

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 Mental Health Association in New Jersey; 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 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;

- 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 unauthorized disclosures; 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.