52:9YY-1

LEGISLATIVE HISTORY CHECKLIST

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- **LAWS OF:** 2001 **CHAPTER:** 192
- NJSA: 52:9YY-1 ("Health Data Commission Act")
- BILL NO: A314 (Substituted for S374)
- **SPONSOR(S):** Vandervalk and Cohen
- DATE INTRODUCED: January 11, 2000
- COMMITTEE: ASSEMBLY: Health

SENATE: Health

AMENDED DURING PASSAGE: Yes

DATE OF PASSAGE:ASSEMBLY:October 5, 2000

- **SENATE:** June 28, 2001
- DATE OF APPROVAL: July 31, 2001

FOLLOWING ARE ATTACHED IF AVAILABLE:

FINAL TEXT OF BILL (2nd reprint enacted)

(Amendments during passage denoted by superscript numbers)

A314

	SPONSORS STATEMENT: (Begins on page 8 of original bill)		Yes
	COMMITTEE STATEMENT:	ASSEMBLY:	Yes
		SENATE:	Yes
	FLOOR AMENDMENT STATEMENTS:		No
	LEGISLATIVE FISCAL NOTE:		Yes
S374			

SPONSORS STATEMENT: (Begins on page 8 of original bill) Yes

Bill and Sponsors Statement identical to A314

COMMITTEE STATEMENT:	ASSEMBLY:	No
	SENATE:	Yes
FLOOR AMENDMENT STATEMENTS:		No
LEGISLATIVE FISCAL ESTIMATE:		No
VETO MESSAGE:		No
GOVERNOR'S PRESS RELEASE ON SIGNING):	Yes
FOLLOWING WERE PRINTED:		
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REPORTS:		No
HEARINGS:		No
NEWSPAPER ARTICLES:		No

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ASSEMBLY, No. 314 STATE OF NEW JERSEY 209th LEGISLATURE

PRE-FILED FOR INTRODUCTION IN THE 2000 SESSION

Sponsored by: Assemblywoman CHARLOTTE VANDERVALK District 39 (Bergen)

Co-Sponsored by: Assemblymen Thompson and Cohen

SYNOPSIS

"Health Data Commission Act;" appropriates \$94,000.

CURRENT VERSION OF TEXT

Introduced Pending Technical Review by Legislative Counsel.



(Sponsorship Updated As Of: 2/1/2000)

1 AN ACT establishing the New Jersey Health Data Commission, 2 supplementing Title 52 of the Revised Statutes and making an 3 appropriation. 4 5 **BE IT ENACTED** by the Senate and General Assembly of the State 6 of New Jersey: 7 8 1. This act shall be known and may be cited as the "Health Data 9 Commission Act." 10 11 2. The Legislature finds and declares that: a. It is the intention of the Legislature to establish a single point of 12 13 contact for members of the public to obtain health data through the 14 creation of the New Jersey Health Data Commission; b. The purpose of this commission is to compile health care access, 15 quality and cost data produced within the State from public and 16 17 private entities and maximize the usefulness of the data for the public 18 without duplicating existing data collection efforts by State agencies; 19 and 20 c. It is anticipated that the expense to the State of compiling and disseminating the available and useful health data for the benefit of the 21 public will be minimal and will be partially offset by subscriptions to 22 routinely published commission documents, the purchase of special 23 24 commission reports, and the receipt of grants to provide health data 25 information to the public. 26 27 3. As used in this act: "Commission" means the New Jersey Health Data Commission 28 29 established pursuant to this act. 30 "Disclosure" means the disclosure of health data to a person or 31 entity outside the commission. 32 "Health data" means any information, except vital statistics as 33 defined in R.S.26:8-1, relating to the health status of people, the availability of health care resources and services, or the use and cost 34 35 of these resources and services. 36 "Identifiable health data" means any item, collection or grouping of 37 health data which makes the person supplying it or described in it identifiable. 38 39 "Research and statistical purposes" means the performance of 40 certain activities relating to health data, including, but not limited to: describing the group characteristics of persons or entities; analyzing 41 42 the interrelationships among various characteristics of persons or 43 entities; the conduct of statistical procedures or studies to improve the 44 quality of health data; the design of sample surveys and the selection 45 of samples of persons or entities; the preparation and publication of reports describing these activities; and other related functions; but 46

excluding the use of health data for a person or entity to make a
 determination directly affecting the rights, benefits or entitlements of
 that person or entity.

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5 4. a. There is created a permanent commission to be known as the 6 "New Jersey Health Data Commission." The commission shall consist 7 of 32 members as follows: the Commissioners of Health and Senior 8 Services, Human Services, Banking and Insurance, Labor, Community 9 Affairs and Personnel and the State Treasurer, or their designees, as 10 ex officio members; two members each from the Senate and General 11 Assembly to be appointed by the President of the Senate and the 12 Speaker of the General Assembly, respectively, who in each case shall 13 be members of different political parties; and 21 public members who 14 shall be appointed by the Governor as follows: one person upon the 15 recommendation of the New Jersey Health Care Payers Coalition; one person upon the recommendation of the New Jersey Health Care 16 17 Quality Institute; one person upon the recommendation of the New 18 Jersey Business and Industry Association; one person upon the 19 recommendation of the New Jersey AFL-CIO; one person upon the 20 recommendation of the Medical Society of New Jersey; one person 21 upon the recommendation of the New Jersey Hospital Association; one 22 person upon the recommendation of the New Jersey Association of 23 Health Care Facilities, one person upon the recommendation of the 24 New Jersey State Nurses Association; one person upon the 25 recommendation of the New Jersey Dental Association; one person 26 upon the recommendation of the Home Health Assembly of New 27 Jersey, Inc.; one person upon the recommendation of the Mental 28 Health Association in New Jersey; one person upon the 29 recommendation of the New Jersey Pharmacists Association; one 30 person upon the recommendation of the New Jersey Health Officers 31 Association; one person upon the recommendation of Horizon Blue 32 Cross Blue Shield of New Jersey; one person upon the 33 recommendation of the Health Insurance Association of America; one 34 person upon the recommendation of the New Jersey Association of Health Plans; one person upon the recommendation of a domestic 35 stock health insurance carrier based in New Jersey; one person who 36 represents teaching and research hospitals, upon the joint 37 38 recommendation of the University of Medicine and Dentistry of New 39 Jersey, the University Health System of New Jersey, Robert Wood 40 Johnson University Hospital and Cooper Hospital/University Medical 41 Center; and three other public members who are consumers of health 42 care services and are not represented by any of the other categories of 43 public members included on the commission, one of whom shall be 44 enrolled as a beneficiary of the Medicare program established pursuant 45 to the federal Social Security Act, Pub.L.89-97 (42 U.S.C. s.1395 et 46 seq.).

b. All appointments to the commission shall be made no later than
 the 90th day after the effective date of this act. The commission shall
 organize upon the appointment of a majority of its authorized
 membership.

c. Appointed members of the commission shall serve for three-year
terms, except that of the public members first appointed, five shall be
appointed for terms of one year, eight for terms of two years and eight
for terms of three years.

9 d. Each member shall hold office for the term of appointment and 10 until a successor is appointed and qualified. All vacancies shall be 11 filled in the same manner as the original appointment. Members 12 appointed to fill a vacancy occurring for any reason other than the 13 expiration of the term shall serve for the unexpired term only. An 14 appointed member of the commission shall be eligible for 15 reappointment. An appointed member may be removed for cause.

e. Appointed members shall serve without compensation, but shall
be reimbursed for necessary expenses incurred in the performance of
their duties.

19 f. The commission shall select a chairman from among the public 20 members, who shall serve a one-year term but may serve consecutive 21 terms. The commission shall adopt by-laws. The commission shall 22 meet at least quarterly and may meet at other times at the call of the 23 chairman. The commission shall in all respects comply with the provisions of the "Open Public Meetings Act," P.L.1975, c.231 24 (C.10:4-6 et seq.). No motion to take any action by the commission 25 shall be valid except upon the affirmative vote of a majority of the 26 27 quorum required to conduct business.

28 g. The commission shall appoint a full-time executive director, who 29 shall serve as secretary to the commission. The executive director shall serve at the pleasure of the commission and shall be qualified by 30 31 training and experience to perform the duties of the position. The 32 executive director shall be in the unclassified service of the Civil Service and may hire properly qualified employees, within the limits of 33 34 funds appropriated or otherwise made available to the commission, who shall also be employed in the unclassified service of the Civil 35 Service; except that employees performing stenographic or clerical 36 duties shall be in the career service and appointed pursuant to Title 37 38 11A of the New Jersey Statutes.

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40 5. a. The commission may:

41 (1) collect and maintain health data from State government agencies42 or other entities on:

43 (a) the extent, nature and impact of illness and disability on the44 population of the State;

45 (b) the determinants of health and health hazards;

46 (c) health resources, including the extent of available personnel and

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resources; (d) utilization of health care; (e) health care costs and financing; and (f) other health-related matters; (2) undertake and support research, demonstrations and evaluations concerning new or improved methods for obtaining current data with respect to any of the health data described in paragraph (1) of this subsection; and (3) promote standards for health data that will facilitate the comparison of information and ease the burden of data preparation and reporting. b. The commission may collect health data on behalf of other entities. c. The commission shall collect health data only on a voluntary basis from persons and entities, except to the extent that specific statutory authority exists to compel the reporting of such data. When requesting health data from a person or entity, the agency shall notify the person or entity in writing as to the following: (1) whether the person or entity is required to supply the health data and any sanctions which may be imposed for noncompliance; (2) the purposes for which the health data is being collected; and (3) if the commission intends to disclose identifiable health data for other than research and statistical purposes, the information to be disclosed, to whom it is to be disclosed, and for what purposes. d. Except as provided in section 6 of this act, no health data obtained by the commission may be used for any purpose other than the purpose for which they were supplied or for which the person or entity described in the data has otherwise consented. e. The commission shall: (1) take such actions as may be necessary to assure that the health data which it obtains and maintains are accurate, timely and comprehensive, as well as specific, standardized and adequately analyzed and indexed; and (2) publish, disseminate and otherwise make available these data on as wide a basis as practicable. f. The commission shall take such actions as are appropriate to effect the collection and compilation of health data produced within the State and to maximize the usefulness of the data collected. g. The commission shall: (1) participate with federal, State and local government agencies in the design and implementation of a cooperative system of producing comparable and uniform health data at the federal, State and local levels: (2) undertake and support research, development, demonstrations and evaluations concerning such a cooperative system; and (3) assume its fair share of the data costs associated with

1 implementing and maintaining such a system. 2 3 6. a. The commission shall make no disclosure of any health data 4 which identifies a person's health status or utilization of health care unless: 5 6 (1) the person described in the data has consented to the disclosure; 7 or 8 (2) the disclosure is to a federal government agency or a state 9 government agency in this or another state, except that: 10 (a) the data shall be used for a purpose for which the data was collected by the commission; and 11 12 (b) the recipient of the data shall enter into a written agreement with the commission that it will protect the data in accordance with the 13 14 requirements of this act and will not permit further disclosure without 15 the prior approval of the commission; or (3) the disclosure is to a person or entity, for a specified period of 16 17 time determined by the commission, solely for bona fide research and statistical purposes, as determined in accordance with guidelines 18 19 adopted by the commission, when: 20 (a) the commission determines that the disclosure of the data to the 21 requesting person or entity is required for the research and statistical 22 purposes proposed; and 23 (b) the requesting person or entity has entered into a written agreement with the commission that it will protect the data in 24 accordance with the requirements of this act and will not permit 25 further disclosure without the prior approval of the commission; 26 except that the name, address or other unique personal identifier of a 27 28 person supplying the data or identified in it shall not be disclosed to 29 the requesting person or entity. 30 b. Any disclosure provided for in this section shall be made at the 31 discretion of the commission. 32 c. No identifiable health data obtained by the commission shall be subject to subpoena or similar compulsory process in a civil or 33 34 criminal, judicial, administrative or legislative proceeding, nor shall a person or entity with lawful access to identifiable health data pursuant 35 to this act be compelled to testify with regard to that data; except that 36 37 data pertaining to a party in litigation may be subject to subpoena or 38 similar compulsory process in an action brought by or on behalf of that 39 party to enforce a liability arising under this act. 40 41 7. The commission shall take appropriate measures to protect the security of health data which it obtains, including: 42 43 a. limiting access to the data to authorized persons; 44 b. designating a person to be responsible for the physical security 45 of the data; 46 c. developing and implementing a system for monitoring the

1 security of the data; 2 d. periodically reviewing all health data to evaluate whether it is 3 appropriate to remove identifying characteristics from the data; and 4 e. developing a program for the routine scheduled destruction of 5 all forms, records or electronic files maintained by the commission 6 which contain identifiable health data. 7 8 8. In addition to any other powers authorized by law, the 9 commission shall have the authority, in accordance with State law, to: 10 a. make and enter into contracts to purchase services and supplies 11 and to hire consultants; 12 b. develop and submit a proposed budget; c. accept gifts and charitable contributions; 13 14 d. apply for, receive and expend grants; 15 e. adopt regulations, pursuant to the "Administrative Procedure Act," P.L.1968, c.410 (C.52:14B-1 et seq.), to effectuate the purposes 16 17 of this act; f. establish charges for and collect payment from persons and 18 entities for the provision of services, including the dissemination of 19 20 health data; 21 g. receive and expend appropriations; 22 h. enter into a reimbursable work program with other State 23 government agencies or private entities under which funds are transferred from the other agencies or entities to the commission for 24 25 the performance of activities pursuant to this act; and 26 i. provide such other services and perform such other functions as 27 the commission deems necessary to fulfill its responsibilities under this 28 act. 29 30 9. a. A person or entity whom the commission determines has violated any of the provisions of section 6 of this act regarding the 31 32 disclosure of health data shall be subject, in addition to any other penalties that may be prescribed by law, to: a civil penalty of not more 33 34 than \$10,000 for each such violation, but not to exceed \$50,000 in the aggregate for multiple violations; or a civil penalty of not more than 35 \$250,000, if the commission finds that these violations have occurred 36 with such frequency as to constitute a general business practice. 37 38 The penalty shall be sued for and collected in the name of the 39 commission in a summary proceeding in accordance with the "penalty 40 enforcement law," N.J.S.A.2A:58-1 et seq. 41 b. The commission or an entity acting on its behalf shall be liable to a person or entity injured by the intentional or negligent violation 42 of any provision of section 6 of this act in an amount equal to the 43 44 damages sustained by the person or entity, together with the cost of 45 the action and reasonable attorney's fees, as determined by the court.

1 10. There is appropriated \$94,000 from the General Fund to the 2 New Jersey Health Data Commission to carry out the provisions of 3 this act. 4 5 11. This act shall take effect immediately. 6 7 8 **STATEMENT** 9 10 This bill establishes a permanent commission to be known as the "New Jersey Health Data Commission." 11 The commission shall consist of 32 members as follows: the 12 13 Commissioners of Health and Senior Services, Human Services, Banking and Insurance, Labor, Community Affairs and Personnel and 14 15 the State Treasurer, or their designees; two members each from the Senate and General Assembly, who in each case shall be members of 16 17 different political parties; and 21 public members appointed by the 18 Governor, including a representative from each of the following: the 19 New Jersey Health Care Payers Coalition, the New Jersey Health Care 20 Quality Institute, the New Jersey Business and Industry Association, 21 the New Jersey AFL-CIO, the Medical Society of New Jersey, the 22 New Jersey Hospital Association, the New Jersey Association of 23 Health Care Facilities, the New Jersey State Nurses Association, the New Jersey Dental Association, the Home Health Assembly of New 24 25 Jersey, Inc., the Mental Health Association in New Jersey, the New Jersey Pharmacists Association, the New Jersey Health Officers 26 27 Association, Horizon Blue Cross Blue Shield of New Jersey, the 28 Health Insurance Association of America, the New Jersey Association 29 of Health Plans, a domestic stock health insurance carrier based in 30 New Jersey, and teaching and research hospitals; in addition to three health care consumers, one of whom is a Medicare enrollee. 31 32 The bill provides that the commission may: 33 (1) collect and maintain health data from State government agencies 34 or other entities on: (a) the extent, nature and impact of illness and disability on the 35 36 population of the State; 37 (b) the determinants of health and health hazards; 38 (c) health resources, including the extent of available manpower and 39 resources; 40 (d) utilization of health care; 41 (e) health care costs and financing; and 42 (f) other health-related matters; 43 (2) undertake and support research, demonstrations and evaluations 44 concerning new or improved methods for obtaining current health 45 data; and (3) promote standards for health data that will facilitate the 46

1 comparison of information and ease the burden of data preparation and 2 reporting. 3 The commission shall collect health data only on a voluntary basis 4 from persons and entities, except to the extent that specific statutory authority exists to compel the reporting of such data. Except as 5 specified in the bill, no health data obtained by the commission may be 6 7 used for any purpose other than the purpose for which they were 8 supplied or for which the person or entity described in the data has 9 otherwise consented. 10 The commission shall: 11 (1) take such actions as may be necessary to assure that the health 12 data which it obtains and maintains are accurate, timely and comprehensive, as well as specific, standardized and adequately 13 14 analyzed and indexed; and 15 (2) publish, disseminate and otherwise make available these data on as wide a basis as practicable. 16 17 The commission shall make no disclosure of any health data which identifies a person's health status or utilization of health care unless: 18 (1) the person described in the data has consented to the disclosure; 19 20 or 21 (2) the disclosure is to a federal government agency or a state 22 government agency in this or another state, except that: 23 (a) the data shall be used for a purpose for which the data was collected by the commission; and 24 (b) the recipient of the data shall enter into a written agreement 25 with the commission that it will protect the data in accordance with the 26 27 requirements of this bill and will not permit further disclosure without 28 the prior approval of the commission; or 29 (3) the disclosure is to a person or entity, for a specified period of 30 time determined by the commission, solely for bona fide research and 31 statistical purposes, as determined in accordance with guidelines 32 adopted by the commission, when: 33 (a) the commission determines that the disclosure of the data to the 34 requesting person or entity is required for the research and statistical purposes proposed; and 35 (b) the requesting person or entity has entered into a written 36 37 agreement with the commission that it will protect the data in 38 accordance with the requirements of this bill and will not permit 39 further disclosure without the prior approval of the commission;

40 except that the name, address or other unique personal identifier of a 41 person supplying the data or identified in it shall not be disclosed to 42 the requesting person or entity.

Any disclosure provided for in this bill shall be made at the 43 44 discretion of the commission.

No identifiable health data obtained by the commission shall be 45 46 subject to subpoena or similar compulsory process in a civil or

1 criminal, judicial, administrative or legislative proceeding, nor shall a

2 person or entity with lawful access to identifiable health data pursuant

3 to this bill be compelled to testify with regard to that data; except that

4 data pertaining to a party in litigation may be subject to subpoena or

5 similar compulsory process in an action brought by or on behalf of that

6 party to enforce a liability arising under this bill.

7 The commission shall take appropriate measures to protect the 8 security of health data which it obtains, including:

9 a. limiting access to the data to authorized persons who have 10 received training in handling the data;

b. designating a person to be responsible for the physical securityof the data;

c. developing and implementing a system for monitoring thesecurity of the data;

d. periodically reviewing all health data to evaluate whether it is
appropriate to remove identifying characteristics from the data; and

e. developing a program for the routine scheduled destruction of
all forms, records or electronic files maintained by the commission
which contain identifiable health data.

The commission shall adopt regulations, pursuant to the "Administrative Procedure Act," P.L.1968, c.410 (C.52:14B-1 et seq.), to effectuate the purposes of this bill, and shall appoint an executive director who may hire staff within the limits of available funds. A \$94,000 appropriation to the commission is provided in the bill.

ASSEMBLY HEALTH COMMITTEE

STATEMENT TO

ASSEMBLY, No. 314

with committee amendments

STATE OF NEW JERSEY

DATED: MAY 1, 2000

The Assembly Health Committee reports favorably and with committee amendments Assembly Bill No. 314.

As amended by the committee, this bill establishes a permanent commission to be known as the "New Jersey Health Data Commission."

The commission shall consist of 32 members as follows: the Commissioners of Health and Senior Services, Human Services, Banking and Insurance, Labor, Community Affairs and Personnel and the State Treasurer, or their designees; two members each from the Senate and General Assembly, who in each case shall be members of different political parties; and 21 public members appointed by the Governor, including a representative from each of the following: the New Jersey Health Care Payers Coalition, the New Jersey Health Care Quality Institute, the New Jersey Business and Industry Association, the New Jersey AFL-CIO, the Medical Society of New Jersey, the New Jersey Hospital Association, the New Jersey Association of Health Care Facilities, the New Jersey State Nurses Association, the New Jersey Dental Association, the Home Health Assembly of New Jersey, Inc., the Mental Health Association in New Jersey, the New Jersey Pharmacists Association, the New Jersey Health Officers Association, Horizon Blue Cross Blue Shield of New Jersey, the Health Insurance Association of America, the New Jersey Association of Health Plans, a domestic stock health insurance carrier based in New Jersey, and teaching and research hospitals; in addition to three health care consumers, one of whom is a Medicare enrollee.

The bill provides that the commission may:

(1) collect and maintain health data from State government agencies or other entities on:

(a) the extent, nature and impact of illness and disability on the population of the State;

(b) the determinants of health and health hazards;

(c) health resources, including the extent of available manpower and resources;

(d) utilization of health care;

(e) health care costs and financing; and

(f) other health-related matters;

(2) undertake and support research, demonstrations and evaluations concerning new or improved methods for obtaining current health data; and

(3) promote standards for health data that will facilitate the comparison of information and ease the burden of data preparation and reporting.

The commission shall collect health data only on a voluntary basis from persons and entities, except to the extent that specific statutory authority exists to compel the reporting of such data. No health data obtained by the commission may be used for any purpose other than the purpose for which they were supplied or for which the person or entity described in the data has otherwise consented.

The commission shall:

(1) take such actions as may be necessary to assure that the health data which it obtains and maintains are accurate, timely and comprehensive, as well as specific, standardized and adequately analyzed and indexed; and

(2) publish, disseminate and otherwise make available these data on as wide a basis as practicable.

The commission shall make no disclosure of any health data which identifies a person's health status or utilization of health care unless the person described in the data has consented to the disclosure. The same restriction applies to a person or entity to whom the commission has disclosed health data.

No identifiable health data obtained by the commission shall be subject to subpoena or similar compulsory process in a civil or criminal, judicial, administrative or legislative proceeding, nor shall a person or entity with lawful access to identifiable health data pursuant to this bill be compelled to testify with regard to that data; except that data pertaining to a party in litigation may be subject to subpoena or similar compulsory process in an action brought by or on behalf of that party to enforce a liability arising under this bill.

The commission shall take appropriate measures to protect the security of health data which it obtains, including:

a. limiting access to the data to authorized persons who have received training in handling the data;

b. designating a person to be responsible for the physical security of the data;

c. developing and implementing a system for monitoring the security of the data;

d. periodically reviewing all health data to evaluate whether it is appropriate to remove identifying characteristics from the data; and

e. developing a program for the routine scheduled destruction of all forms, records or electronic files maintained by the commission which contain identifiable health data.

The commission shall adopt regulations, pursuant to the "Administrative Procedure Act," N.J.S.A.52:14B-1 et seq., to

effectuate the purposes of this bill, and shall appoint an executive director who may hire staff within the limits of available funds. A \$94,000 appropriation to the commission is provided in the bill.

The committee amended the bill to strengthen its confidentiality provisions (in section 6) by providing that neither the commission, nor a person or entity to whom the commission has disclosed health data, shall disclose any health data which identifies a person's health status or utilization of health care unless the person described in the data has consented to the disclosure.

This bill is similar to Assembly Bill No. 2432 (1R) of 1998 (Vandervalk) which this committee reported during the prior session, and which passed the General Assembly 75-1-1 on March 15, 1999.

This bill was prefiled for introduction in the 2000-2001 session pending technical review. As reported, the bill includes the changes required by technical review which has been performed.

[First Reprint] ASSEMBLY, No. 314 _____ STATE OF NEW JERSEY 209th LEGISLATURE

PRE-FILED FOR INTRODUCTION IN THE 2000 SESSION

Sponsored by: Assemblywoman CHARLOTTE VANDERVALK District 39 (Bergen) Assemblyman NEIL M. COHEN District 20 (Union)

Co-Sponsored by: Assemblymen Thompson

SYNOPSIS

"Health Data Commission Act;" appropriates \$94,000.

CURRENT VERSION OF TEXT

As reported by the Assembly Health Committee on May 1, 2000, with amendments.



(Sponsorship Updated As Of: 10/6/2000)

1 AN ACT establishing the New Jersey Health Data Commission, 2 supplementing Title 52 of the Revised Statutes and making an 3 appropriation. 4 5 **BE IT ENACTED** by the Senate and General Assembly of the State of New Jersey: 6 7 8 1. This act shall be known and may be cited as the "Health Data 9 Commission Act." 10 11 2. The Legislature finds and declares that: a. It is the intention of the Legislature to establish a single point of 12 13 contact for members of the public to obtain health data through the 14 creation of the New Jersey Health Data Commission; b. The purpose of this commission is to compile health care access, 15 quality and cost data produced within the State from public and 16 17 private entities and maximize the usefulness of the data for the public 18 without duplicating existing data collection efforts by State agencies; 19 and 20 c. It is anticipated that the expense to the State of compiling and disseminating the available and useful health data for the benefit of the 21 public will be minimal and will be partially offset by subscriptions to 22 routinely published commission documents, the purchase of special 23 24 commission reports, and the receipt of grants to provide health data 25 information to the public. 26 27 3. As used in this act: "Commission" means the New Jersey Health Data Commission 28 29 established pursuant to this act. 30 "Disclosure" means the disclosure of health data to a person or 31 entity outside the commission. 32 "Health data" means any information, except vital statistics as 33 defined in R.S.26:8-1, relating to the health status of people, the availability of health care resources and services, or the use and cost 34 35 of these resources and services. 36 "Identifiable health data" means any item, collection or grouping of 37 health data which makes the person supplying it or described in it identifiable. 38 39 "Research and statistical purposes" means the performance of 40 certain activities relating to health data, including, but not limited to: 41 describing the group characteristics of persons or entities; analyzing 42 the interrelationships among various characteristics of persons or

EXPLANATION - Matter enclosed in **bold-faced** brackets [thus] in the above bill is not enacted and intended to be omitted in the law.

Matter underlined thus is new matter.

Matter enclosed in superscript numerals has been adopted as follows:

¹ Assembly AHL committee amendments adopted May 1, 2000.

entities; the conduct of statistical procedures or studies to improve the quality of health data; the design of sample surveys and the selection of samples of persons or entities; the preparation and publication of reports describing these activities; and other related functions; but excluding the use of health data for a person or entity to make a determination directly affecting the rights, benefits or entitlements of that person or entity.

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9 4. a. There is created a permanent commission to be known as the 10 "New Jersey Health Data Commission." The commission shall consist of 32 members as follows: the Commissioners of Health and Senior 11 12 Services, Human Services, Banking and Insurance, Labor, Community 13 Affairs and Personnel and the State Treasurer, or their designees, as 14 ex officio members; two members each from the Senate and General 15 Assembly to be appointed by the President of the Senate and the Speaker of the General Assembly, respectively, who in each case shall 16 17 be members of different political parties; and 21 public members who 18 shall be appointed by the Governor as follows: one person upon the 19 recommendation of the New Jersey Health Care Payers Coalition; one 20 person upon the recommendation of the New Jersey Health Care 21 Quality Institute; one person upon the recommendation of the New 22 Jersey Business and Industry Association; one person upon the 23 recommendation of the New Jersey AFL-CIO; one person upon the recommendation of the Medical Society of New Jersey; one person 24 25 upon the recommendation of the New Jersey Hospital Association; one 26 person upon the recommendation of the New Jersey Association of 27 Health Care Facilities, one person upon the recommendation of the 28 New Jersey State Nurses Association; one person upon the 29 recommendation of the New Jersey Dental Association; one person 30 upon the recommendation of the Home Health Assembly of New 31 Jersey, Inc.; one person upon the recommendation of the Mental 32 Health Association in New Jersey; one person upon the 33 recommendation of the New Jersey Pharmacists Association; one 34 person upon the recommendation of the New Jersey Health Officers Association; one person upon the recommendation of Horizon Blue 35 36 Cross Blue Shield of New Jersey; one person upon the 37 recommendation of the Health Insurance Association of America; one 38 person upon the recommendation of the New Jersey Association of 39 Health Plans; one person upon the recommendation of a domestic 40 stock health insurance carrier based in New Jersey; one person who 41 represents teaching and research hospitals, upon the joint 42 recommendation of the University of Medicine and Dentistry of New 43 Jersey, the University Health System of New Jersey, Robert Wood 44 Johnson University Hospital and Cooper Hospital/University Medical 45 Center; and three other public members who are consumers of health care services and are not represented by any of the other categories of 46

1 public members included on the commission, one of whom shall be

2 enrolled as a beneficiary of the Medicare program established pursuant

3 to the federal Social Security Act, Pub.L.89-97 (42 U.S.C. s.1395 et

4 seq.).

b. All appointments to the commission shall be made no later than
the 90th day after the effective date of this act. The commission shall
organize upon the appointment of a majority of its authorized
membership.

9 c. Appointed members of the commission shall serve for three-year 10 terms, except that of the public members first appointed, five shall be 11 appointed for terms of one year, eight for terms of two years and eight 12 for terms of three years.

d. Each member shall hold office for the term of appointment and until a successor is appointed and qualified. All vacancies shall be filled in the same manner as the original appointment. Members appointed to fill a vacancy occurring for any reason other than the expiration of the term shall serve for the unexpired term only. An appointed member of the commission shall be eligible for reappointment. An appointed member may be removed for cause.

e. Appointed members shall serve without compensation, but shall
be reimbursed for necessary expenses incurred in the performance of
their duties.

23 f. The commission shall select a chairman from among the public members, who shall serve a one-year term but may serve consecutive 24 25 terms. The commission shall adopt by-laws. The commission shall 26 meet at least quarterly and may meet at other times at the call of the 27 chairman. The commission shall in all respects comply with the provisions of the "Open Public Meetings Act," P.L.1975, c.231 28 29 (C.10:4-6 et seq.). No motion to take any action by the commission 30 shall be valid except upon the affirmative vote of a majority of the 31 quorum required to conduct business.

32 g. The commission shall appoint a full-time executive director, who shall serve as secretary to the commission. The executive director shall 33 34 serve at the pleasure of the commission and shall be qualified by training and experience to perform the duties of the position. The 35 executive director shall be in the unclassified service of the Civil 36 Service and may hire properly qualified employees, within the limits of 37 38 funds appropriated or otherwise made available to the commission, 39 who shall also be employed in the unclassified service of the Civil 40 Service; except that employees performing stenographic or clerical 41 duties shall be in the career service and appointed pursuant to Title 11A of the New Jersey Statutes. 42

43

44 5. a. The commission may:

45 (1) collect and maintain health data from State government agencies

46 or other entities on:

(a) the extent, nature and impact of illness and disability on the
 population of the State;

3 (b) the determinants of health and health hazards;

4 (c) health resources, including the extent of available personnel and

5 resources;

25

6 (d) utilization of health care;

7 (e) health care costs and financing; and

8 (f) other health-related matters;

9 (2) undertake and support research, demonstrations and evaluations 10 concerning new or improved methods for obtaining current data with 11 respect to any of the health data described in paragraph (1) of this 12 subsection; and

(3) promote standards for health data that will facilitate the
comparison of information and ease the burden of data preparation and
reporting.

b. The commission may collect health data on behalf of otherentities.

c. The commission shall collect health data only on a voluntary
basis from persons and entities, except to the extent that specific
statutory authority exists to compel the reporting of such data. When
requesting health data from a person or entity, the agency shall notify
the person or entity in writing as to the following:

(1) whether the person or entity is required to supply the healthdata and any sanctions which may be imposed for noncompliance;

(2) the purposes for which the health data is being collected; and

(3) if the commission intends to disclose identifiable health data for
other than research and statistical purposes, the information to be
disclosed, to whom it is to be disclosed, and for what purposes.

d. ¹[Except as provided in section 6 of this act, no] No¹ health
data obtained by the commission may be used for any purpose other
than the purpose for which they were supplied or for which the person
or entity described in the data has otherwise consented.

e. The commission shall:

(1) take such actions as may be necessary to assure that the health
data which it obtains and maintains are accurate, timely and
comprehensive, as well as specific, standardized and adequately
analyzed and indexed; and

38 (2) publish, disseminate and otherwise make available these data on39 as wide a basis as practicable.

f. The commission shall take such actions as are appropriate to
effect the collection and compilation of health data produced within
the State and to maximize the usefulness of the data collected.

43 g. The commission shall:

(1) participate with federal, State and local government agencies in
the design and implementation of a cooperative system of producing
comparable and uniform health data at the federal, State and local

1 levels; 2 (2) undertake and support research, development, demonstrations 3 and evaluations concerning such a cooperative system; and 4 (3) assume its fair share of the data costs associated with 5 implementing and maintaining such a system. 6 7 6. a. The commission shall make no disclosure of any health data 8 which identifies a person's health status or utilization of health care 9 unless¹[: (1)]¹ the person described in the data has consented to the 10 disclosure¹[; or 11 (2) the disclosure is to a federal government agency or a state 12 13 government agency in this or another state, except that: (a) the data shall be used for a purpose for which the data was 14 15 collected by the commission; and 16 (b) the recipient of the data shall enter into a written agreement 17 with the commission that it will protect the data in accordance with the requirements of this act and will not permit further disclosure without 18 19 the prior approval of the commission; or 20 (3) the disclosure is to a person or entity, for a specified period of 21 time determined by the commission, solely for bona fide research and 22 statistical purposes, as determined in accordance with guidelines 23 adopted by the commission, when: (a) the commission determines that the disclosure of the data to the 24 25 requesting person or entity is required for the research and statistical 26 purposes proposed; and 27 (b) the requesting person or entity has entered into a written 28 agreement with the commission that it will protect the data in 29 accordance with the requirements of this act and will not permit 30 further disclosure without the prior approval of the commission; 31 except that the name, address or other unique personal identifier of a 32 person supplying the data or identified in it shall not be disclosed to the requesting person or entity]¹. 33 34 b. ¹[Any disclosure provided for in this section shall be made at 35 the discretion of the commission] <u>A person or entity to whom the</u> 36 commission has disclosed health data shall make no disclosure of any 37 health data which identifies a person's health status or utilization of 38 health care unless the person described in the data has consented to the disclosure¹. 39 40 c. No identifiable health data obtained by the commission shall be 41 subject to subpoena or similar compulsory process in a civil or 42 criminal, judicial, administrative or legislative proceeding, nor shall a 43 person or entity with lawful access to identifiable health data pursuant 44 to this act be compelled to testify with regard to that data; except that 45 data pertaining to a party in litigation may be subject to subpoena or similar compulsory process in an action brought by or on behalf of that 46

1 2	party to enforce a liability arising under this act.
-3	7. The commission shall take appropriate measures to protect the
4	security of health data which it obtains, including:
- 5	a. limiting access to the data to authorized persons;
6 7	b. designating a person to be responsible for the physical security
7	of the data;
8	c. developing and implementing a system for monitoring the
9	security of the data;
10	d. periodically reviewing all health data to evaluate whether it is
11	appropriate to remove identifying characteristics from the data; and
12	e. developing a program for the routine scheduled destruction of
13	all forms, records or electronic files maintained by the commission
14	which contain identifiable health data.
15	
16	8. In addition to any other powers authorized by law, the
17	commission shall have the authority, in accordance with State law, to:
18	a. make and enter into contracts to purchase services and supplies
19	and to hire consultants;
20	b. develop and submit a proposed budget;
21	c. accept gifts and charitable contributions;
22	d. apply for, receive and expend grants;
23	e. adopt regulations, pursuant to the "Administrative Procedure
24	Act," P.L.1968, c.410 (C.52:14B-1 et seq.), to effectuate the purposes
25	of this act;
26	f. establish charges for and collect payment from persons and
27	entities for the provision of services, including the dissemination of
28	health data;
29	g. receive and expend appropriations;
30	h. enter into a reimbursable work program with other State
31	government agencies or private entities under which funds are
32	transferred from the other agencies or entities to the commission for
33	the performance of activities pursuant to this act; and
34	i. provide such other services and perform such other functions as
35	the commission deems necessary to fulfill its responsibilities under this
36	act.
37	
38	9. a. A person or entity whom the commission determines has
39	violated ¹ [any of] ¹ the provisions of section 6 of this act regarding
40	the disclosure of health data shall be subject, in addition to any other
41	penalties that may be prescribed by law, to: a civil penalty of not more
42	than \$10,000 for each such violation, but not to exceed \$50,000 in the
43	aggregate for multiple violations; or a civil penalty of not more than
44	\$250,000, if the commission finds that these violations have occurred
45	with such frequency as to constitute a general business practice.
46	The penalty shall be sued for and collected in the name of the
υF	The penalty shall be such for and concerne in the name of the

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commission in a summary proceeding in accordance with the "Penalty
 Enforcement Law of 1999," C.2A:58-10 et seq.
 b. The commission or an entity acting on its behalf shall be liable
 to a person or entity injured by the intentional or negligent violation
 of ¹[any provision] the provisions¹ of section 6 of this act in an

amount equal to the damages sustained by the person or entity,
together with the cost of the action and reasonable attorney's fees, as
determined by the court.

9

10. There is appropriated \$94,000 from the General Fund to the
11 New Jersey Health Data Commission to carry out the provisions of
12 this act.

13

14 11. This act shall take effect immediately.

FISCAL NOTE [First Reprint] ASSEMBLY, No. 314 STATE OF NEW JERSEY 209th LEGISLATURE

DATED: OCTOBER 24, 2000

SUMMARY

Synopsis:	"Health Data Commission Act;" appropriates \$94,000.
Type of Impact: Potential increase in State expenditures.	
Agencies Affected:	Department of Health and Senior Serivices and all State and local government agencies that collect various types of health data.

Executive Estimate			
Fiscal Impact	<u>Year 1</u>	<u>Year 2</u>	<u>Year 3</u>
State Cost	\$1,200,000	\$1,200,000	\$1,200,000

Office of Legislative Services Estimate

Fiscal Impact	<u>Year 1</u>	<u>Year 2</u>	<u>Year 3</u>
State Cost	Commission costs e broadly its mission	each year will depend up is defined.	pon how narrowly or

BILL DESCRIPTION

Assembly Bill No. 314 (1R) of 2000 establishes a permanent commission to be known as the "New Jersey Health Data Commission" consisting of 32 members from various public agencies, private organizations that are involved in health care matters and three health care consumers, one of whom is a Medicare enrollee.

The commission is provided with various duties and responsibilities such: collecting and maintaining health data from State government agencies and other entities; undertaking and supporting research, demonstrations and evaluations concerning new or improved methods for obtaining current health data; and promoting standards for health data that will facilitate the comparison of information and ease the burden of data preparation and reporting.

The commission would take such necessary actions to assure that the health data it obtains and maintains are accurate, timely and comprehensive, as well as specific, standardized and adequately analyzed and indexed; and the commission would publish, disseminate and otherwise make available these data on as wide a basis as practicable. Finally, the commission would take appropriate measures to protect the security of health data it obtains and seek financial penalties for the unauthorized disclosure of health data..

Assembly Bill No. 314 (1R) appropriates \$94,000 from the General Fund to implement the legislation.



FISCAL ANALYSIS

EXECUTIVE BRANCH

DHSS and the Office of Management and Budget (OMB) have estimated the annual cost of the legislation at \$1,200,000.

The Executive states that the Commission costs should be comparable to what it takes to operate the Center for Health Statistics, or \$1.3 million annually. With the appropriation there would be a net additional cost of \$1.2 million per year for several years, however that could vary since the mission of the Commission is not totally clear based on the language of the bill.

OFFICE OF LEGISLATIVE SERVICES

The adequacy of the \$94,000 appropriation cannot be determined until the commission submits a proposed budget pursuant to section 8.b. of the legislation.

If the commission avails itself of the significant amounts of health data currently being collected, compiled and analyzed by State and local agencies and does not require significant new analysis to be initiated, the \$94,000 should be sufficient to employ a full-time executive director and clerical support.

If, however, the commission requires new data to be collected, additional reporting forms to be completed and additional analysis of existing and new data, State and local agencies are likely to incur additional costs and the commission might require additional funds. It is not known how much additional costs State and local agencies would incur to collect such additional data; similarly, how much additional funds the commission might require would not be known until the commission submits a proposed budget.

Section:	Human Services
Analyst:	Jay Hershberg Principal Fiscal Analyst
Approved:	Alan R. Kooney Legislative Budget and Finance Officer

This fiscal note has been prepared pursuant to P.L.1980, c.67.

SENATE HEALTH COMMITTEE

STATEMENT TO

[First Reprint] ASSEMBLY, No. 314

with committee amendments

STATE OF NEW JERSEY

DATED: JANUARY 22, 2001

The Senate Health Committee reports favorably and with committee amendments Assembly Bill No. 314 (1R).

As amended by committee, this bill establishes a permanent commission to be known as the "New Jersey Health Data Commission."

The commission shall consist of 33 members as follows: the Commissioners of Health and Senior Services, Human Services, Banking and Insurance, Labor, Community Affairs and Personnel and the State Treasurer, or their designees; two members each from the Senate and General Assembly, who in each case shall be members of different political parties; and 22 public members appointed by the Governor, including a representative from each of the following: the New Jersey Health Care Payers Coalition, the New Jersey Health Care Quality Institute, the New Jersey Business and Industry Association, the New Jersey AFL-CIO, the Medical Society of New Jersey, the New Jersey Association of Osteopathic Physicians and Surgeons, the New Jersey Hospital Association, the New Jersey Association of Health Care Facilities, the New Jersey State Nurses Association, the New Jersey Dental Association, the Home Health Assembly of New Jersey, Inc., the Mental Health Association in New Jersey, the New Jersey Pharmacists Association, the New Jersey Health Officers Association, Horizon Blue Cross Blue Shield of New Jersey, the Health Insurance Association of America, the New Jersey Association of Health Plans, a domestic stock health insurance carrier based in New Jersey, and teaching and research hospitals. Also, three public members shall be health care consumers, one of whom is a Medicare enrollee.

The bill provides that the commission may:

(1) collect and maintain health data from State government agencies or other entities on:

(a) the extent, nature and impact of illness and disability on the population of the State;

(b) the determinants of health and health hazards;

(c) health resources, including the extent of available manpower and resources;

(d) utilization of health care;

(e) health care costs and financing; and

(f) other health-related matters;

(2) undertake and support research, demonstrations and evaluations concerning new or improved methods for obtaining current health data; and

(3) promote standards for health data that will facilitate the comparison of information and ease the burden of data preparation and reporting.

The commission shall collect health data only on a voluntary basis from persons and entities, except to the extent that specific statutory authority exists to compel the reporting of such data. No health data obtained by the commission may be used for any purpose other than the purpose for which they were supplied or for which the person or entity described in the data has otherwise consented.

The commission shall:

(1) take such actions as may be necessary to assure that the health data which it obtains and maintains are accurate, timely and comprehensive, as well as specific, standardized and adequately analyzed and indexed; and

(2) publish, disseminate and otherwise make available these data on as wide a basis as practicable.

The commission shall make no disclosure of any health data which identifies a person's health status or utilization of health care unless the person described in the data has consented to the disclosure. The same restriction applies to a person or entity to whom the commission has disclosed health data.

No identifiable health data obtained by the commission shall be subject to subpoena or similar compulsory process in a civil or criminal, judicial, administrative or legislative proceeding, nor shall a person or entity with lawful access to identifiable health data pursuant to this bill be compelled to testify with regard to that data; except that data pertaining to a party in litigation may be subject to subpoena or similar compulsory process in an action brought by or on behalf of that party to enforce a liability arising under this bill.

The commission shall take appropriate measures to protect the security of health data which it obtains, including:

(1) limiting access to the data to authorized persons who have received training in handling the data;

(2) designating a person to be responsible for the physical security of the data;

(3) developing and implementing a system for monitoring the security of the data;

(4) periodically reviewing all health data to evaluate whether it is appropriate to remove identifying characteristics from the data; and (5) developing a program for the routine scheduled destruction of all forms, records or electronic files maintained by the commission which contain identifiable health data.

The commission shall adopt regulations, pursuant to the "Administrative Procedure Act," N.J.S.A.52:14B-1 et seq., to effectuate the purposes of this bill, and shall appoint an executive director who may hire staff within the limits of available funds. A \$94,000 appropriation to the commission is provided in the bill.

The committee amended the bill to add a representative of the New Jersey Association of Osteopathic Physicians and Surgeons to the commission and to specify in the definition of "health data" that the term shall not include information that is created or received by members of the clergy or others who use spiritual means alone for healing.

This bill is identical to Senate Bill No. 374 SCA (Sinagra/Adler), which the committee also reported favorably on this date.

[Second Reprint] ASSEMBLY, No. 314 _____ STATE OF NEW JERSEY 209th LEGISLATURE

PRE-FILED FOR INTRODUCTION IN THE 2000 SESSION

Sponsored by: Assemblywoman CHARLOTTE VANDERVALK District 39 (Bergen) Assemblyman NEIL M. COHEN District 20 (Union)

Co-Sponsored by: Assemblyman Thompson, Senators Sinagra and Adler

SYNOPSIS

"Health Data Commission Act;" appropriates \$94,000.

CURRENT VERSION OF TEXT

As reported by the Senate Health Committee on January 22, 2001, with amendments.



(Sponsorship Updated As Of: 5/15/2001)

1 AN ACT establishing the New Jersey Health Data Commission, 2 supplementing Title 52 of the Revised Statutes and making an 3 appropriation. 4 5 **BE IT ENACTED** by the Senate and General Assembly of the State of New Jersey: 6 7 8 1. This act shall be known and may be cited as the "Health Data 9 Commission Act." 10 11 2. The Legislature finds and declares that: 12 a. It is the intention of the Legislature to establish a single point of 13 contact for members of the public to obtain health data through the 14 creation of the New Jersey Health Data Commission; b. The purpose of this commission is to compile health care access, 15 16 quality and cost data produced within the State from public and 17 private entities and maximize the usefulness of the data for the public 18 without duplicating existing data collection efforts by State agencies; 19 and 20 c. It is anticipated that the expense to the State of compiling and disseminating the available and useful health data for the benefit of the 21 public will be minimal and will be partially offset by subscriptions to 22 23 routinely published commission documents, the purchase of special 24 commission reports, and the receipt of grants to provide health data 25 information to the public. 26 27 3. As used in this act: "Commission" means the New Jersey Health Data Commission 28 29 established pursuant to this act. 30 "Disclosure" means the disclosure of health data to a person or 31 entity outside the commission. 32 "Health data" means any information, except vital statistics as 33 defined in R.S.26:8-1, relating to the health status of people, the availability of health care resources and services, or the use and cost 34 of these resources and services. ²Health data shall not include 35 information that is created or received by members of the clergy or 36 37 others who use spiritual means alone for healing.² "Identifiable health data" means any item, collection or grouping of 38 39 health data which makes the person supplying it or described in it 40 identifiable. 41 "Research and statistical purposes" means the performance of

EXPLANATION - Matter enclosed in bold-faced brackets [thus] in the above bill is not enacted and intended to be omitted in the law.

Matter underlined <u>thus</u> is new matter.

Matter enclosed in superscript numerals has been adopted as follows:

¹ Assembly AHL committee amendments adopted May 1, 2000.

² Senate SHH committee amendments adopted January 22, 2001.

certain activities relating to health data, including, but not limited to: 1 2 describing the group characteristics of persons or entities; analyzing 3 the interrelationships among various characteristics of persons or 4 entities; the conduct of statistical procedures or studies to improve the quality of health data; the design of sample surveys and the selection 5 6 of samples of persons or entities; the preparation and publication of reports describing these activities; and other related functions; but 7 8 excluding the use of health data for a person or entity to make a 9 determination directly affecting the rights, benefits or entitlements of 10 that person or entity.

11

12 4. a. There is created a permanent commission to be known as the 13 "New Jersey Health Data Commission." The commission shall consist 14 of ²[32] <u>33</u>² members as follows: the Commissioners of Health and Senior Services, Human Services, Banking and Insurance, Labor, 15 16 Community Affairs and Personnel and the State Treasurer, or their designees, as ex officio members; two members each from the Senate 17 and General Assembly to be appointed by the President of the Senate 18 19 and the Speaker of the General Assembly, respectively, who in each 20 case shall be members of different political parties; and ${}^{2}[21] \underline{22}^{2}$ public members who shall be appointed by the Governor as follows: 21 22 one person upon the recommendation of the New Jersey Health Care 23 Payers Coalition; one person upon the recommendation of the New Jersey Health Care Quality Institute; one person upon the 24 25 recommendation of the New Jersey Business and Industry Association; 26 one person upon the recommendation of the New Jersey AFL-CIO; 27 one person upon the recommendation of the Medical Society of New Jersey; ²one person upon the recommendation of the New Jersey 28 Association of Osteopathic Physicians and Surgeons;² one person 29 30 upon the recommendation of the New Jersey Hospital Association; one 31 person upon the recommendation of the New Jersey Association of 32 Health Care Facilities, one person upon the recommendation of the 33 New Jersey State Nurses Association; one person upon the 34 recommendation of the New Jersey Dental Association; one person 35 upon the recommendation of the Home Health Assembly of New 36 Jersey, Inc.; one person upon the recommendation of the Mental Health Association in New Jersey; one person upon the 37 recommendation of the New Jersey Pharmacists Association; one 38 39 person upon the recommendation of the New Jersey Health Officers 40 Association; one person upon the recommendation of Horizon Blue 41 Cross Blue Shield of New Jersey; one person upon the 42 recommendation of the Health Insurance Association of America; one 43 person upon the recommendation of the New Jersey Association of 44 Health Plans; one person upon the recommendation of a domestic 45 stock health insurance carrier based in New Jersey; one person who 46 represents teaching and research hospitals, upon the joint

1 recommendation of the University of Medicine and Dentistry of New 2 Jersey, the University Health System of New Jersey, Robert Wood 3 Johnson University Hospital and Cooper Hospital/University Medical 4 Center; and three other public members who are consumers of health 5 care services and are not represented by any of the other categories of public members included on the commission, one of whom shall be 6 7 enrolled as a beneficiary of the Medicare program established pursuant 8 to the federal Social Security Act, Pub.L.89-97 (42 U.S.C. s.1395 et 9 seq.).

b. All appointments to the commission shall be made no later than
the 90th day after the effective date of this act. The commission shall
organize upon the appointment of a majority of its authorized
membership.

c. Appointed members of the commission shall serve for three-year
terms, except that of the public members first appointed, ²[five] six²
shall be appointed for terms of one year, eight for terms of two years
and eight for terms of three years.

d. Each member shall hold office for the term of appointment and
until a successor is appointed and qualified. All vacancies shall be
filled in the same manner as the original appointment. Members
appointed to fill a vacancy occurring for any reason other than the
expiration of the term shall serve for the unexpired term only. An
appointed member of the commission shall be eligible for
reappointment. An appointed member may be removed for cause.

e. Appointed members shall serve without compensation, but shall
be reimbursed for necessary expenses incurred in the performance of
their duties.

28 f. The commission shall select a chairman from among the public 29 members, who shall serve a one-year term but may serve consecutive 30 terms. The commission shall adopt by-laws. The commission shall 31 meet at least quarterly and may meet at other times at the call of the chairman. The commission shall in all respects comply with the 32 provisions of the "Open Public Meetings Act," P.L.1975, c.231 33 34 (C.10:4-6 et seq.). No motion to take any action by the commission 35 shall be valid except upon the affirmative vote of a majority of the 36 quorum required to conduct business.

37 g. The commission shall appoint a full-time executive director, who 38 shall serve as secretary to the commission. The executive director shall 39 serve at the pleasure of the commission and shall be qualified by 40 training and experience to perform the duties of the position. The 41 executive director shall be in the unclassified service of the Civil 42 Service and may hire properly qualified employees, within the limits of 43 funds appropriated or otherwise made available to the commission, 44 who shall also be employed in the unclassified service of the Civil 45 Service; except that employees performing stenographic or clerical 46 duties shall be in the career service and appointed pursuant to Title 47 11A of the New Jersey Statutes.

1 5. a. The commission may: (1) collect and maintain health data from State government 2 3 agencies or other entities on: 4 (a) the extent, nature and impact of illness and disability on the 5 population of the State; (b) the determinants of health and health hazards; 6 7 (c) health resources, including the extent of available personnel and resources; 8 9 (d) utilization of health care; 10 (e) health care costs and financing; and (f) other health-related matters; 11 undertake and support research, demonstrations and 12 (2)13 evaluations concerning new or improved methods for obtaining current 14 data with respect to any of the health data described in paragraph (1) 15 of this subsection; and (3) promote standards for health data that will facilitate the 16 17 comparison of information and ease the burden of data preparation and 18 reporting. b. The commission may collect health data on behalf of other 19 20 entities. 21 c. The commission shall collect health data only on a voluntary 22 basis from persons and entities, except to the extent that specific 23 statutory authority exists to compel the reporting of such data. When requesting health data from a person or entity, the agency shall notify 24 the person or entity in writing as to the following: 25 26 (1) whether the person or entity is required to supply the health 27 data and any sanctions which may be imposed for noncompliance; 28 (2) the purposes for which the health data is being collected; and 29 (3) if the commission intends to disclose identifiable health data for other than research and statistical purposes, the information to be 30 disclosed, to whom it is to be disclosed, and for what purposes. 31 32 d. ¹[Except as provided in section 6 of this act, no] <u>No¹</u> health data obtained by the commission may be used for any purpose other 33 34 than the purpose for which they were supplied or for which the person 35 or entity described in the data has otherwise consented. e. The commission shall: 36 (1) take such actions as may be necessary to assure that the health 37 data which it obtains and maintains are accurate, timely and 38 39 comprehensive, as well as specific, standardized and adequately 40 analyzed and indexed; and 41 (2) publish, disseminate and otherwise make available these data 42 on as wide a basis as practicable. 43 f. The commission shall take such actions as are appropriate to 44 effect the collection and compilation of health data produced within the State and to maximize the usefulness of the data collected. 45 g. The commission shall: 46

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1 (1) participate with federal. State and local government agencies 2 in the design and implementation of a cooperative system of producing 3 comparable and uniform health data at the federal, State and local 4 levels; (2) undertake and support research, development, demonstrations 5 6 and evaluations concerning such a cooperative system; and (3) assume its fair share of the data costs associated with 7 8 implementing and maintaining such a system. 9 10 6. a. The commission shall make no disclosure of any health data which identifies a person's health status or utilization of health care 11 unless¹[: 12 (1)]¹ the person described in the data has consented to the 13 disclosure¹[; or 14 (2) the disclosure is to a federal government agency or a state 15 government agency in this or another state, except that: 16 17 (a) the data shall be used for a purpose for which the data was 18 collected by the commission; and 19 (b) the recipient of the data shall enter into a written agreement 20 with the commission that it will protect the data in accordance with the 21 requirements of this act and will not permit further disclosure without 22 the prior approval of the commission; or 23 (3) the disclosure is to a person or entity, for a specified period of 24 time determined by the commission, solely for bona fide research and 25 statistical purposes, as determined in accordance with guidelines 26 adopted by the commission, when: 27 (a) the commission determines that the disclosure of the data to the 28 requesting person or entity is required for the research and statistical 29 purposes proposed; and 30 (b) the requesting person or entity has entered into a written 31 agreement with the commission that it will protect the data in 32 accordance with the requirements of this act and will not permit 33 further disclosure without the prior approval of the commission; 34 except that the name, address or other unique personal identifier of a person supplying the data or identified in it shall not be disclosed to 35 36 the requesting person or entity]¹. 37 b. ¹[Any disclosure provided for in this section shall be made at the discretion of the commission] A person or entity to whom the 38 39 commission has disclosed health data shall make no disclosure of any 40 health data which identifies a person's health status or utilization of health care unless the person described in the data has consented to the 41 42 disclosure¹. c. No identifiable health data obtained by the commission shall be 43 44 subject to subpoena or similar compulsory process in a civil or 45 criminal, judicial, administrative or legislative proceeding, nor shall a person or entity with lawful access to identifiable health data pursuant 46

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1 to this act be compelled to testify with regard to that data; except that 2 data pertaining to a party in litigation may be subject to subpoena or 3 similar compulsory process in an action brought by or on behalf of that 4 party to enforce a liability arising under this act. 5 6 7. The commission shall take appropriate measures to protect the 7 security of health data which it obtains, including: 8 a. limiting access to the data to authorized persons; 9 b. designating a person to be responsible for the physical security 10 of the data; 11 c. developing and implementing a system for monitoring the 12 security of the data; 13 d. periodically reviewing all health data to evaluate whether it is 14 appropriate to remove identifying characteristics from the data; and 15 e. developing a program for the routine scheduled destruction of all forms, records or electronic files maintained by the commission 16 17 which contain identifiable health data. 18 In addition to any other powers authorized by law, the 19 8. commission shall have the authority, in accordance with State law, to: 20 21 a. make and enter into contracts to purchase services and supplies 22 and to hire consultants; 23 b. develop and submit a proposed budget; c. accept gifts and charitable contributions; 24 d. apply for, receive and expend grants; 25 26 e. adopt regulations, pursuant to the "Administrative Procedure 27 Act," P.L.1968, c.410 (C.52:14B-1 et seq.), to effectuate the purposes 28 of this act: 29 f. establish charges for and collect payment from persons and entities for the provision of services, including the dissemination of 30 31 health data; 32 g. receive and expend appropriations; 33 h. enter into a reimbursable work program with other State 34 government agencies or private entities under which funds are transferred from the other agencies or entities to the commission for 35 the performance of activities pursuant to this act; and 36 i. provide such other services and perform such other functions as 37 38 the commission deems necessary to fulfill its responsibilities under this 39 act. 40 41 9. a. A person or entity whom the commission determines has violated ¹[any of]¹ the provisions of section 6 of this act regarding 42 43 the disclosure of health data shall be subject, in addition to any other penalties that may be prescribed by law, to: a civil penalty of not more 44 than \$10,000 for each such violation, but not to exceed \$50,000 in the 45 aggregate for multiple violations; or a civil penalty of not more than 46

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1 \$250,000, if the commission finds that these violations have occurred

2 with such frequency as to constitute a general business practice.

3 The penalty shall be sued for and collected in the name of the

4 commission in a summary proceeding in accordance with the "Penalty

5 Enforcement Law of 1999," ²[C.2A:58-10 et seq.] <u>P.L.1999, c.274</u>
6 (C.2A:58-10 et seq.)²

b. The commission or an entity acting on its behalf shall be liable
to a person or entity injured by the intentional or negligent violation
of ¹[any provision] the provisions¹ of section 6 of this act in an
amount equal to the damages sustained by the person or entity,
together with the cost of the action and reasonable attorney's fees, as
determined by the court.

13

10. There is appropriated \$94,000 from the General Fund to the
15 New Jersey Health Data Commission to carry out the provisions of
16 this act.

17

18 11. This act shall take effect immediately.

SENATE, No. 374

STATE OF NEW JERSEY 209th LEGISLATURE

PRE-FILED FOR INTRODUCTION IN THE 2000 SESSION

Sponsored by: Senator JACK SINAGRA District 18 (Middlesex) Senator JOHN H. ADLER District 6 (Camden)

SYNOPSIS

"Health Data Commission Act;" appropriates \$94,000.

CURRENT VERSION OF TEXT

Introduced Pending Technical Review by Legislative Counsel.



1 AN ACT establishing the New Jersey Health Data Commission, 2 supplementing Title 52 of the Revised Statutes and making an 3 appropriation. 4 5 **BE IT ENACTED** by the Senate and General Assembly of the State 6 of New Jersey: 7 8 1. This act shall be known and may be cited as the "Health Data 9 Commission Act." 10 11 2. The Legislature finds and declares that: a. It is the intention of the Legislature to establish a single point of 12 13 contact for members of the public to obtain health data through the 14 creation of the New Jersey Health Data Commission; b. The purpose of this commission is to compile health care access, 15 quality and cost data produced within the State from public and 16 17 private entities and maximize the usefulness of the data for the public 18 without duplicating existing data collection efforts by State agencies; 19 and 20 c. It is anticipated that the expense to the State of compiling and disseminating the available and useful health data for the benefit of the 21 public will be minimal and will be partially offset by subscriptions to 22 routinely published commission documents, the purchase of special 23 24 commission reports, and the receipt of grants to provide health data 25 information to the public. 26 27 3. As used in this act: "Commission" means the New Jersey Health Data Commission 28 29 established pursuant to this act. 30 "Disclosure" means the disclosure of health data to a person or 31 entity outside the commission. 32 "Health data" means any information, except vital statistics as 33 defined in R.S.26:8-1, relating to the health status of people, the availability of health care resources and services, or the use and cost 34 35 of these resources and services. 36 "Identifiable health data" means any item, collection or grouping of 37 health data which makes the person supplying it or described in it identifiable. 38 39 "Research and statistical purposes" means the performance of 40 certain activities relating to health data, including, but not limited to: describing the group characteristics of persons or entities; analyzing 41 42 the interrelationships among various characteristics of persons or 43 entities; the conduct of statistical procedures or studies to improve the 44 quality of health data; the design of sample surveys and the selection 45 of samples of persons or entities; the preparation and publication of reports describing these activities; and other related functions; but 46

excluding the use of health data for a person or entity to make a
 determination directly affecting the rights, benefits or entitlements of
 that person or entity.

4

5 4. a. There is created a permanent commission to be known as the 6 "New Jersey Health Data Commission." The commission shall consist 7 of 32 members as follows: the Commissioners of Health and Senior 8 Services, Human Services, Banking and Insurance, Labor, Community 9 Affairs and Personnel and the State Treasurer, or their designees, as 10 ex officio members; two members each from the Senate and General 11 Assembly to be appointed by the President of the Senate and the 12 Speaker of the General Assembly, respectively, who in each case shall 13 be members of different political parties; and 21 public members who 14 shall be appointed by the Governor as follows: one person upon the 15 recommendation of the New Jersey Health Care Payers Coalition; one person upon the recommendation of the New Jersey Health Care 16 17 Quality Institute; one person upon the recommendation of the New 18 Jersey Business and Industry Association; one person upon the 19 recommendation of the New Jersey AFL-CIO; one person upon the 20 recommendation of the Medical Society of New Jersey; one person 21 upon the recommendation of the New Jersey Hospital Association; one 22 person upon the recommendation of the New Jersey Association of 23 Health Care Facilities, one person upon the recommendation of the 24 New Jersey State Nurses Association; one person upon the 25 recommendation of the New Jersey Dental Association; one person 26 upon the recommendation of the Home Health Assembly of New 27 Jersey, Inc.; one person upon the recommendation of the Mental 28 Health Association in New Jersey; one person upon the 29 recommendation of the New Jersey Pharmacists Association; one 30 person upon the recommendation of the New Jersey Health Officers 31 Association; one person upon the recommendation of Horizon Blue 32 Cross Blue Shield of New Jersey; one person upon the 33 recommendation of the Health Insurance Association of America; one 34 person upon the recommendation of the New Jersey Association of Health Plans; one person upon the recommendation of a domestic 35 36 stock health insurance carrier based in New Jersey; one person who represents teaching and research hospitals, upon the joint 37 38 recommendation of the University of Medicine and Dentistry of New 39 Jersey, the University Health System of New Jersey, Robert Wood 40 Johnson University Hospital and Cooper Hospital/University Medical 41 Center; and three other public members who are consumers of health 42 care services and are not represented by any of the other categories of 43 public members included on the commission, one of whom shall be 44 enrolled as a beneficiary of the Medicare program established pursuant 45 to the federal Social Security Act, Pub.L.89-97 (42 U.S.C. s.1395 et seq.). 46

b. All appointments to the commission shall be made no later than
 the 90th day after the effective date of this act. The commission shall
 organize upon the appointment of a majority of its authorized
 membership.

c. Appointed members of the commission shall serve for three-year
terms, except that of the public members first appointed, five shall be
appointed for terms of one year, eight for terms of two years and eight
for terms of three years.

9 d. Each member shall hold office for the term of appointment and 10 until a successor is appointed and qualified. All vacancies shall be 11 filled in the same manner as the original appointment. Members 12 appointed to fill a vacancy occurring for any reason other than the 13 expiration of the term shall serve for the unexpired term only. An 14 appointed member of the commission shall be eligible for 15 reappointment. An appointed member may be removed for cause.

e. Appointed members shall serve without compensation, but shall
be reimbursed for necessary expenses incurred in the performance of
their duties.

19 f. The commission shall select a chairman from among the public 20 members, who shall serve a one-year term but may serve consecutive 21 terms. The commission shall adopt by-laws. The commission shall 22 meet at least quarterly and may meet at other times at the call of the 23 chairman. The commission shall in all respects comply with the provisions of the "Open Public Meetings Act," P.L.1975, c.231 24 (C.10:4-6 et seq.). No motion to take any action by the commission 25 26 shall be valid except upon the affirmative vote of a majority of the 27 quorum required to conduct business.

28 g. The commission shall appoint a full-time executive director, who 29 shall serve as secretary to the commission. The executive director shall serve at the pleasure of the commission and shall be qualified by 30 31 training and experience to perform the duties of the position. The 32 executive director shall be in the unclassified service of the Civil Service and may hire properly qualified employees, within the limits of 33 34 funds appropriated or otherwise made available to the commission, who shall also be employed in the unclassified service of the Civil 35 Service; except that employees performing stenographic or clerical 36 duties shall be in the career service and appointed pursuant to Title 37 38 11A of the New Jersey Statutes.

39

40 5. a. The commission may:

41 (1) collect and maintain health data from State government42 agencies or other entities on:

43 (a) the extent, nature and impact of illness and disability on the44 population of the State;

45 (b) the determinants of health and health hazards;

46 (c) health resources, including the extent of available personnel and

1 resources;

2 (d) utilization of health care;

3 (e) health care costs and financing; and

4 (f) other health-related matters;

5 (2) undertake and support research, demonstrations and 6 evaluations concerning new or improved methods for obtaining current 7 data with respect to any of the health data described in paragraph (1) 8 of this subsection; and

9 (3) promote standards for health data that will facilitate the 10 comparison of information and ease the burden of data preparation and 11 reporting.

b. The commission may collect health data on behalf of otherentities.

c. The commission shall collect health data only on a voluntary
basis from persons and entities, except to the extent that specific
statutory authority exists to compel the reporting of such data. When
requesting health data from a person or entity, the agency shall notify
the person or entity in writing as to the following:

(1) whether the person or entity is required to supply the healthdata and any sanctions which may be imposed for noncompliance;

(2) the purposes for which the health data is being collected; and
(3) if the commission intends to disclose identifiable health data for
other than research and statistical purposes, the information to be
disclosed, to whom it is to be disclosed, and for what purposes.

d. Except as provided in section 6 of this act, no health data
obtained by the commission may be used for any purpose other than
the purpose for which they were supplied or for which the person or
entity described in the data has otherwise consented.

e. The commission shall:

(1) take such actions as may be necessary to assure that the health
data which it obtains and maintains are accurate, timely and
comprehensive, as well as specific, standardized and adequately
analyzed and indexed; and

34 (2) publish, disseminate and otherwise make available these data35 on as wide a basis as practicable.

f. The commission shall take such actions as are appropriate to
effect the collection and compilation of health data produced within
the State and to maximize the usefulness of the data collected.

39 g. The commission shall:

40 (1) participate with federal, State and local government agencies
41 in the design and implementation of a cooperative system of producing
42 comparable and uniform health data at the federal, State and local
43 levels;

44 (2) undertake and support research, development, demonstrations45 and evaluations concerning such a cooperative system; and

1 (3) assume its fair share of the data costs associated with 2 implementing and maintaining such a system.

3

6. a. The commission shall make no disclosure of any health data which identifies a person's health status or utilization of health care unless:

7 (1) the person described in the data has consented to the 8 disclosure; or

9 (2) the disclosure is to a federal government agency or a state 10 government agency in this or another state, except that:

(a) the data shall be used for a purpose for which the data wascollected by the commission; and

(b) the recipient of the data shall enter into a written agreement
with the commission that it will protect the data in accordance with the
requirements of this act and will not permit further disclosure without
the prior approval of the commission; or

(3) the disclosure is to a person or entity, for a specified period of
time determined by the commission, solely for bona fide research and
statistical purposes, as determined in accordance with guidelines
adopted by the commission, when:

(a) the commission determines that the disclosure of the data to the
requesting person or entity is required for the research and statistical
purposes proposed; and

(b) the requesting person or entity has entered into a written agreement with the commission that it will protect the data in accordance with the requirements of this act and will not permit further disclosure without the prior approval of the commission; except that the name, address or other unique personal identifier of a person supplying the data or identified in it shall not be disclosed to the requesting person or entity.

b. Any disclosure provided for in this section shall be made at thediscretion of the commission.

33 c. No identifiable health data obtained by the commission shall be 34 subject to subpoena or similar compulsory process in a civil or criminal, judicial, administrative or legislative proceeding, nor shall a 35 person or entity with lawful access to identifiable health data pursuant 36 to this act be compelled to testify with regard to that data; except that 37 38 data pertaining to a party in litigation may be subject to subpoena or 39 similar compulsory process in an action brought by or on behalf of that 40 party to enforce a liability arising under this act.

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42 7. The commission shall take appropriate measures to protect the43 security of health data which it obtains, including:

44 a. limiting access to the data to authorized persons;

45 b. designating a person to be responsible for the physical security46 of the data;

1 c. developing and implementing a system for monitoring the 2 security of the data; 3 d. periodically reviewing all health data to evaluate whether it is 4 appropriate to remove identifying characteristics from the data; and e. developing a program for the routine scheduled destruction of 5 all forms, records or electronic files maintained by the commission 6 which contain identifiable health data. 7 8 9 In addition to any other powers authorized by law, the 8. 10 commission shall have the authority, in accordance with State law, to: a. make and enter into contracts to purchase services and supplies 11 12 and to hire consultants; 13 b. develop and submit a proposed budget; 14 c. accept gifts and charitable contributions; 15 d. apply for, receive and expend grants; e. adopt regulations, pursuant to the "Administrative Procedure 16 17 Act," P.L.1968, c.410 (C.52:14B-1 et seq.), to effectuate the purposes 18 of this act; 19 f. establish charges for and collect payment from persons and 20 entities for the provision of services, including the dissemination of 21 health data; 22 g. receive and expend appropriations; 23 h. enter into a reimbursable work program with other State government agencies or private entities under which funds are 24 25 transferred from the other agencies or entities to the commission for 26 the performance of activities pursuant to this act; and 27 i. provide such other services and perform such other functions as 28 the commission deems necessary to fulfill its responsibilities under this 29 act. 30 31 9. a. A person or entity whom the commission determines has 32 violated any of the provisions of section 6 of this act regarding the disclosure of health data shall be subject, in addition to any other 33 34 penalties that may be prescribed by law, to: a civil penalty of not more than \$10,000 for each such violation, but not to exceed \$50,000 in the 35 aggregate for multiple violations; or a civil penalty of not more than 36 \$250,000, if the commission finds that these violations have occurred 37 38 with such frequency as to constitute a general business practice. 39 The penalty shall be sued for and collected in the name of the 40 commission in a summary proceeding in accordance with the "penalty 41 enforcement law," N.J.S.A.2A:58-1 et seq. b. The commission or an entity acting on its behalf shall be liable 42 to a person or entity injured by the intentional or negligent violation 43 44 of any provision of section 6 of this act in an amount equal to the 45 damages sustained by the person or entity, together with the cost of the action and reasonable attorney's fees, as determined by the court. 46

1 10. There is appropriated \$94,000 from the General Fund to the 2 New Jersey Health Data Commission to carry out the provisions of 3 this act. 4 5 11. This act shall take effect immediately. 6 7 8 **STATEMENT** 9 10 This bill establishes a permanent commission to be known as the "New Jersey Health Data Commission." 11 The commission shall consist of 32 members as follows: the 12 13 Commissioners of Health and Senior Services, Human Services, Banking and Insurance, Labor, Community Affairs and Personnel and 14 15 the State Treasurer, or their designees; two members each from the Senate and General Assembly, who in each case shall be members of 16 17 different political parties; and 21 public members appointed by the 18 Governor, including a representative from each of the following: the 19 New Jersey Health Care Payers Coalition, the New Jersey Health Care 20 Quality Institute, the New Jersey Business and Industry Association, 21 the New Jersey AFL-CIO, the Medical Society of New Jersey, the 22 New Jersey Hospital Association, the New Jersey Association of 23 Health Care Facilities, the New Jersey State Nurses Association, the New Jersey Dental Association, the Home Health Assembly of New 24 25 Jersey, Inc., the Mental Health Association in New Jersey, the New Jersey Pharmacists Association, the New Jersey Health Officers 26 27 Association, Horizon Blue Cross Blue Shield of New Jersey, the 28 Health Insurance Association of America, the New Jersey Association 29 of Health Plans, a domestic stock health insurance carrier based in 30 New Jersey, and teaching and research hospitals; in addition to three health care consumers, one of whom is a Medicare enrollee. 31 32 The bill provides that the commission may: (1) collect and maintain health data from State government 33 34 agencies or other entities on: (a) the extent, nature and impact of illness and disability on the 35 population of the State; 36 37 (b) the determinants of health and health hazards; 38 (c) health resources, including the extent of available manpower 39 and resources; 40 (d) utilization of health care; 41 (e) health care costs and financing; and (f) other health-related matters; 42 undertake and support research, demonstrations and 43 (2)44 evaluations concerning new or improved methods for obtaining current 45 health data; and (3) promote standards for health data that will facilitate the 46

comparison of information and ease the burden of data preparation and
 reporting.

The commission shall collect health data only on a voluntary basis from persons and entities, except to the extent that specific statutory authority exists to compel the reporting of such data. Except as specified in the bill, no health data obtained by the commission may be used for any purpose other than the purpose for which they were supplied or for which the person or entity described in the data has otherwise consented.

10 The commission shall:

(1) take such actions as may be necessary to assure that the health
data which it obtains and maintains are accurate, timely and
comprehensive, as well as specific, standardized and adequately
analyzed and indexed; and

(2) publish, disseminate and otherwise make available these dataon as wide a basis as practicable.

The commission shall make no disclosure of any health data which
identifies a person's health status or utilization of health care unless:
(1) the person described in the data has consented to the
disclosure; or

(2) the disclosure is to a federal government agency or a stategovernment agency in this or another state, except that:

(a) the data shall be used for a purpose for which the data wascollected by the commission; and

(b) the recipient of the data shall enter into a written agreement
with the commission that it will protect the data in accordance with the
requirements of this bill and will not permit further disclosure without
the prior approval of the commission; or

(3) the disclosure is to a person or entity, for a specified period of
time determined by the commission, solely for bona fide research and
statistical purposes, as determined in accordance with guidelines
adopted by the commission, when:

(a) the commission determines that the disclosure of the data to the
requesting person or entity is required for the research and statistical
purposes proposed; and

(b) the requesting person or entity has entered into a written
agreement with the commission that it will protect the data in
accordance with the requirements of this bill and will not permit
further disclosure without the prior approval of the commission;
except that the name, address or other unique personal identifier of a
person supplying the data or identified in it shall not be disclosed to
the requesting person or entity.

43 Any disclosure provided for in this bill shall be made at the44 discretion of the commission.

45 No identifiable health data obtained by the commission shall be 46 subject to subpoena or similar compulsory process in a civil or 1 criminal, judicial, administrative or legislative proceeding, nor shall a

2 person or entity with lawful access to identifiable health data pursuant

3 to this bill be compelled to testify with regard to that data; except that

4 data pertaining to a party in litigation may be subject to subpoena or

5 similar compulsory process in an action brought by or on behalf of that

6 party to enforce a liability arising under this bill.

7 The commission shall take appropriate measures to protect the8 security of health data which it obtains, including:

9 a. limiting access to the data to authorized persons who have 10 received training in handling the data;

b. designating a person to be responsible for the physical securityof the data;

c. developing and implementing a system for monitoring thesecurity of the data;

d. periodically reviewing all health data to evaluate whether it is
appropriate to remove identifying characteristics from the data; and

e. developing a program for the routine scheduled destruction of
all forms, records or electronic files maintained by the commission
which contain identifiable health data.

The commission shall adopt regulations, pursuant to the "Administrative Procedure Act," P.L.1968, c.410 (C.52:14B-1 et seq.), to effectuate the purposes of this bill, and shall appoint an executive director who may hire staff within the limits of available funds. A \$94,000 appropriation to the commission is provided in the bill.

SENATE HEALTH COMMITTEE

STATEMENT TO

SENATE, No. 374

with committee amendments

STATE OF NEW JERSEY

DATED: JANUARY 22, 2001

The Senate Health Committee reports favorably and with committee amendments Senate Bill No. 374.

As amended by committee, this bill establishes a permanent commission to be known as the "New Jersey Health Data Commission."

The commission shall consist of 33 members as follows: the Commissioners of Health and Senior Services, Human Services, Banking and Insurance, Labor, Community Affairs and Personnel and the State Treasurer, or their designees; two members each from the Senate and General Assembly, who in each case shall be members of different political parties; and 22 public members appointed by the Governor, including a representative from each of the following: the New Jersey Health Care Payers Coalition, the New Jersey Health Care Quality Institute, the New Jersey Business and Industry Association, the New Jersey AFL-CIO, the Medical Society of New Jersey, the New Jersey Association of Osteopathic Physicians and Surgeons, the New Jersey Hospital Association, the New Jersey Association of Health Care Facilities, the New Jersey State Nurses Association, the New Jersey Dental Association, the Home Health Assembly of New Jersey, Inc., the Mental Health Association in New Jersey, the New Jersey Pharmacists Association, the New Jersey Health Officers Association, Horizon Blue Cross Blue Shield of New Jersey, the Health Insurance Association of America, the New Jersey Association of Health Plans, a domestic stock health insurance carrier based in New Jersey, and teaching and research hospitals. Also, three public members shall be health care consumers, one of whom is a Medicare enrollee.

The bill provides that the commission may:

(1) collect and maintain health data from State government agencies or other entities on:

(a) the extent, nature and impact of illness and disability on the population of the State;

(b) the determinants of health and health hazards;

(c) health resources, including the extent of available manpower and resources;

(d) utilization of health care;

(e) health care costs and financing; and

(f) other health-related matters;

(2) undertake and support research, demonstrations and evaluations concerning new or improved methods for obtaining current health data; and

(3) promote standards for health data that will facilitate the comparison of information and ease the burden of data preparation and reporting.

The commission shall collect health data only on a voluntary basis from persons and entities, except to the extent that specific statutory authority exists to compel the reporting of such data. No health data obtained by the commission may be used for any purpose other than the purpose for which they were supplied or for which the person or entity described in the data has otherwise consented.

The commission shall:

(1) take such actions as may be necessary to assure that the health data which it obtains and maintains are accurate, timely and comprehensive, as well as specific, standardized and adequately analyzed and indexed; and

(2) publish, disseminate and otherwise make available these data on as wide a basis as practicable.

The commission shall make no disclosure of any health data which identifies a person's health status or utilization of health care unless the person described in the data has consented to the disclosure. The same restriction applies to a person or entity to whom the commission has disclosed health data.

No identifiable health data obtained by the commission shall be subject to subpoena or similar compulsory process in a civil or criminal, judicial, administrative or legislative proceeding, nor shall a person or entity with lawful access to identifiable health data pursuant to this bill be compelled to testify with regard to that data; except that data pertaining to a party in litigation may be subject to subpoena or similar compulsory process in an action brought by or on behalf of that party to enforce a liability arising under this bill.

The commission shall take appropriate measures to protect the security of health data which it obtains, including:

(1) limiting access to the data to authorized persons who have received training in handling the data;

(2) designating a person to be responsible for the physical security of the data;

(3) developing and implementing a system for monitoring the security of the data;

(4) periodically reviewing all health data to evaluate whether it is appropriate to remove identifying characteristics from the data; and

(5) developing a program for the routine scheduled destruction of all forms, records or electronic files maintained by the commission

which contain identifiable health data.

The commission shall adopt regulations, pursuant to the "Administrative Procedure Act," N.J.S.A.52:14B-1 et seq., to effectuate the purposes of this bill, and shall appoint an executive director who may hire staff within the limits of available funds. A \$94,000 appropriation to the commission is provided in the bill.

The committee amended the bill to add a representative of the New Jersey Association of Osteopathic Physicians and Surgeons to the commission and to specify in the definition of "health data" that the term shall not include information that is created or received by members of the clergy or others who use spiritual means alone for healing. Other amendments, which make this bill identical to Assembly Bill No. 314 (1R), strengthen the confidentiality provisions in section 6 by providing that neither the commission, nor a person or entity to whom the commission has disclosed health data, shall disclose any health data which identifies a person's health status or utilization of health care unless the person described in the data has consented to the disclosure.

As amended, this bill is identical to Assembly Bill No. 314 (1R) SCA (Vandervalk/Cohen), which the committee also reported favorably on this date.

This bill was prefiled for introduction in the 2000-2001 session pending technical review. As reported, the bill includes the changes required by technical review which has been performed.

[First Reprint] SENATE, No. 374 STATE OF NEW JERSEY 209th LEGISLATURE

PRE-FILED FOR INTRODUCTION IN THE 2000 SESSION

Sponsored by: Senator JACK SINAGRA District 18 (Middlesex) Senator JOHN H. ADLER District 6 (Camden)

SYNOPSIS

"Health Data Commission Act;" appropriates \$94,000.

CURRENT VERSION OF TEXT

As reported by the Senate Health Committee on January 22, 2001, with amendments.



1 AN ACT establishing the New Jersey Health Data Commission, 2 supplementing Title 52 of the Revised Statutes and making an 3 appropriation. 4 5 **BE IT ENACTED** by the Senate and General Assembly of the State of New Jersey: 6 7 8 1. This act shall be known and may be cited as the "Health Data 9 Commission Act." 10 11 2. The Legislature finds and declares that: a. It is the intention of the Legislature to establish a single point of 12 13 contact for members of the public to obtain health data through the 14 creation of the New Jersey Health Data Commission; b. The purpose of this commission is to compile health care access, 15 quality and cost data produced within the State from public and 16 17 private entities and maximize the usefulness of the data for the public 18 without duplicating existing data collection efforts by State agencies; 19 and 20 c. It is anticipated that the expense to the State of compiling and disseminating the available and useful health data for the benefit of the 21 public will be minimal and will be partially offset by subscriptions to 22 routinely published commission documents, the purchase of special 23 24 commission reports, and the receipt of grants to provide health data 25 information to the public. 26 27 3. As used in this act: "Commission" means the New Jersey Health Data Commission 28 29 established pursuant to this act. 30 "Disclosure" means the disclosure of health data to a person or 31 entity outside the commission. 32 "Health data" means any information, except vital statistics as 33 defined in R.S.26:8-1, relating to the health status of people, the availability of health care resources and services, or the use and cost 34 of these resources and services. ¹<u>Health data shall not include</u> 35 information that is created or received by members of the clergy or 36 37 others who use spiritual means alone for healing.¹ "Identifiable health data" means any item, collection or grouping of 38 39 health data which makes the person supplying it or described in it 40 identifiable. 41 "Research and statistical purposes" means the performance of 42 certain activities relating to health data, including, but not limited to:

EXPLANATION - Matter enclosed in **bold-faced** brackets [thus] in the above bill is not enacted and intended to be omitted in the law.

Matter enclosed in superscript numerals has been adopted as follows:

¹ Senate SHH committee amendments adopted January 22, 2001.

Matter underlined thus is new matter.

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1 describing the group characteristics of persons or entities; analyzing 2 the interrelationships among various characteristics of persons or 3 entities; the conduct of statistical procedures or studies to improve the 4 quality of health data; the design of sample surveys and the selection 5 of samples of persons or entities; the preparation and publication of 6 reports describing these activities; and other related functions; but excluding the use of health data for a person or entity to make a 7 8 determination directly affecting the rights, benefits or entitlements of 9 that person or entity.

10

11 4. a. There is created a permanent commission to be known as the 12 "New Jersey Health Data Commission." The commission shall consist 13 of ¹[32] <u>33</u>¹ members as follows: the Commissioners of Health and Senior Services, Human Services, Banking and Insurance, Labor, 14 15 Community Affairs and Personnel and the State Treasurer, or their 16 designees, as ex officio members; two members each from the Senate and General Assembly to be appointed by the President of the Senate 17 18 and the Speaker of the General Assembly, respectively, who in each 19 case shall be members of different political parties; and $1[21] \underline{22}^{1}$ 20 public members who shall be appointed by the Governor as follows: 21 one person upon the recommendation of the New Jersey Health Care 22 Payers Coalition; one person upon the recommendation of the New 23 Jersey Health Care Quality Institute; one person upon the recommendation of the New Jersey Business and Industry Association; 24 25 one person upon the recommendation of the New Jersey AFL-CIO; one person upon the recommendation of the Medical Society of New 26 Jersey; ¹<u>one person upon the recommendation of the New Jersey</u> 27 Association of Osteopathic Physicians and Surgeons;¹ one person 28 29 upon the recommendation of the New Jersey Hospital Association; one person upon the recommendation of the New Jersey Association of 30 31 Health Care Facilities, one person upon the recommendation of the 32 New Jersey State Nurses Association; one person upon the 33 recommendation of the New Jersey Dental Association; one person 34 upon the recommendation of the Home Health Assembly of New 35 Jersey, Inc.; one person upon the recommendation of the Mental Health Association in New Jersey; one person upon the 36 37 recommendation of the New Jersey Pharmacists Association; one person upon the recommendation of the New Jersey Health Officers 38 39 Association; one person upon the recommendation of Horizon Blue 40 Cross Blue Shield of New Jersey; one person upon the 41 recommendation of the Health Insurance Association of America; one 42 person upon the recommendation of the New Jersey Association of 43 Health Plans; one person upon the recommendation of a domestic 44 stock health insurance carrier based in New Jersey; one person who 45 represents teaching and research hospitals, upon the joint 46 recommendation of the University of Medicine and Dentistry of New

1 Jersey, the University Health System of New Jersey, Robert Wood 2 Johnson University Hospital and Cooper Hospital/University Medical 3 Center; and three other public members who are consumers of health 4 care services and are not represented by any of the other categories of public members included on the commission, one of whom shall be 5 6 enrolled as a beneficiary of the Medicare program established pursuant 7 to the federal Social Security Act, Pub.L.89-97 (42 U.S.C. s.1395 et seq.). 8

9 b. All appointments to the commission shall be made no later than 10 the 90th day after the effective date of this act. The commission shall organize upon the appointment of a majority of its authorized 11 12 membership.

13 c. Appointed members of the commission shall serve for three-year 14 terms, except that of the public members first appointed, ¹[five] \underline{six}^{1} shall be appointed for terms of one year, eight for terms of two years 15 16 and eight for terms of three years.

d. Each member shall hold office for the term of appointment and 17 until a successor is appointed and qualified. All vacancies shall be 18 19 filled in the same manner as the original appointment. Members 20 appointed to fill a vacancy occurring for any reason other than the 21 expiration of the term shall serve for the unexpired term only. An 22 appointed member of the commission shall be eligible for 23 reappointment. An appointed member may be removed for cause.

24 e. Appointed members shall serve without compensation, but shall 25 be reimbursed for necessary expenses incurred in the performance of their duties. 26

27 f. The commission shall select a chairman from among the public 28 members, who shall serve a one-year term but may serve consecutive 29 terms. The commission shall adopt by-laws. The commission shall meet at least quarterly and may meet at other times at the call of the 30 chairman. The commission shall in all respects comply with the 31 32 provisions of the "Open Public Meetings Act," P.L.1975, c.231 33 (C.10:4-6 et seq.). No motion to take any action by the commission 34 shall be valid except upon the affirmative vote of a majority of the 35 quorum required to conduct business.

g. The commission shall appoint a full-time executive director, who 36 shall serve as secretary to the commission. The executive director shall 37 38 serve at the pleasure of the commission and shall be qualified by 39 training and experience to perform the duties of the position. The 40 executive director shall be in the unclassified service of the Civil 41 Service and may hire properly qualified employees, within the limits of 42 funds appropriated or otherwise made available to the commission, 43 who shall also be employed in the unclassified service of the Civil 44 Service; except that employees performing stenographic or clerical duties shall be in the career service and appointed pursuant to Title 45 11A of the New Jersey Statutes. 46

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1 5. a. The commission may: 2 (1) collect and maintain health data from State government 3 agencies or other entities on: 4 (a) the extent, nature and impact of illness and disability on the 5 population of the State; (b) the determinants of health and health hazards; 6 7 (c) health resources, including the extent of available personnel and resources; 8 9 (d) utilization of health care; 10 (e) health care costs and financing; and (f) other health-related matters; 11 undertake and support research, demonstrations and 12 (2)13 evaluations concerning new or improved methods for obtaining current data with respect to any of the health data described in paragraph (1) 14 15 of this subsection; and (3) promote standards for health data that will facilitate the 16 17 comparison of information and ease the burden of data preparation and 18 reporting. b. The commission may collect health data on behalf of other 19 20 entities. 21 c. The commission shall collect health data only on a voluntary 22 basis from persons and entities, except to the extent that specific 23 statutory authority exists to compel the reporting of such data. When requesting health data from a person or entity, the agency shall notify 24 the person or entity in writing as to the following: 25 26 (1) whether the person or entity is required to supply the health 27 data and any sanctions which may be imposed for noncompliance; 28 (2) the purposes for which the health data is being collected; and 29 (3) if the commission intends to disclose identifiable health data for other than research and statistical purposes, the information to be 30 disclosed, to whom it is to be disclosed, and for what purposes. 31 32 d. ¹[Except as provided in section 6 of this act, no] <u>No¹</u> health data obtained by the commission may be used for any purpose other 33 34 than the purpose for which they were supplied or for which the person 35 or entity described in the data has otherwise consented. e. The commission shall: 36 (1) take such actions as may be necessary to assure that the health 37 data which it obtains and maintains are accurate, timely and 38 39 comprehensive, as well as specific, standardized and adequately 40 analyzed and indexed; and 41 (2) publish, disseminate and otherwise make available these data 42 on as wide a basis as practicable. 43 f. The commission shall take such actions as are appropriate to 44 effect the collection and compilation of health data produced within the State and to maximize the usefulness of the data collected. 45 g. The commission shall: 46

1 (1) participate with federal, State and local government agencies 2 in the design and implementation of a cooperative system of producing 3 comparable and uniform health data at the federal, State and local 4 levels; (2) undertake and support research, development, demonstrations 5 6 and evaluations concerning such a cooperative system; and 7 (3) assume its fair share of the data costs associated with 8 implementing and maintaining such a system. 9 10 6. a. The commission shall make no disclosure of any health data 11 which identifies a person's health status or utilization of health care unless¹[: 12 (1)]¹ the person described in the data has consented to the 13 disclosure¹[; or 14 15 (2) the disclosure is to a federal government agency or a state government agency in this or another state, except that: 16 17 (a) the data shall be used for a purpose for which the data was 18 collected by the commission; and 19 (b) the recipient of the data shall enter into a written agreement 20 with the commission that it will protect the data in accordance with the 21 requirements of this act and will not permit further disclosure without 22 the prior approval of the commission; or 23 (3) the disclosure is to a person or entity, for a specified period of 24 time determined by the commission, solely for bona fide research and 25 statistical purposes, as determined in accordance with guidelines 26 adopted by the commission, when: 27 (a) the commission determines that the disclosure of the data to the 28 requesting person or entity is required for the research and statistical 29 purposes proposed; and 30 (b) the requesting person or entity has entered into a written 31 agreement with the commission that it will protect the data in 32 accordance with the requirements of this act and will not permit 33 further disclosure without the prior approval of the commission; 34 except that the name, address or other unique personal identifier of a person supplying the data or identified in it shall not be disclosed to 35 36 the requesting person or entity]¹. 37 b. ¹[Any disclosure provided for in this section shall be made at the discretion of the commission] A person or entity to whom the 38 39 commission has disclosed health data shall make no disclosure of any 40 health data which identifies a person's health status or utilization of health care unless the person described in the data has consented to the 41 42 disclosure¹. c. No identifiable health data obtained by the commission shall be 43 44 subject to subpoena or similar compulsory process in a civil or 45 criminal, judicial, administrative or legislative proceeding, nor shall a person or entity with lawful access to identifiable health data pursuant 46

to this act be compelled to testify with regard to that data; except that 1 2 data pertaining to a party in litigation may be subject to subpoena or 3 similar compulsory process in an action brought by or on behalf of that 4 party to enforce a liability arising under this act. 5 6 7. The commission shall take appropriate measures to protect the 7 security of health data which it obtains, including: 8 a. limiting access to the data to authorized persons; 9 b. designating a person to be responsible for the physical security 10 of the data; 11 c. developing and implementing a system for monitoring the 12 security of the data; 13 d. periodically reviewing all health data to evaluate whether it is 14 appropriate to remove identifying characteristics from the data; and 15 e. developing a program for the routine scheduled destruction of all forms, records or electronic files maintained by the commission 16 17 which contain identifiable health data. 18 In addition to any other powers authorized by law, the 19 8. commission shall have the authority, in accordance with State law, to: 20 21 a. make and enter into contracts to purchase services and supplies 22 and to hire consultants; 23 b. develop and submit a proposed budget; c. accept gifts and charitable contributions; 24 d. apply for, receive and expend grants; 25 26 e. adopt regulations, pursuant to the "Administrative Procedure 27 Act," P.L.1968, c.410 (C.52:14B-1 et seq.), to effectuate the purposes 28 of this act: 29 f. establish charges for and collect payment from persons and entities for the provision of services, including the dissemination of 30 31 health data; 32 g. receive and expend appropriations; 33 h. enter into a reimbursable work program with other State 34 government agencies or private entities under which funds are transferred from the other agencies or entities to the commission for 35 the performance of activities pursuant to this act; and 36 i. provide such other services and perform such other functions as 37 38 the commission deems necessary to fulfill its responsibilities under this 39 act. 40 41 9. a. A person or entity whom the commission determines has violated ¹[any of]¹ the provisions of section 6 of this act regarding the 42 43 disclosure of health data shall be subject, in addition to any other penalties that may be prescribed by law, to: a civil penalty of not more 44 than \$10,000 for each such violation, but not to exceed \$50,000 in the 45

46 aggregate for multiple violations; or a civil penalty of not more than

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1 \$250,000, if the commission finds that these violations have occurred 2 with such frequency as to constitute a general business practice. The penalty shall be sued for and collected in the name of the 3 4 commission in a summary proceeding in accordance with the ¹["penalty enforcement law," N.J.S.A.2A:58-1 et seq.] <u>"Penalty</u> 5 Enforcement Law of 1999," P.L.1999, c.274 (C.2A:58-10 et seq.).¹ 6 7 b. The commission or an entity acting on its behalf shall be liable to a person or entity injured by the intentional or negligent violation 8 of ¹[any provision] <u>the provisions</u>¹ of section 6 of this act in an 9 amount equal to the damages sustained by the person or entity, 10 together with the cost of the action and reasonable attorney's fees, as 11 12 determined by the court. 13 14 10. There is appropriated \$94,000 from the General Fund to the New Jersey Health Data Commission to carry out the provisions of 15 16 this act. 17

18 11. This act shall take effect immediately.

Title 52. Chapter 9YY (New) Health Data Commission §§1-9 C.52:9YY-1 to 52: 9YY-9 §10 Approp.

P.L. 2001, CHAPTER 192, approved July 31, 2001 Assembly, No. 314 (Second Reprint)

1 AN ACT establishing the New Jersey Health Data Commission, 2 supplementing Title 52 of the Revised Statutes and making an 3 appropriation. 4 5 **BE IT ENACTED** by the Senate and General Assembly of the State 6 of New Jersey: 7 8 1. This act shall be known and may be cited as the "Health Data Commission Act." 9 10 11 2. The Legislature finds and declares that: a. It is the intention of the Legislature to establish a single point of 12 13 contact for members of the public to obtain health data through the 14 creation of the New Jersey Health Data Commission; 15 b. The purpose of this commission is to compile health care access, quality and cost data produced within the State from public and 16 private entities and maximize the usefulness of the data for the public 17 without duplicating existing data collection efforts by State agencies; 18 19 and c. It is anticipated that the expense to the State of compiling and 20 21 disseminating the available and useful health data for the benefit of the 22 public will be minimal and will be partially offset by subscriptions to 23 routinely published commission documents, the purchase of special 24 commission reports, and the receipt of grants to provide health data 25 information to the public. 26 27 3. As used in this act: 28 "Commission" means the New Jersey Health Data Commission 29 established pursuant to this act. 30 "Disclosure" means the disclosure of health data to a person or 31 entity outside the commission. 32 "Health data" means any information, except vital statistics as 33 defined in R.S.26:8-1, relating to the health status of people, the EXPLANATION - Matter enclosed in bold-faced brackets [thus] in the above bill is not enacted and intended to be omitted in the law. Matter underlined <u>thus</u> is new matter. Matter enclosed in superscript numerals has been adopted as follows:

Assembly AHL committee amendments adopted May 1, 2000.

² Senate SHH committee amendments adopted January 22, 2001.

1 availability of health care resources and services, or the use and cost of these resources and services. ²Health data shall not include 2 3 information that is created or received by members of the clergy or 4

others who use spiritual means alone for healing.²

5 "Identifiable health data" means any item, collection or grouping of health data which makes the person supplying it or described in it 6 7 identifiable.

8 "Research and statistical purposes" means the performance of 9 certain activities relating to health data, including, but not limited to: 10 describing the group characteristics of persons or entities; analyzing 11 the interrelationships among various characteristics of persons or entities; the conduct of statistical procedures or studies to improve the 12 quality of health data; the design of sample surveys and the selection 13 14 of samples of persons or entities; the preparation and publication of 15 reports describing these activities; and other related functions; but excluding the use of health data for a person or entity to make a 16 17 determination directly affecting the rights, benefits or entitlements of 18 that person or entity.

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20 4. a. There is created a permanent commission to be known as the 21 "New Jersey Health Data Commission." The commission shall consist of ²[32] 33² members as follows: the Commissioners of Health and 22 Senior Services, Human Services, Banking and Insurance, Labor, 23 24 Community Affairs and Personnel and the State Treasurer, or their 25 designees, as ex officio members; two members each from the Senate 26 and General Assembly to be appointed by the President of the Senate 27 and the Speaker of the General Assembly, respectively, who in each case shall be members of different political parties; and $^{2}[21] \underline{22}^{2}$ 28 public members who shall be appointed by the Governor as follows: 29 30 one person upon the recommendation of the New Jersey Health Care 31 Payers Coalition; one person upon the recommendation of the New Jersey Health Care Quality Institute; one person upon the 32 33 recommendation of the New Jersey Business and Industry Association; 34 one person upon the recommendation of the New Jersey AFL-CIO; 35 one person upon the recommendation of the Medical Society of New Jersey; ²one person upon the recommendation of the New Jersey 36 Association of Osteopathic Physicians and Surgeons;² one person 37 upon the recommendation of the New Jersey Hospital Association; one 38 39 person upon the recommendation of the New Jersey Association of 40 Health Care Facilities, one person upon the recommendation of the 41 New Jersey State Nurses Association; one person upon the 42 recommendation of the New Jersey Dental Association; one person 43 upon the recommendation of the Home Health Assembly of New 44 Jersey, Inc.; one person upon the recommendation of the Mental 45 Health Association in New Jersey; one person upon the recommendation of the New Jersey Pharmacists Association; one 46

1 person upon the recommendation of the New Jersey Health Officers 2 Association; one person upon the recommendation of Horizon Blue Cross Blue Shield of New Jersey; one person upon the 3 4 recommendation of the Health Insurance Association of America; one 5 person upon the recommendation of the New Jersey Association of Health Plans; one person upon the recommendation of a domestic 6 7 stock health insurance carrier based in New Jersey; one person who 8 represents teaching and research hospitals, upon the joint 9 recommendation of the University of Medicine and Dentistry of New 10 Jersey, the University Health System of New Jersey, Robert Wood 11 Johnson University Hospital and Cooper Hospital/University Medical 12 Center; and three other public members who are consumers of health 13 care services and are not represented by any of the other categories of 14 public members included on the commission, one of whom shall be 15 enrolled as a beneficiary of the Medicare program established pursuant 16 to the federal Social Security Act, Pub.L.89-97 (42 U.S.C. s.1395 et 17 seq.).

b. All appointments to the commission shall be made no later than
the 90th day after the effective date of this act. The commission shall
organize upon the appointment of a majority of its authorized
membership.

c. Appointed members of the commission shall serve for three-year
terms, except that of the public members first appointed, ²[five] six²
shall be appointed for terms of one year, eight for terms of two years
and eight for terms of three years.

d. Each member shall hold office for the term of appointment and until a successor is appointed and qualified. All vacancies shall be filled in the same manner as the original appointment. Members appointed to fill a vacancy occurring for any reason other than the expiration of the term shall serve for the unexpired term only. An appointed member of the commission shall be eligible for reappointment. An appointed member may be removed for cause.

e. Appointed members shall serve without compensation, but shall
be reimbursed for necessary expenses incurred in the performance of
their duties.

36 f. The commission shall select a chairman from among the public 37 members, who shall serve a one-year term but may serve consecutive 38 terms. The commission shall adopt by-laws. The commission shall 39 meet at least quarterly and may meet at other times at the call of the 40 chairman. The commission shall in all respects comply with the 41 provisions of the "Open Public Meetings Act," P.L.1975, c.231 42 (C.10:4-6 et seq.). No motion to take any action by the commission 43 shall be valid except upon the affirmative vote of a majority of the 44 quorum required to conduct business.

g. The commission shall appoint a full-time executive director, who
shall serve as secretary to the commission. The executive director shall
serve at the pleasure of the commission and shall be qualified by

training and experience to perform the duties of the position. The 1 2 executive director shall be in the unclassified service of the Civil 3 Service and may hire properly qualified employees, within the limits of 4 funds appropriated or otherwise made available to the commission, 5 who shall also be employed in the unclassified service of the Civil Service; except that employees performing stenographic or clerical 6 7 duties shall be in the career service and appointed pursuant to Title 11A of the New Jersey Statutes. 8 9 10 5. a. The commission may: 11 (1) collect and maintain health data from State government 12 agencies or other entities on: (a) the extent, nature and impact of illness and disability on the 13 14 population of the State; 15 (b) the determinants of health and health hazards; (c) health resources, including the extent of available personnel and 16 17 resources; (d) utilization of health care; 18 19 (e) health care costs and financing; and 20 (f) other health-related matters; 21 (2) undertake and support research, demonstrations and 22 evaluations concerning new or improved methods for obtaining current 23 data with respect to any of the health data described in paragraph (1) of this subsection; and 24 25 (3) promote standards for health data that will facilitate the comparison of information and ease the burden of data preparation and 26 27 reporting. 28 b. The commission may collect health data on behalf of other 29 entities. 30 c. The commission shall collect health data only on a voluntary basis from persons and entities, except to the extent that specific 31 statutory authority exists to compel the reporting of such data. When 32 33 requesting health data from a person or entity, the agency shall notify 34 the person or entity in writing as to the following: 35 (1) whether the person or entity is required to supply the health data and any sanctions which may be imposed for noncompliance; 36 37 (2) the purposes for which the health data is being collected; and (3) if the commission intends to disclose identifiable health data for 38 other than research and statistical purposes, the information to be 39 disclosed, to whom it is to be disclosed, and for what purposes. 40 d. ¹[Except as provided in section 6 of this act, no] <u>No</u>¹ health 41 42 data obtained by the commission may be used for any purpose other 43 than the purpose for which they were supplied or for which the person 44 or entity described in the data has otherwise consented. 45 e. The commission shall: (1) take such actions as may be necessary to assure that the health 46

data which it obtains and maintains are accurate, timely and 1 2 comprehensive, as well as specific, standardized and adequately 3 analyzed and indexed; and 4 (2) publish, disseminate and otherwise make available these data 5 on as wide a basis as practicable. f. The commission shall take such actions as are appropriate to 6 effect the collection and compilation of health data produced within 7 the State and to maximize the usefulness of the data collected. 8 9 g. The commission shall: 10 (1) participate with federal, State and local government agencies in the design and implementation of a cooperative system of producing 11 12 comparable and uniform health data at the federal, State and local 13 levels: 14 (2) undertake and support research, development, demonstrations 15 and evaluations concerning such a cooperative system; and (3) assume its fair share of the data costs associated with 16 17 implementing and maintaining such a system. 18 19 6. a. The commission shall make no disclosure of any health data which identifies a person's health status or utilization of health care 20 unless¹[: 21 (1)]¹ the person described in the data has consented to the 22 23 disclosure¹[; or 24 (2) the disclosure is to a federal government agency or a state government agency in this or another state, except that: 25 (a) the data shall be used for a purpose for which the data was 26 27 collected by the commission; and 28 (b) the recipient of the data shall enter into a written agreement 29 with the commission that it will protect the data in accordance with the requirements of this act and will not permit further disclosure without 30 31 the prior approval of the commission; or 32 (3) the disclosure is to a person or entity, for a specified period of 33 time determined by the commission, solely for bona fide research and 34 statistical purposes, as determined in accordance with guidelines 35 adopted by the commission, when: 36 (a) the commission determines that the disclosure of the data to the requesting person or entity is required for the research and statistical 37 38 purposes proposed; and 39 (b) the requesting person or entity has entered into a written 40 agreement with the commission that it will protect the data in 41 accordance with the requirements of this act and will not permit further disclosure without the prior approval of the commission; 42 43 except that the name, address or other unique personal identifier of a person supplying the data or identified in it shall not be disclosed to 44 the requesting person or entity]¹. 45

46 b. ¹[Any disclosure provided for in this section shall be made at

1 the discretion of the commission] A person or entity to whom the commission has disclosed health data shall make no disclosure of any 2 3 health data which identifies a person's health status or utilization of 4 health care unless the person described in the data has consented to the 5 disclosure¹. 6 c. No identifiable health data obtained by the commission shall be 7 subject to subpoena or similar compulsory process in a civil or 8 criminal, judicial, administrative or legislative proceeding, nor shall a 9 person or entity with lawful access to identifiable health data pursuant to this act be compelled to testify with regard to that data; except that 10 11 data pertaining to a party in litigation may be subject to subpoena or 12 similar compulsory process in an action brought by or on behalf of that party to enforce a liability arising under this act. 13 14 15 7. The commission shall take appropriate measures to protect the 16 security of health data which it obtains, including: 17 a. limiting access to the data to authorized persons; b. designating a person to be responsible for the physical security 18 19 of the data; 20 c. developing and implementing a system for monitoring the 21 security of the data; 22 d. periodically reviewing all health data to evaluate whether it is 23 appropriate to remove identifying characteristics from the data; and 24 e. developing a program for the routine scheduled destruction of 25 all forms, records or electronic files maintained by the commission 26 which contain identifiable health data. 27 In addition to any other powers authorized by law, the 28 8. 29 commission shall have the authority, in accordance with State law, to: 30 a. make and enter into contracts to purchase services and supplies and to hire consultants; 31 32 b. develop and submit a proposed budget; 33 c. accept gifts and charitable contributions; 34 d. apply for, receive and expend grants; 35 e. adopt regulations, pursuant to the "Administrative Procedure 36 Act," P.L.1968, c.410 (C.52:14B-1 et seq.), to effectuate the purposes 37 of this act; f. establish charges for and collect payment from persons and 38 39 entities for the provision of services, including the dissemination of 40 health data; 41 g. receive and expend appropriations; 42 h. enter into a reimbursable work program with other State 43 government agencies or private entities under which funds are 44 transferred from the other agencies or entities to the commission for 45 the performance of activities pursuant to this act; and

46 i. provide such other services and perform such other functions as

the commission deems necessary to fulfill its responsibilities under this
 act.

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4 9. a. A person or entity whom the commission determines has 5 violated ¹[any of]¹ the provisions of section 6 of this act regarding the disclosure of health data shall be subject, in addition to any other 6 penalties that may be prescribed by law, to: a civil penalty of not more 7 8 than \$10,000 for each such violation, but not to exceed \$50,000 in the 9 aggregate for multiple violations; or a civil penalty of not more than 10 \$250,000, if the commission finds that these violations have occurred 11 with such frequency as to constitute a general business practice. 12 The penalty shall be sued for and collected in the name of the 13 commission in a summary proceeding in accordance with the "Penalty Enforcement Law of 1999," ²[C.2A:58-10 et seq.] P.L.1999, c.274 14 (C.2A:58-10 et seq.)² 15 16 b. The commission or an entity acting on its behalf shall be liable 17 to a person or entity injured by the intentional or negligent violation of ¹[any provision] <u>the provisions</u>¹ of section 6 of this act in an 18 amount equal to the damages sustained by the person or entity, 19 together with the cost of the action and reasonable attorney's fees, as 20 21 determined by the court. 22 23 10. There is appropriated \$94,000 from the General Fund to the 24 New Jersey Health Data Commission to carry out the provisions of this act. 25 26 27 11. This act shall take effect immediately. 28 29 30 31 32 "Health Data Commission Act;" appropriates \$94,000.

CHAPTER 192

AN ACT establishing the New Jersey Health Data Commission, supplementing Title 52 of the Revised Statutes and making an appropriation.

BE IT ENACTED by the Senate and General Assembly of the State of New Jersey:

C.52:9YY-1 Short title.

1. This act shall be known and may be cited as the "Health Data Commission Act."

C.52:9YY-2 Findings, declarations relative to the New Jersey Health Data Commission.

2. The Legislature finds and declares that:

a. It is the intention of the Legislature to establish a single point of contact for members of the public to obtain health data through the creation of the New Jersey Health Data Commission;

b. The purpose of this commission is to compile health care access, quality and cost data produced within the State from public and private entities and maximize the usefulness of the data for the public without duplicating existing data collection efforts by State agencies; and

c. It is anticipated that the expense to the State of compiling and disseminating the available and useful health data for the benefit of the public will be minimal and will be partially offset by subscriptions to routinely published commission documents, the purchase of special commission reports, and the receipt of grants to provide health data information to the public.

C.52:9YY-3 Definitions relative to the New Jersey Health Data Commission.

3. As used in this act:

"Commission" means the New Jersey Health Data Commission established pursuant to this act.

"Disclosure" means the disclosure of health data to a person or entity outside the commission.

"Health data" means any information, except vital statistics as defined in R.S.26:8-1, relating to the health status of people, the availability of health care resources and services, or the use and cost of these resources and services. Health data shall not include information that is created or received by members of the clergy or others who use spiritual means alone for healing.

"Identifiable health data" means any item, collection or grouping of health data which makes the person supplying it or described in it identifiable.

"Research and statistical purposes" means the performance of certain activities relating to health data, including, but not limited to: describing the group characteristics of persons or entities; analyzing the interrelationships among various characteristics of persons or entities; the conduct of statistical procedures or studies to improve the quality of health data; the design of sample surveys and the selection of samples of persons or entities; the preparation and publication of reports describing these activities; and other related functions; but excluding the use of health data for a person or entity to make a determination directly affecting the rights, benefits or entitlements of that person or entity.

C.52:9YY-4 New Jersey Health Data Commission created.

4. a. There is created a permanent commission to be known as the "New Jersey Health Data Commission." The commission shall consist of 33 members as follows: the Commissioners of Health and Senior Services, Human Services, Banking and Insurance, Labor, Community Affairs and Personnel and the State Treasurer, or their designees, as ex officio members; two members each from the Senate and General Assembly to be appointed by the President of the Senate and the Speaker of the General Assembly, respectively, who in each case shall be members of different political parties; and 22 public members who shall be appointed by the Governor as follows: one person upon the recommendation of the New Jersey Health Care Payers Coalition; one person upon the recommendation of the New Jersey Health Care Quality Institute; one person upon the recommendation of the New Jersey Business and Industry Association; one person upon the recommendation of the New Jersey AFL-CIO; one person upon the recommendation of the Medical Society of New Jersey; one person upon the recommendation of the New Jersey Association of Osteopathic Physicians and Surgeons; one person upon the recommendation of the New Jersey Hospital Association; one person upon the recommendation of the New Jersey Association of Health Care Facilities, one person upon the recommendation of the New Jersey State Nurses Association; one person upon the recommendation of the New

Jersey Dental Association; one person upon the recommendation of the Home Health Assembly of New Jersey, Inc.; one person upon the recommendation of the New Jersey Pharmacists Association; one person upon the recommendation of the New Jersey Pharmacists Association; one person upon the recommendation of the New Jersey Health Officers Association; one person upon the recommendation of Horizon Blue Cross Blue Shield of New Jersey; one person upon the recommendation of the New Jersey Health Officers and person upon the recommendation of the Health Insurance Association of America; one person upon the recommendation of the New Jersey Association of Health Plans; one person upon the recommendation of a domestic stock health insurance carrier based in New Jersey; one person who represents teaching and research hospitals, upon the joint recommendation of the University of Medicine and Dentistry of New Jersey, the University Health System of New Jersey, Robert Wood Johnson University Hospital and Cooper Hospital/University Medical Center; and three other public members who are consumers of health care services and are not represented by any of the other categories of public members included on the commission, one of whom shall be enrolled as a beneficiary of the Medicare program established pursuant to the federal Social Security Act, Pub.L.89-97 (42 U.S.C. s.1395 et seq.).

b. All appointments to the commission shall be made no later than the 90th day after the effective date of this act. The commission shall organize upon the appointment of a majority of its authorized membership.

c. Appointed members of the commission shall serve for three-year terms, except that of the public members first appointed, six shall be appointed for terms of one year, eight for terms of two years and eight for terms of three years.

d. Each member shall hold office for the term of appointment and until a successor is appointed and qualified. All vacancies shall be filled in the same manner as the original appointment. Members appointed to fill a vacancy occurring for any reason other than the expiration of the term shall serve for the unexpired term only. An appointed member of the commission shall be eligible for reappointment. An appointed member may be removed for cause.

e. Appointed members shall serve without compensation, but shall be reimbursed for necessary expenses incurred in the performance of their duties.

f. The commission shall select a chairman from among the public members, who shall serve a one-year term but may serve consecutive terms. The commission shall adopt by-laws. The commission shall meet at least quarterly and may meet at other times at the call of the chairman. The commission shall in all respects comply with the provisions of the "Open Public Meetings Act," P.L.1975, c.231 (C.10:4-6 et seq.). No motion to take any action by the commission shall be valid except upon the affirmative vote of a majority of the quorum required to conduct business.

g. The commission shall appoint a full-time executive director, who shall serve as secretary to the commission. The executive director shall serve at the pleasure of the commission and shall be qualified by training and experience to perform the duties of the position. The executive director shall be in the unclassified service of the Civil Service and may hire properly qualified employees, within the limits of funds appropriated or otherwise made available to the commission, who shall also be employed in the unclassified service of the Civil Service; except that employees performing stenographic or clerical duties shall be in the career service and appointed pursuant to Title 11A of the New Jersey Statutes.

C.52:9YY-5 Commission duties.

5. a. The commission may:

- (1) collect and maintain health data from State government agencies or other entities on:
- (a) the extent, nature and impact of illness and disability on the population of the State;
- (b) the determinants of health and health hazards;
- (c) health resources, including the extent of available personnel and resources;
- (d) utilization of health care;
- (e) health care costs and financing; and
- (f) other health-related matters;

(2) undertake and support research, demonstrations and evaluations concerning new or improved methods for obtaining current data with respect to any of the health data described in

paragraph (1) of this subsection; and

(3) promote standards for health data that will facilitate the comparison of information and ease the burden of data preparation and reporting.

b. The commission may collect health data on behalf of other entities.

c. The commission shall collect health data only on a voluntary basis from persons and entities, except to the extent that specific statutory authority exists to compel the reporting of such data. When requesting health data from a person or entity, the agency shall notify the person or entity in writing as to the following:

(1) whether the person or entity is required to supply the health data and any sanctions which may be imposed for noncompliance;

(2) the purposes for which the health data is being collected; and

(3) if the commission intends to disclose identifiable health data for other than research and statistical purposes, the information to be disclosed, to whom it is to be disclosed, and for what purposes.

d. No health data obtained by the commission may be used for any purpose other than the purpose for which they were supplied or for which the person or entity described in the data has otherwise consented.

e. The commission shall:

(1) take such actions as may be necessary to assure that the health data which it obtains and maintains are accurate, timely and comprehensive, as well as specific, standardized and adequately analyzed and indexed; and

(2) publish, disseminate and otherwise make available these data on as wide a basis as practicable.

f. The commission shall take such actions as are appropriate to effect the collection and compilation of health data produced within the State and to maximize the usefulness of the data collected.

g. The commission shall:

(1) participate with federal, State and local government agencies in the design and implementation of a cooperative system of producing comparable and uniform health data at the federal, State and local

levels;

(2) undertake and support research, development, demonstrations and evaluations concerning such a cooperative system; and

(3) assume its fair share of the data costs associated with implementing and maintaining such a system.

C.52:9YY-6 Disclosure of health data, conditions.

6. a. The commission shall make no disclosure of any health data which identifies a person's health status or utilization of health care unless the person described in the data has consented to the disclosure.

b. A person or entity to whom the commission has disclosed health data shall make no disclosure of any health data which identifies a person's health status or utilization of health care unless the person described in the data has consented to the disclosure.

c. No identifiable health data obtained by the commission shall be subject to subpoena or similar compulsory process in a civil or criminal, judicial, administrative or legislative proceeding, nor shall a person or entity with lawful access to identifiable health data pursuant to this act be compelled to testify with regard to that data; except that data pertaining to a party in litigation may be subject to subpoena or similar compulsory process in an action brought by or on behalf of that party to enforce a liability arising under this act.

C.52:9YY-7 Security of health data.

7. The commission shall take appropriate measures to protect the security of health data which it obtains, including:

a. limiting access to the data to authorized persons;

b. designating a person to be responsible for the physical security of the data;

c. developing and implementing a system for monitoring the security of the data;

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d. periodically reviewing all health data to evaluate whether it is appropriate to remove identifying characteristics from the data; and

e. developing a program for the routine scheduled destruction of all forms, records or electronic files maintained by the commission which contain identifiable health data.

C.52:9YY-8 Additional powers of commission.

8. In addition to any other powers authorized by law, the commission shall have the authority, in accordance with State law, to:

a. make and enter into contracts to purchase services and supplies and to hire consultants;b. develop and submit a proposed budget;

c. accept gifts and charitable contributions;

d. apply for, receive and expend grants;

e. adopt regulations, pursuant to the "Administrative Procedure Act," P.L.1968, c.410 (C.52:14B-1 et seq.), to effectuate the purposes of this act;

f. establish charges for and collect payment from persons and entities for the provision of services, including the dissemination of health data;

g. receive and expend appropriations;

h. enter into a reimbursable work program with other State government agencies or private entities under which funds are transferred from the other agencies or entities to the commission for the performance of activities pursuant to this act; and

i. provide such other services and perform such other functions as the commission deems necessary to fulfill its responsibilities under this act.

C.52:9YY-9 Penalties for unautorized discolsures; liability of commission.

9. a. A person or entity whom the commission determines has violated the provisions of section 6 of this act regarding the disclosure of health data shall be subject, in addition to any other penalties that may be prescribed by law, to: a civil penalty of not more than \$10,000 for each such violation, but not to exceed \$50,000 in the aggregate for multiple violations; or a civil penalty of not more than \$250,000, if the commission finds that these violations have occurred with such frequency as to constitute a general business practice.

The penalty shall be sued for and collected in the name of the commission in a summary proceeding in accordance with the "Penalty Enforcement Law of 1999," P.L.1999, c.274 (C.2A:58-10 et seq.)

b. The commission or an entity acting on its behalf shall be liable to a person or entity injured by the intentional or negligent violation of the provisions of section 6 of this act in an amount equal to the damages sustained by the person or entity, together with the cost of the action and reasonable attorney's fees, as determined by the court.

10. There is appropriated \$94,000 from the General Fund to the New Jersey Health Data Commission to carry out the provisions of this act.

11. This act shall take effect immediately.

Approved July 31, 2001.

Office of the Governor

NEWS RELEASE

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RELEASE: August 2, 2001

Acting Governor Donald T. DiFrancesco has signed the following legislation:

S-1239, sponsored by Senators Joseph Palaia (R-Monmouth) and Jack Sinagra (R-Middlesex) and Assembly members Marion Crecco (R-Essex/Passaic) and Guy Talarico (R-Bergen), requires parental consent prior to tattooing or body piercing of minors. This bill makes it a disorderly offense for a person to knowingly tattoo or body pierce a minor under the age of 18 without prior consent of the parent or guardian.

S-232, sponsored by Senator Wayne Bryant (D-Camden/Gloucester) and Assemblymen Neil Cohen (D-Union), requires a child support order relating to health care coverage be enforced through National Medical Support Notice and indicate the party responsible for maintaining the coverage.

S-812, sponsored by Senators Joseph Kyrillos (R-Middlesex/Monmouth) and Bernard Kenny (D-Hudson) and Assemblyman Joseph Azzolina (R-Middlesex/Monmouth), provides that a municipal authority may allow certain employees to waive the SHBP coverage to which the employee is entitled by virtue of employment with the municipal authority.

S-1641, sponsored by Senators John Matheussen (R-Camden/Gloucester) and Norman Robertson (R-Essex/Passaic) and Assemblymen Kip Bateman (R-Morris/Somerset) and Charles Zisa (D-Bergen), directs certain juvenile justice records be available to law enforcement agencies and prosecutors on a 24-hour basis. Types of information which would be made available under this bill includes juvenile arrest information, juvenile disposition information, juvenile pretrial detention information and information concerning the probation status of a juvenile.

A-1980, sponsored by Senate Majority Leader John Bennett (R-Monmouth) and Assemblyman Neil Cohen (D-Union), permits a corporation to change from an operating corporation to a holding corporation without shareholder approval and without the need to transfer assets and liabilities.

A-3219, sponsored by Senators Gerald Cardinale (R-Bergen) and Garry Furnari (D-Bergen/Essex/Passaic) and Assemblymen Kip Bateman (R-Morris/Somerset) and Richard Merkt (R-Morris), limits the cost of a "Y2K" examination of a domestic fraternal benefit society to no more than one percent of the society's 1999 net premiums received. The balance for any such examination would be paid by the Department of Banking and Insurance.

A-314, sponsored by Senators Jack Sinagra (R-Middlesex) and John Adler (D-Camden) and Assembly members Charlotte Vandervalk (R-Bergen) and Neil Cohen (D-Union), establishes a permanent commission to be known as the "New Jersey Health Data Commission. The 33-

member Commission would collect and maintain health data from State government agencies or other entities.

The bill also appropriates \$94,000 and assumes that the cost to the State to operate the Commission will be partially offset by payments for Commission documents and receipt of grants.