Director	Date
_____ S		
_____ SA		
_____ N	Brian Putler	4/29/05
_____ NA		
_____ O		
_____ OUA		
_____ NP		
_____ NAR		
<u>_____ X</u> PENDING		

THIS BILL

This bill adds minimum safeguarding requirements for personal information disclosed to the University of California or a nonprofit educational institution conducting scientific research. This bill requires the CPHS to approve the request for information. The following criteria must be met by CPHS before approval is granted:

- the researcher must provide a sufficient plan to protect personal information from improper use and disclosure,
- the researcher must provide a sufficient plan to destroy or return all personal information as soon as it is no longer needed for the research project, and
- the researcher must provide sufficient written assurance that the personal information will not be reused or disclosed to another person or entity.

The bill requires CPHS as part of its review to:

- determine if the requested personal information is needed to conduct research,
- permit access to personal information only if it is needed for the research project,
- permit access only to the minimum personal information necessary to conduct the research,
- require the use of unique subject codes instead of social security numbers, and
- allow the agency providing the personal information to conduct a portion of the data processing, if cost effective.

The bill provides that any cost to the agency providing the personal information may be billed to the researcher. Examples of some costs that may be billed are costs for conducting data processing, removing personal information, encrypting and securing personal information, and assigning subject codes.

IMPLEMENTATION CONSIDERATIONS

Implementing this bill would not significantly impact the department's programs and operations. The department already follows strict rules to protect the confidentiality of personal information. Certain limited exceptions are provided by statutes that require sharing with other specified government agencies such as the Office of the Attorney General.

In addition, the department receives several requests each year from private and public research sectors for data. If information is provided, it is done so cumulative data is not identifiable to any individual taxpayer.

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