

SENATE, No. 3220

STATE OF NEW JERSEY 216th LEGISLATURE

INTRODUCED OCTOBER 19, 2015

Sponsored by:

Senator STEPHEN M. SWEENEY

District 3 (Cumberland, Gloucester and Salem)

Senator KEVIN J. O'TOOLE

District 40 (Bergen, Essex, Morris and Passaic)

Senator JOSEPH F. VITALE

District 19 (Middlesex)

Co-Sponsored by:

Senator Whelan

SYNOPSIS

Establishes Statewide health data system.

CURRENT VERSION OF TEXT

As introduced.



(Sponsorship Updated As Of: 12/11/2015)

1 AN ACT concerning the establishment of a health data system and
2 supplementing Title 30 of the Revised Statutes.

3

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

6

7 1. The Legislature finds and declares that:

8 a. Many New Jersey administrative departments and agencies,
9 including, but not limited to, the Departments of Health, Human
10 Services, Community Affairs, Corrections, and Agriculture,
11 currently create, maintain, receive, and transmit individually
12 identifiable data and aggregated data sets in order to perform
13 necessary and vital administrative functions delegated to the
14 agencies.

15 b. These administrative departments and agencies often lack
16 the technological and operational resources necessary to create,
17 receive, maintain, and transmit individually identifiable data and
18 data sets created or maintained by other agencies or to execute
19 linkages among data sets and conduct valid statistical analyses
20 while protecting the privacy and security of such and data sets.

21 c. The creation of a mechanism by which a State or federal
22 administrative department or agency or an authorized researcher can
23 access data and data sets created or maintained by a federal, State,
24 or local administrative department or agency will help facilitate the
25 development and evaluation of this data, reduce duplicative data
26 collection and maintenance efforts, and allow for comparison of
27 data for accuracy and reliability.

28 d. The linkage of multiple sources of State, federal, and local
29 data and the application of valid statistical techniques can facilitate
30 the identification of population trends and individual and
31 community-level determinants directly related to the health, safety,
32 security, and well-being of New Jersey residents.

33 e. The establishment of a secure, Statewide, integrated
34 population health data system (“iPHD”) containing data collected
35 by New Jersey administrative departments and agencies, that
36 includes data related to public health and safety and social services
37 programs, will facilitate analysis and research and the development
38 of the most effective means for improving the health, safety,
39 security, and well-being of New Jersey residents and the overall
40 cost-efficiency of government programs.

41 f. The Medicaid Accountable Care Organization
42 Demonstration Project established pursuant to P.L.2011,
43 c.114 (C.30:4D-8.1 et seq.) requires the Rutgers Center for State
44 Health Policy to analyze patient data received from the Department
45 of Human Services and from certified Medicaid Accountable Care
46 Organizations in order to evaluate the achievement of the health
47 care quality improvement and cost containment goals of the
48 Demonstration Project, and the Rutgers Center for State Health

1 Policy currently has the technological and operational resources
2 required to receive, maintain, and transmit individually identifiable
3 data and data sets in a secure database.

4 g. The Rutgers Center for State Health Policy is responsible for
5 evaluating New Jersey's Comprehensive Medicaid Waiver
6 Demonstration Project with funding from the New Jersey
7 Department of Human Services and the Robert Wood Johnson
8 Foundation, whereby it receives comprehensive Medicaid
9 enrollment data, fee-for-service claims data, and managed care
10 encounter data, and conducts analyses of Medicaid claims and
11 encounter data to inform recommendations to improve care and
12 reduce costs for the top one percent of Medicaid beneficiaries who
13 account for a disproportionate share of program spending.

14

15 2. As used in this act:

16 "Aggregated data" means information that has been combined
17 into groups showing averages or other summary statistics, and that
18 is not individually identifiable information as defined in this act.

19 "De-identified data" means information that does not identify an
20 individual and for which there is no reasonable basis to believe that
21 the information can be used to identify an individual, and which
22 meets the requirements for de-identification of protected health
23 information under HIPAA.

24 "Governing Board" or "Board" means the board charged with
25 responsibility for governing the integrated population health data
26 system established pursuant to section 3 of this act.

27 "Health data" means information that is created or received by a
28 governmental department or agency that relates to the past, present,
29 or future physical or mental health or condition of an individual or
30 the past, present, or future payment for the provision of health care
31 to an individual.

32 "HIPAA" means the "Health Insurance Portability and
33 Accountability Act of 1996," Pub.L.104-191, and any regulations
34 promulgated thereunder by the Secretary of the U.S. Department of
35 Health and Human Services.

36 "Individually identifiable information" means information that
37 identifies an individual, or with respect to which there is a
38 reasonable basis to believe the information can be used to identify
39 an individual.

40 "IRB" means an institutional review board designated by the
41 Governing Board and established pursuant to federal regulations (45
42 CFR 46) with a Federalwide Assurance for the Protection of Human
43 Subjects approved by the U.S. Department of Health and Human
44 Services, Office for Human Research Protections, to review and
45 monitor research involving human subjects to ensure that the
46 subjects are protected from harm and that the rights of subjects are
47 adequately protected.

1 “iPHD” means the integrated population health data system
2 established pursuant to section 4 of this act.

3 “Medicaid Accountable Care Organization” means an
4 organization established pursuant to P.L.2011, c.114 (C.30:4D-8.1
5 et seq.).

6 “Protected health information” has the same meaning as defined
7 under HIPAA.

8 “Research” means a systematic investigation, including research
9 development, testing, and evaluation, which is designed to develop
10 or contribute to generalizable knowledge as defined pursuant to 45
11 C.F.R. 46.102(d).

12 “Researcher” means a private entity or public entity that
13 conducts research under the review and monitoring of an IRB.

14 “Social services data” means information relating to an
15 individual’s receipt of services from or through public support
16 programs administered by a federal, State, or local government or
17 by a private entity, including, but not limited to, an individual’s
18 participation in or eligibility for Medicaid benefits, Supplemental
19 Nutrition Assistance Program benefits, Low Income Home Energy
20 Assistance Program benefits, and Social Services for the Homeless
21 program benefits.

22

23 3. a. The iPHD Governing Board is hereby established in, but
24 not of, the Department of State. The Governing Board shall consist
25 of ten members: one of whom shall be the Director of the Rutgers
26 Center for State Health Policy, who shall serve as a non-voting, ex-
27 officio member; and four of whom shall be public members
28 appointed by the Governor with the advice and consent of the
29 Senate, as follows:

30 (1) An individual representing an organization capable of
31 advocating on behalf of persons whose social services data may be
32 received, maintained, or transmitted by the iPHD in accordance
33 with this act;

34 (2) An individual with legal expertise and interest in protecting
35 the privacy and security of individually identifiable information;

36 (3) An individual with technical expertise and interest in the
37 creation and maintenance of large data systems and data security;
38 and

39 (4) An individual with experience in human subjects research,
40 who is affiliated with a research university in New Jersey.

41 The five remaining members shall be voting, ex-officio members
42 representing the Commissioner of Human Services; the
43 Commissioner of Health; the Attorney General; the Chief
44 Information Officer for Rutgers, The State University of New
45 Jersey; and the Secretary of State, who shall also serve as chair of
46 the Board. Ex-officio members may be represented by designees.

47 Of the public members first appointed to the Governing Board,
48 two shall be appointed to terms of three years, one shall be

1 appointed to a term of two years, and one shall be appointed to a
2 term of one year. Following the expiration of the initial terms,
3 public members of the Board shall be appointed for terms of three
4 years. The voting ex-officio members of the Board shall serve
5 during their respective terms of office. Any vacancy occurring in
6 the membership of the Board shall be filled in the same manner as
7 the original appointment, but for the unexpired term only. The
8 Board shall meet at least quarterly, and at such other times as it
9 determines, in its judgment, to be necessary. The appointed
10 members of the Board shall serve without compensation but may be
11 reimbursed for necessary expenses incurred in the performance of
12 their duties. In addition, the Board shall be entitled to and avail
13 itself of the assistance and services of the staff of the Department of
14 State, and of the employees of any other State department, board,
15 bureau, commission, or agency, as it may require and as may be
16 available for its purposes.

17 b. A member of the Governing Board shall not, by reason of
18 the member's performance of any duty, function, or activity
19 required of, or authorized to be undertaken by, the Board, be liable
20 in an action for damages to any person for any action taken or
21 recommendation made by the member within the scope of the
22 member's duty, function, or activity as a member of the Board, if
23 the action or recommendation was taken or made without malice.
24 The members of the Board shall be indemnified and their defense of
25 any action provided for in the same manner and to the same extent
26 as employees of the State under the "New Jersey Tort Claims Act,"
27 P.L.1972, c.45 (C.59:1-1 et seq.), on the basis of acts or omissions
28 in the scope of their service.

29 c. A member of the Governing Board shall not vote on any
30 matter before the Board concerning an individual or entity with
31 which the member has, or within the last 12 months has had, any
32 substantial ownership, employment, medical staff, fiduciary,
33 contractual, creditor, or consultative relationship. A member who
34 has or who has had such a relationship with an individual or entity
35 involved in any matter before the Board shall make a written
36 disclosure before any action is taken by the Board with respect to
37 the matter, and shall make the relationship public in any meeting in
38 which action on the matter is to be taken.

39 d. The iPHD Governing Board shall be a public body for the
40 purposes of the "Senator Byron M. Baer Open Public Meetings
41 Act," P.L.1975, c.231 (C.10:4-8), and shall conduct its business in
42 accordance with the provisions of that act.

43
44 4. a. No later than 12 months after the effective date of this
45 act, the Rutgers Center for State Health Policy shall establish an
46 operational iPHD capable of securely receiving, maintaining, and
47 transmitting data in accordance with this act and the HIPAA privacy
48 and security standards applicable to this act. The Rutgers Center

1 for State Health Policy may employ staff to assist with carrying out
2 the functions associated with the establishment and maintenance of
3 the iPHD.

4 b. Notwithstanding any provision of this act to the contrary, the
5 iPHD shall seek to receive, maintain, and transmit de-identified
6 data wherever possible, and shall only receive, maintain, and
7 transmit individually identifiable information in a form and format
8 that is secured to prevent disclosure of individually identifiable
9 information.

10

11 5. Oversight of the operations of the iPHD, established
12 pursuant to section 4 of this act, shall be vested in the Governing
13 Board. The iPHD shall receive, maintain, and transmit data only as
14 permitted by this act and approved by the Governing Board. The
15 Governing Board's responsibilities shall include:

16 a. Identification of social services data that has been created,
17 received, or maintained by agencies that may be appropriate for
18 receipt, maintenance, and transmission by the iPHD in furtherance
19 of the purposes of this act;

20 b. Prior to the receipt of data by the iPHD, the review and
21 approval of the appropriateness of such receipt, including
22 consideration of the following factors:

23 (1) whether the transmitting department or agency has authority
24 to collect the data proposed to be received by the iPHD, particularly
25 if the data includes individually identifiable information;

26 (2) whether collection of the data proposed to be received by the
27 iPHD is expected to further the purpose of this act, namely, the
28 improvement of public health, safety, security, or well-being of
29 New Jersey residents or the improvement of the overall cost-
30 efficiency of government assistance programs; and

31 (3) whether reasonable efforts have been made to ensure that the
32 iPHD will receive only the appropriate data needed to accomplish
33 the purposes of this act;

34 c. Prior to the receipt or transmission of data by the iPHD, the
35 review and approval of any necessary data use agreements or
36 business associate agreements with any person or entity from which
37 or to which information is received or transmitted in compliance
38 with all applicable privacy and security standards, including, but
39 not limited to, HIPAA, when such data includes individually
40 identifiable information that is protected health information as
41 defined under HIPAA; and

42 d. Adopting and publishing policies and procedures for the
43 efficient and transparent operation of the iPHD, including, but not
44 limited to, the following:

45 (1) Privacy and data security policies and procedures that
46 comply with the applicable federal and State privacy and security
47 statutes and regulations, including HIPAA; and

1 (2) Data access policies and procedures that allow access by a
2 public entity or a private entity, including a researcher, only when
3 such access request meets the standards set forth in the data access
4 policies and procedures and has been approved by the Governing
5 Board. When data access is requested by any private entity,
6 including a researcher, for the purpose of conducting research, the
7 Governing Board shall only approve access to data after review and
8 approval by an IRB, and such access shall be limited to data
9 identified in approved IRB research protocols and only for the
10 period of the approval. In no event shall the Governing Board
11 approve access to health data that identifies, or that may be used to
12 identify, rates of payment by a private entity for the provision of
13 health care services to an individual unless the party seeking access
14 agrees to keep such information confidential and to prevent public
15 disclosure of such data or the rates of payment derived from such
16 data.

17

18 6. No later than 12 months following the receipt of data by the
19 iPHD pursuant to this act, and on an annual basis thereafter, the
20 Governing Board shall publish a report that is made available and
21 accessible to the public and that contains the following information:

22 a. A description of the implementation of the iPHD, including
23 identification of the sources and types of data received and
24 maintained by the iPHD over the prior 12 months;

25 b. A list of all aggregated data maintained by the iPHD;

26 c. A description of each IRB-approved disclosure of data or
27 data sets by the iPHD;

28 d. A description of disclosures to Medicaid Accountable Care
29 Organizations recognized by the state in accordance with P.L.2011,
30 c.114 (C.30:4D-8.1 et seq.);

31 e. A list of publications and other reports based on iPHD data;

32 f. A strategic plan for achieving the purposes of this act during
33 the successive 12 month period; and

34 g. Any other information deemed appropriate by the Governing
35 Board.

36

37 7. The iPHD Governing Board and the Rutgers Center for State
38 Health Policy may apply for and receive funding in relation to the
39 iPHD from the following sources:

40 a. Grants or other financial assistance from State or local
41 departments, agencies, authorities, and organizations;

42 b. Federal grants;

43 c. Grants from other public or private entities; and

44 d. Fees paid by persons or entities requesting access to iPHD
45 data or the performance of analyses by the iPHD, which fees have
46 been approved by the Governing Board to support the cost of
47 preparing data for access or the performance of analyses.

1 8. Any department or agency that creates, receives, or
2 maintains social services data or health data shall transmit or allow
3 access to such data as is necessary and appropriate to further the
4 goals of this act and shall cooperate with iPHD requests for receipt
5 of, or access to, such data. Notwithstanding the foregoing, no
6 department or agency shall be required to transmit data it creates,
7 receives, or maintains to the iPHD, or to allow access to such data,
8 if the Attorney General determines that such transmission or access
9 would violate State or federal law. This section shall not prohibit
10 the Rutgers Center for State Health Policy or any department or
11 agency from creating, receiving, maintaining, or transmitting data
12 in data systems that are separate and distinct from the iPHD.

13
14 9. This act shall take effect immediately and within 60 days
15 after the effective date of this act, the Governor shall appoint four
16 public members to the iPHD Governing Board in accordance with
17 section 3 of this act.

18

19

20

STATEMENT

21

22 This bill establishes a secure, Statewide, integrated, de-identified
23 population health data system to improve the health, safety,
24 security, and well being of New Jersey residents and the cost-
25 efficiency of government programs.

26 The Medicaid Accountable Care Organization Demonstration
27 Project requires the Rutgers Center for State Health Policy (Center)
28 to analyze patient data received from the Department of Human
29 Services and from certified Medicaid Accountable Care
30 Organizations to evaluate the achievement of the health care quality
31 improvement and cost containment goals of the Demonstration
32 Project. The Center is also responsible for evaluating New Jersey's
33 Comprehensive Medicaid Waiver Demonstration Project with
34 funding from the New Jersey Department of Human Services and
35 the Robert Wood Johnson Foundation.

36 The Center receives comprehensive Medicaid enrollment data,
37 fee-for-service claims data, and managed care encounter data, and
38 conducts analyses of Medicaid claims and encounter data to inform
39 recommendations to improve care and reduce costs for the top one
40 percent of Medicaid beneficiaries who account for a
41 disproportionate share of program spending.

42 Many New Jersey administrative departments and agencies,
43 including, but not limited to, the Departments of Health, Human
44 Services, Community Affairs, Corrections, and Agriculture,
45 currently create, maintain, receive, and transmit individually
46 identifiable data and aggregated data sets in order to perform
47 necessary and vital administrative functions delegated to the
48 agencies. These administrative departments and agencies often lack

1 the technological and operational resources necessary to create,
2 receive, maintain, and transmit individually identifiable data and
3 data sets created or maintained by other agencies or to execute
4 linkages among data sets and conduct valid statistical analyses
5 while protecting the privacy and security of such and data sets.

6 The Center currently has the technological and operational
7 resources required to receive, maintain, and transmit individually
8 identifiable data and data sets in a secure database.

9 This bill therefore directs the Center to create the integrated
10 population health data system (iPHD). The iPHD will contain data
11 collected by New Jersey administrative departments and agencies
12 related to public health and safety and social services programs.
13 Furthermore, the bill establishes the iPHD Governing Board, in but
14 not of the Department of State, to oversee the iPHD and facilitate
15 analysis and research.

16 The Governing Board will consist of ten members: one of whom
17 will be the Director of the Rutgers Center for State Health Policy,
18 who will serve as a non-voting, ex-officio member; four of whom
19 will be public members appointed by the Governor; and five of
20 whom will be voting, ex-officio members representing the Secretary
21 of State; the Commissioner of Human Services; the Commissioner
22 of Health; the Attorney General; and the Chief Information Officer
23 for Rutgers, The State University, or their designees. The Secretary
24 of State will be the chair of the Governing Board.

25 The purpose of the iPHD will be to reduce duplicative data
26 collection and maintenance efforts and allow for comparison of data
27 for accuracy and reliability. The linkage of the data sources will
28 facilitate the identification of population trends and individual and
29 community-level determinants directly related to the health, safety,
30 security, and well-being of New Jersey residents.