

30:4D-65 TO 30:4D-72
LEGISLATIVE HISTORY CHECKLIST

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LAWS OF: 2015 **CHAPTER:** 193

NJSA: 30:4D-65 TO 30:4D-72 (Establishes a process to integrate certain health data and other data from publicly supported programs for population health research.)

BILL NO: S3220 (Substituted for A4790 (1R))

SPONSOR(S) Sweeney, Stephen M., and others

DATE INTRODUCED: October 19, 2015

COMMITTEE: **ASSEMBLY:** ---

SENATE: Health, Human Services and Senior Citizens

AMENDED DURING PASSAGE: Yes

DATE OF PASSAGE: **ASSEMBLY:** 12/17/2015

SENATE: 12/17/2015

DATE OF APPROVAL: January 11, 2016

FOLLOWING ARE ATTACHED IF AVAILABLE:

FINAL TEXT OF BILL (First Reprint enacted) Yes

S3220

INTRODUCED BILL: (Includes sponsor(s) statement) Yes

COMMITTEE STATEMENT: **ASSEMBLY:** No

SENATE: Yes

(Audio archived recordings of the committee meetings, corresponding to the date of the committee statement, *may possibly* be found at www.njleg.state.nj.us)

FLOOR AMENDMENT STATEMENT: No

LEGISLATIVE FISCAL ESTIMATE: Yes

A4790 (1R)

INTRODUCED BILL: (Includes sponsor(s) statement) Yes

COMMITTEE STATEMENT: **ASSEMBLY:** Yes

SENATE: No

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FLOOR AMENDMENT STATEMENT: No

LEGISLATIVE FISCAL ESTIMATE: Yes

VETO MESSAGE: No

GOVERNOR'S PRESS RELEASE ON SIGNING: Yes

FOLLOWING WERE PRINTED:

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REPORTS: No

HEARINGS: No

NEWSPAPER ARTICLES: No

end

Title 30.
Chapter 4D.
Article VI (New)
"Health Data"
§§1-8 -
C.30:4D-65 to
30:4D-72
§9 - Note

P.L.2015, CHAPTER 193, *approved January 11, 2016*
Senate, No. 3220 (*First Reprint*)

1 AN ACT concerning the establishment of a ¹**[health data system]**
2 process to integrate certain health data and other data from
3 publicly supported programs for population health research¹ and
4 supplementing Title 30 of the Revised Statutes.
5

6 **BE IT ENACTED** by the Senate and General Assembly of the State
7 of New Jersey:
8

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

17 b. ¹**[These administrative departments and agencies often lack**
18 **the technological and operational resources necessary to create,**
19 **receive, maintain, and transmit individually identifiable data and**
20 **data sets created or maintained by other agencies or to execute**
21 **linkages among data sets and conduct valid statistical analyses**
22 **while protecting the privacy and security of such and data sets.**

23 c. ¹**[** The creation of a ¹**[mechanism] process¹ by which a**
24 **State or federal administrative department or agency or an**
25 **authorized researcher can access data and data sets created or**
26 **maintained by a federal, State, or local administrative department or**
27 **agency will help facilitate the development and evaluation of this**
28 **data, reduce duplicative data collection and maintenance efforts,**
29 **and allow for comparison of data for accuracy and reliability.**

30 ¹**[d.] c.¹** The linkage of multiple sources of State, federal, and
31 local data and the application of valid statistical techniques can
32 facilitate the identification of population trends and individual and
33 community-level determinants directly related to the health, safety,
34 security, and well-being of New Jersey residents.

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

Matter underlined thus is new matter.

Matter enclosed in superscript numerals has been adopted as follows:

¹**Senate SHH committee amendments adopted December 10, 2015.**

1 **1[e.] d.**¹ The establishment of a secure, Statewide, integrated
2 **1[population health data system (“iPHD”)] Population Health Data**
3 **Project (“iPHD Project”)**¹ containing **1certain**¹ data collected by
4 New Jersey administrative departments and agencies, that includes
5 data related to **1[public health and safety and social services**
6 **programs,] health and publicly supported programs that**¹ will
7 facilitate **1approved, project-by-project**¹ analysis and research and
8 the development of the most effective means for improving the
9 health, safety, security, and well-being of New Jersey residents and
10 the overall cost-efficiency of government programs.

11 **1[f.] e.**¹ The Medicaid Accountable Care Organization
12 Demonstration Project established pursuant to P.L.2011, c.114
13 (C.30:4D-8.1 et seq.) requires the Rutgers Center for State Health
14 Policy to analyze patient data received from the Department of
15 Human Services and from certified Medicaid Accountable Care
16 Organizations in order to evaluate the achievement of the health
17 care quality improvement and cost containment goals of the
18 Demonstration Project, and the Rutgers Center for State Health
19 Policy currently has the technological and operational resources
20 required to receive, maintain, and transmit individually identifiable
21 data and data sets in a secure database.

22 **1[g.] f.**¹ The Rutgers Center for State Health Policy is
23 responsible for evaluating New Jersey’s Comprehensive Medicaid
24 Waiver Demonstration Project with funding from the New Jersey
25 Department of Human Services and the Robert Wood Johnson
26 Foundation, whereby it receives comprehensive Medicaid
27 enrollment data, fee-for-service claims data, and managed care
28 encounter data, and conducts analyses of Medicaid claims and
29 encounter data to inform recommendations to improve care and
30 reduce costs for the top one percent of Medicaid beneficiaries who
31 account for a disproportionate share of program spending.

32

33 2. As used in this act:

34 “Aggregated data” means information that has been combined
35 into groups showing averages or other summary statistics, and that
36 is not individually identifiable information as defined in this act.

37 “De-identified data” means information that does not identify an
38 individual and for which there is no reasonable basis to believe that
39 the information can be used to identify an individual, and which
40 meets the requirements for de-identification of protected health
41 information under HIPAA.

42 “Governing Board” or “Board” means the board charged with
43 responsibility for governing the integrated population health data
44 **1[system] project**¹ established pursuant to section 3 of this act.

45 “Health data” means information that is created or received by a
46 governmental department or agency that relates to the past, present,
47 or future physical or mental health or condition of an individual or

1 the past, present, or future payment for the provision of health care
2 to an individual.

3 “HIPAA” means the “Health Insurance Portability and
4 Accountability Act of 1996,” Pub.L.104-191, and any regulations
5 promulgated thereunder by the Secretary of the U.S. Department of
6 Health and Human Services.

7 “Individually identifiable information” means information that
8 identifies an individual, or with respect to which there is a
9 reasonable basis to believe the information can be used to identify
10 an individual.

11 “IRB” means an institutional review board designated by the
12 Governing Board and established pursuant to federal regulations (45
13 CFR 46) with a Federalwide Assurance for the Protection of Human
14 Subjects approved by the U.S. Department of Health and Human
15 Services, Office for Human Research Protections, to review and
16 monitor research involving human subjects to ensure that the
17 subjects are protected from harm and that the rights of subjects are
18 adequately protected.

19 “iPHD ¹Project¹” means the integrated population health data
20 ¹[system] project¹ established pursuant to section 4 of this act.

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

24 “Protected health information” has the same meaning as defined
25 under HIPAA.

26 ¹“Publicly supported programs data” means information relating
27 to an individual’s receipt of services from or through public support
28 programs administered by a federal, State, or local government or
29 by a private entity, including, but not limited to, an individual’s
30 participation in or eligibility for Medicaid benefits, Supplemental
31 Nutrition Assistance Program benefits, Low Income Home Energy
32 Assistance Program benefits, and Social Services for the Homeless
33 program benefits.¹

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

38 “Researcher” means a private entity or public entity that
39 conducts research under the review and monitoring of an IRB ¹and
40 has received approval from the data steward for the purpose of
41 requested data elements¹.

42 ¹“Social services data” means information relating to an
43 individual’s receipt of services from or through public support
44 programs administered by a federal, State, or local government or
45 by a private entity, including, but not limited to, an individual’s
46 participation in or eligibility for Medicaid benefits, Supplemental
47 Nutrition Assistance Program benefits, Low Income Home Energy

1 Assistance Program benefits, and Social Services for the Homeless
2 program benefits.】¹

3
4 3. a. The iPHD Project¹ Governing Board is hereby
5 established in, but not of, the Department of State Health¹. The
6 Governing Board shall consist of ten 10¹ members: one of
7 whom shall be the Director of the Rutgers Center for State Health
8 Policy, who shall serve as a non-voting, ex-officio member; one of
9 whom shall be a public member appointed by the President of the
10 Senate, representing an organization capable of advocating on
11 behalf of persons whose data may be received, maintained, or
12 transmitted by the iPHD Project in accordance with this act; one of
13 whom shall be a public member appointed by the Speaker of the
14 General Assembly, with experience in human subjects research who
15 is affiliated with a research university in New Jersey;¹ and four
16 two¹ of whom shall be public members appointed by the Governor
17 with the advice and consent of the Senate¹, as follows:

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

22 (2) An individual with legal expertise and interest in
23 protecting the privacy and security of individually identifiable
24 information; and¹

25 (3) (2)¹ An individual with technical expertise and interest in
26 the creation and maintenance of large data systems and data
27 security ; and

28 (4) An individual with experience in human subjects research,
29 who is affiliated with a research university in New Jersey¹.

30 The five remaining members shall be voting, ex-officio members
31 representing the Commissioner of Health, who shall also serve as
32 chair of the Board;¹ the Commissioner of Human Services; the
33 Commissioner of Health State Treasurer¹; the Attorney General;
34 and¹ the Chief Information Officer for Rutgers, The State
35 University of New Jersey ;¹ and the Secretary of State, who shall
36 also serve as chair of the Board¹. Ex-officio members may be
37 represented by designees.

38 Of the public members first appointed to the Governing Board,
39 two shall be appointed to terms of three years, one shall be
40 appointed to a term of two years, and one shall be appointed to a
41 term of one year. Following the expiration of the initial terms,
42 public members of the Board shall be appointed for terms of three
43 years. The voting ex-officio members of the Board shall serve
44 during their respective terms of office. Any vacancy occurring in
45 the membership of the Board shall be filled in the same manner as
46 the original appointment, but for the unexpired term only. The

1 Board shall meet at least quarterly, and at such other times as it
2 determines, in its judgment, to be necessary. The appointed
3 members of the Board shall serve without compensation but may be
4 reimbursed for necessary expenses incurred in the performance of
5 their duties. In addition, the Board shall be entitled to and avail
6 itself of the assistance and services of the staff of the Department of
7 ¹ **State** Health¹, and of the employees of any other State
8 department, board, bureau, commission, or agency, as it may
9 require and as may be available for its purposes.

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

22 c. A member of the Governing Board shall not ¹ participate in
23 deliberations or¹ vote on any matter before the Board concerning an
24 individual or entity with which the member has, or within the last
25 12 months has had, any substantial ownership, employment,
26 medical staff, fiduciary, contractual, creditor, or consultative
27 relationship. A member who has or who has had such a relationship
28 with an individual or entity involved in any matter before the Board
29 shall make a written disclosure before any action is taken by the
30 Board with respect to the matter, and shall make the relationship
31 public in any meeting in which action on the matter is to be taken.

32 d. The iPHD ¹ Project¹ Governing Board shall be a public body
33 for the purposes of the "Senator Byron M. Baer Open Public
34 Meetings Act," P.L.1975, c.231 ¹ **[(C.10:4-8)] (C.10:4-6 et seq.)**¹,
35 and shall conduct its business in accordance with the provisions of
36 that act. ¹ All proceedings of the Governing Board shall be subject
37 to P.L.2001, c.404 (C.47:1A-5 et al.).¹

38
39 4. a. No later than 12 months after the effective date of this
40 act, the Rutgers Center for State Health Policy shall establish an
41 operational iPHD ¹ Project¹ capable of securely receiving,
42 maintaining, and transmitting data in accordance with this act and
43 the HIPAA privacy and security standards applicable to this act.
44 The Rutgers Center for State Health Policy may employ staff to
45 assist with carrying out the functions associated with the
46 establishment and maintenance of the iPHD ¹ Project¹.

1 b. Notwithstanding any provision of this act to the contrary, the
2 iPHD 'Project' shall seek to receive, maintain, and transmit de-
3 identified data wherever possible, and shall only receive, maintain,
4 and transmit individually identifiable information 'if permitted by
5 this section and other applicable law and if the information is' in a
6 form and format that is secured to prevent disclosure of individually
7 identifiable information.

8 'c. A consortium of researchers from New Jersey academic
9 institutions and from medical schools affiliated with New Jersey
10 universities will be organized by the Rutgers Center for State
11 Health Policy to facilitate actionable population health research to
12 help improve health outcomes for New Jersey residents, as well as
13 promote New Jersey's research institutions as leaders in social
14 science research.'¹

15
16 5. Oversight of the operations of the iPHD 'Project',
17 established pursuant to section 4 of this act, shall be vested in the
18 Governing Board. The iPHD 'Project' shall receive, maintain, and
19 transmit data only as permitted by this act and approved by the
20 Governing Board 'and agency or department whose data is
21 requested'. The Governing Board's responsibilities shall include:

22 a. Identification of '[social services] publicly supported
23 programs' data that has been created, received, or maintained by
24 agencies that may be appropriate for receipt, maintenance, and
25 transmission by the iPHD 'Project' in furtherance of the purposes
26 of this act;

27 b. Prior to the receipt of data by the iPHD 'Project', the review
28 and approval of the appropriateness of such receipt, including
29 consideration of the following factors:

30 (1) whether the transmitting department or agency has authority
31 to collect the data proposed to be received by the iPHD 'Project',
32 particularly if the data includes individually identifiable
33 information;

34 (2) whether collection of the data proposed to be received by the
35 iPHD 'Project' is expected to further the purpose of this act,
36 namely, the improvement of public health, safety, security, '[or]
37 and' well-being of New Jersey residents '[or] and' the
38 improvement of the overall cost-efficiency of government
39 assistance programs; and

40 (3) whether reasonable efforts have been made to ensure that the
41 iPHD 'Project' will receive only the appropriate data needed to
42 accomplish the purposes of this act;

43 c. Prior to the receipt or transmission of data by the iPHD
44 'Project', the review and approval of any necessary data use
45 agreements or business associate agreements with any person or
46 entity from which or to which information is received or transmitted

1 in compliance with all applicable privacy and security standards,
2 including, but not limited to, HIPAA, when such data includes
3 individually identifiable information that is protected health
4 information as defined under HIPAA; and

5 d. Adopting and publishing policies and procedures for the
6 efficient and transparent operation of the iPHD 'Project', including,
7 but not limited to, the following:

8 (1) Privacy and data security policies and procedures that
9 comply with the applicable federal and State privacy and security
10 statutes and regulations, including HIPAA; '[and]'

11 (2) Data access policies and procedures that allow access by a
12 public entity or a private entity, including a researcher, only when
13 such access request meets the standards set forth in the data access
14 policies and procedures and has been approved by the Governing
15 Board 'and the appropriate agency or department'. When data
16 access is requested by any 'public or' private entity, including a
17 researcher, for the purpose of conducting research, the Governing
18 Board shall only approve access to data after review and approval
19 by an IRB, and such access shall be limited to data identified in
20 approved IRB research protocols and only for the period of the
21 approval. In no event shall the Governing Board approve access to
22 health data that identifies, or that may be used to identify, rates of
23 payment by a private entity for the provision of health care services
24 to an individual unless the party seeking access agrees to keep such
25 information confidential and to prevent public disclosure of such
26 data or the rates of payment derived from such data ';

27 (3) Data retention policies identifying that data shall be returned
28 to sponsoring agencies or destroyed when it is no longer in the
29 State's interest to promote analysis of the data and in accordance
30 with applicable HIPAA regulations, data use agreements, and
31 provisions of IRB approvals;

32 (4) Policies to require researchers to consult with subject matter
33 experts in the datasets being linked on a specific project. The
34 purpose of such consultation shall be to help researchers understand
35 and interpret the data being linked for a specific project; and

36 (5) Policies that establish processes to engage researchers and
37 academic institutions across New Jersey to help set research
38 priorities and promote the use of the iPHD Project to accelerate
39 population health research in this State'.

40
41 6. No later than 12 months following the receipt of data by the
42 iPHD 'Project' pursuant to this act, and on an annual basis
43 thereafter, the 'Rutgers Center for State Health Policy, in
44 consultation with the' Governing Board '; shall publish a report
45 that is made available and accessible to the public and that contains
46 the following information:

- 1 a. A description of the implementation of the iPHD 'Project',
2 including identification of the sources and types of data received
3 and maintained by the iPHD 'Project' over the prior 12 months;
- 4 b. A list of all aggregated data maintained by the iPHD
5 'Project';
- 6 c. A description of each IRB-approved disclosure of data or
7 data sets by the iPHD 'Project';
- 8 d. A description of disclosures to Medicaid Accountable Care
9 Organizations recognized by the '[state] State' in accordance with
10 P.L.2011, c.114 (C.30:4D-8.1 et seq.);
- 11 e. A list of publications and other reports based on iPHD
12 'Project' data;
- 13 f. A strategic plan for achieving the purposes of this act during
14 the successive 12 month period; and
- 15 g. Any other information deemed appropriate by the Governing
16 Board.

17
18 7. The iPHD 'Project' Governing Board and the Rutgers
19 Center for State Health Policy may apply for and receive funding in
20 relation to the iPHD 'Project' from the following sources:

- 21 a. '[Grants or other financial assistance from State or local
22 departments, agencies, authorities, and organizations;
- 23 b. Federal grants;
- 24 c.]' Grants from '[other public or] research or other' private
25 entities; '[and
26 d.] b.' Fees paid by persons or entities requesting access to
27 iPHD 'Project' data or the performance of analyses by the iPHD
28 'Project', which fees have been approved by the Governing Board
29 to support the cost of preparing data for access or the performance
30 of analyses ';
- 31 c. Federal grants; and
- 32 d. Grants or other financial assistance from State or local
33 departments, agencies, authorities, and organizations at the
34 discretion of these entities, for specific projects of interest to these
35 entities'.

36
37 8. Any department or agency that creates, receives, or
38 maintains '[social services] publicly supported programs' data or
39 health data shall ' , only after execution of an enforceable data use,
40 data sharing, or other similar agreement that is acceptable to the
41 department or agency,' transmit or allow access to such data as is
42 necessary and appropriate to further the goals of this act and shall
43 cooperate with iPHD 'Project' requests for receipt of, or access to,
44 such data. Notwithstanding the foregoing, no department or agency
45 shall be required to transmit data it creates, receives, or maintains to
46 the iPHD 'Project', or to allow access to such data, if the Attorney

1 ~~1~~**[General]** General's review or the applicable department's or
2 agency's review¹ determines that such transmission or access would
3 violate State or federal law. The Attorney General's review shall
4 include consideration of an analysis from the department or agency
5 whose data is being requested.¹ This section shall not prohibit the
6 Rutgers Center for State Health Policy or any department or agency
7 from creating, receiving, maintaining, or transmitting data in data
8 systems that are separate and distinct from the iPHD Project¹.

9

10 9. This act shall take effect immediately and within 60 days
11 after the effective date of this act, the Governor shall appoint four
12 public members to the iPHD Project¹ Governing Board in
13 accordance with section 3 of this act.

14

15

16

17

18 Establishes a process to integrate certain health data and other
19 data from publicly supported programs for population health
20 research.

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.

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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.

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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.

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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.

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

SENATE HEALTH, HUMAN SERVICES AND SENIOR
CITIZENS COMMITTEE

STATEMENT TO
SENATE, No. 3220

with committee amendments

STATE OF NEW JERSEY

DATED: DECEMBER 10, 2015

The Senate Health, Human Services and Senior Citizens Committee reports favorably and with amendments Senate Bill No. 3220.

As amended, this bill establishes a secure, Statewide, integrated Population Health Data (iPHD) Project ("Project") containing certain data collected by New Jersey administrative departments and agencies, that includes data related to health and publicly supported programs that will facilitate approved, project-by-project analysis and research and the development of the most effective means for improving the health, safety, security, and well-being of New Jersey residents and the overall cost-efficiency of government programs.

Under the bill, the Rutgers Center for State Health Policy will be required to establish an operational iPHD Project capable of securely receiving, maintaining, and transmitting data. The project will be required to meet the requirements set forth in the bill, including ensuring individually identifiable information is secured in a form to prevent disclosure, as well as applicable HIPAA privacy and security standards. The Rutgers Center for State Health Policy will be required to organize a consortium of researchers from New Jersey academic institutions and affiliated medical schools to facilitate actionable population health research to help improve health outcomes and promote New Jersey's research institutions. Departments and agencies receiving, maintaining, and transmitting data will be required to execute the necessary data sharing agreements, and data requests and transmissions will be subject to review by the Attorney General.

Oversight of the operations of the Project will be vested in the iPHD Project Governing Board, established under the bill. The bill requires that data may be received, maintained, and transmitted only with the approval of the Governing Board and the agency or department whose data is requested. Specifically, the Governing Board will be responsible for: (1) identifying publicly supported programs data that has been created, received, or maintained by agencies that may be appropriate for receipt, maintenance, and transmission by the Project; (2) reviewing and approving the

appropriateness of receiving data, including consideration of whether the transmitting department or agency has authority to collect the data, whether collection of the data is expected to further the purposes of the bill, and whether reasonable efforts have been made to ensure that the Project will receive only the appropriate data needed to accomplish the purposes of the bill; (3) reviewing and approving any necessary data use agreements or business associate agreements when data will include individually identifiable information; and (4) adopting and publishing policies and procedures for the efficient and transparent operation of the Project, including privacy and data security policies and procedures, data access policies and procedures that restrict access to appropriate entities, data retention policies identifying data that is to be returned to sponsoring agencies or destroyed when it is no longer needed by the Project, policies to require researchers to consult with subject matter experts in the datasets, and policies that establish processes to engage researchers and academic institutions across New Jersey to help set research priorities and promote the use of the Project.

The Governing Board will consist of 10 members, including: the Director of the Rutgers Center for State Health Policy, who will serve as a non-voting, ex-officio member; four public members with background expertise relevant to the Project, with one each appointed by the Speaker of the General Assembly and the President of the Senate and two appointed by the Governor; and five ex officio voting members, including the Commissioners of Health and Human Services, the State Treasurer, the Attorney General, and the Chief Information officer for Rutgers, the State University of New Jersey, or their designees. The Commissioner of Health will serve as chair of the Board.

Public members will serve for a term of three years; of the public members first appointed to the Board, two will be appointed to terms of three years, one will be appointed to a term of two years, and one will be appointed to a term of one year. The Board will meet at least quarterly and at such other times as it determines to be necessary. The members will serve without compensation but may be reimbursed for necessary expenses incurred in the performance of their duties. The Board will be entitled to and avail itself of the assistance and services of the staff of the Department of Health and of the employees of any other State department, board, bureau, commission, or agency, as it may require and as may be available for its purposes. Members of the Board will not be liable in any civil action for actions or recommendations made in their capacity as Board members.

Members of the Board may not participate in deliberations or vote on any matter before the Board concerning an individual or entity with which the member has, or within the last 12 months has had, any substantial ownership, employment, medical staff, fiduciary, contractual, creditor, or consultative relationship. A member who has

or who has had such a relationship with an individual or entity involved in any matter before the Board will be required to make a written disclosure before any action is taken by the Board with respect to the matter, and will be required to make the relationship public in any meeting in which action on the matter is to be taken.

No later than 12 months following the receipt of data by the Project, and annually thereafter, the Rutgers Center for State Health Policy, in consultation with the Governing Board will be required to publish a report that is to be made available and accessible to the public concerning the implementation of the Project, a list of data received and disclosures made, a list of publications and reports based on Project data, and a strategic plan for achieving the goals of the bill.

The Governing Board and the Rutgers Center for State Health Policy may apply for and receive funding from research and private entities, fees paid by persons and entities requesting access to Project data, and federal, State, and local grants.

The committee amendments make several changes to the composition of the iPHD Project Governing Board: the Commissioner of Health is designated as the chair of the Board; two of the public members will be appointed by the President of the Senate and the Speaker of the General Assembly rather than by the Governor; the Secretary of State is removed from the Board; and the State Treasurer is added. In addition, the two public members appointed by the Governor will no longer require the advice and consent of the Senate.

The committee amendments provide that the Rutgers Center for State Health Policy will be required to organize a consortium of researchers from New Jersey academic institutions and from medical schools affiliated with New Jersey universities to facilitate actionable population health research to help improve health outcomes for New Jersey residents, as well as promote New Jersey's research institutions as leaders in social science research.

The committee amendments require the Governing Board, in addition to its obligations under the original version of the bill, to develop: data retention policies, data use agreements, and provisions of institutional review board approvals; policies to require researchers to consult with subject matter experts in the datasets being linked on a specific project; and policies that establish processes to engage researchers and academic institutions across New Jersey to help set research priorities and promote the use of the Project to accelerate population health research in this State.

The committee amendments require that the Rutgers Center for State Health Policy is to public annual public reports in consultation with the Governing Board; as introduced, the Governing Board alone was responsible for the reports.

The committee amendments clarify that departments or agencies holding data are required to approve the sharing of data that they collect, and are required to accept a data use, data sharing, or other

similar agreement before being obligated to share data with the Project.

The committee amendments make several clarifying, technical, and stylistic changes, including replacing references to the “iPHD” with “iPHD Project,” and replacing references to “social services data” with “publicly supported programs data.”

LEGISLATIVE FISCAL ESTIMATE

[First Reprint]

SENATE, No. 3220

STATE OF NEW JERSEY 216th LEGISLATURE

DATED: DECEMBER 21, 2015

SUMMARY

- Synopsis:** Establishes a process to integrate certain health data and other data from publicly supported programs for population health research.
- Type of Impact:** No direct impact, but General Fund costs may be incurred to implement optional provisions of the bill.
- Agencies Affected:** Any agency of State or local government, within its own discretion.

Office of Legislative Services Estimate

Fiscal Impact	<u>Years 1-3</u>
State Cost	No direct impact; however, see comments below.
Local Cost	No direct impact; however, see comments below.

- Most of the mandatory costs of the bill, including administration of the integrated Population Health Data (iPHD) Project, staffing the Governing Board, and assembling a consortium of researchers from academic institutions and medical schools, can be accomplished at no cost to the State. The Director of the Rutgers Center for State Health Policy has testified that the Center can support these costs without a State appropriation, relying on private and federal grants.
- Costs borne by State and local agencies that may provide publicly supported programs data to the iPHD project would be optional, and the bill would have little effect on these agencies' current options and obligations. The Governing Board would perform some functions related to data sharing, including establishment of data sharing and use agreements and reviewing individual research project applications, which might allow agencies to reduce their own investments of staff time in such functions, allowing staff to spend time on other functions.
- The bill does not require any information technology investments to be made by the State or local entities. Investments in better data collection, storage, and organization would advance the aims of the bill, but are not directly required by the bill.

- Over time, research on the impacts of publicly supported programs that would be enabled by the iPHD Project may possibly allow for reforms in these programs that may improve performance or reduce costs. Any such potential effects are unknown and unquantifiable at this time.

BILL DESCRIPTION

Senate Bill No. 3220 (1R) of 2014 establishes a secure, Statewide, iPHD Project containing certain data collected by New Jersey administrative departments and agencies, that includes data related to health and publicly supported programs that will facilitate approved, project-by-project analysis and research and the development of the most effective means for improving the health, safety, security, and well-being of New Jersey residents and the overall cost-efficiency of government programs.

Under the bill, the Rutgers Center for State Health Policy will be required to establish an operational iPHD Project capable of securely receiving, maintaining, and transmitting data. The project will be required to meet the requirements set forth in the bill, including ensuring individually identifiable information is secured in a form that prevents disclosure, and will also be required to meet applicable HIPAA privacy and security standards. The Rutgers Center for State Health Policy will be required to organize a consortium of researchers from New Jersey academic institutions and affiliated medical schools to facilitate actionable population health research to help improve health outcomes and promote New Jersey's research institutions. Departments and agencies receiving, maintaining, and transmitting data will be required to execute the necessary data sharing agreements, and data requests and transmissions will be subject to review by the Attorney General.

Oversight of the operations of the Project will be vested in the iPHD Project Governing Board, established under the bill. The bill requires that data may be received, maintained, and transmitted only with the approval of the Governing Board and the agency or department whose data is requested. Specifically, the Governing Board will be responsible for: (1) identifying publicly supported programs data that has been created, received, or maintained by agencies that may be appropriate for receipt, maintenance, and transmission by the Project; (2) reviewing and approving the appropriateness of receiving data, including consideration of whether the transmitting department or agency has authority to collect the data, whether collection of the data is expected to further the purposes of the bill, and whether reasonable efforts have been made to ensure that the Project will receive only the appropriate data needed to accomplish the purposes of the bill; (3) reviewing and approving any necessary data use agreements or business associate agreements when data will include individually identifiable information; and (4) adopting and publishing policies and procedures for the efficient and transparent operation of the Project, including privacy and data security policies and procedures, data access policies and procedures that restrict access to appropriate entities, data retention policies identifying data that is to be returned to sponsoring agencies or destroyed when it is no longer needed by the Project, policies to require researchers to consult with subject matter experts in the datasets, and policies that establish processes to engage researchers and academic institutions across New Jersey to help set research priorities and promote the use of the Project.

The Governing Board will consist of 10 appointed and ex-officio members. The Board will meet at least quarterly and at such other times as it determines to be necessary. The members will serve without compensation but may be reimbursed for necessary expenses incurred in the performance of their duties. The Board will be entitled to and avail itself of the assistance and services of the staff of the Department of Health and of the employees of any other State department, board, bureau, commission, or agency, as it may require and as may be available for

its purposes. Members of the Board will not be liable in any civil action for actions or recommendations made in their capacity as Board members.

No later than 12 months following the receipt of data by the Project, and annually thereafter, the Rutgers Center for State Health Policy, in consultation with the Governing Board, will be required to publish a report that is to be made available and accessible to the public concerning the implementation of the Project, a list of data received and disclosures made, a list of publications and reports based on Project data, and a strategic plan for achieving the goals of the bill.

The Governing Board and the Rutgers Center for State Health Policy may apply for and receive funding from research and private entities, fees paid by persons and entities requesting access to Project data, and federal, State, and local grants.

FISCAL ANALYSIS

EXECUTIVE BRANCH

None received.

OFFICE OF LEGISLATIVE SERVICES

Most of the mandatory costs of the bill, including administration of the iPHD Project, staffing the Governing Board, and assembling a consortium of researchers from academic institutions and medical schools, can be accomplished at no cost to the State. The Director of the Rutgers Center for State Health Policy has testified that the Center can support these costs without a State appropriation. Initially, the project could be supported through grant funding from private foundations and federal agencies. After several years, the Center expects that project fees for access to the data would fund most of its operational costs.

Costs borne by State and local agencies that may provide publicly supported programs data to the iPHD project would be optional, and the bill would have little effect on these agencies' current options and obligations. The bill requires agencies to share data with the iPHD only after execution of an enforceable data use, data sharing, or other similar agreement that is acceptable to the department or agency – in effect giving the agency an option not to participate in the Project if it desires not to do so. Current law permits public agencies to share data for research purposes with essentially the same limitations, but very often agencies fail to execute any such agreement or share data. The reasons may vary, but often agencies lack the staff time to appropriately review such agreements, or they lack internal capacity or staff to transform the data into a form that is in compliance with applicable data privacy and data security laws. The bill would require the iPHD Governing Board to establish various data access policies and procedures that may lessen the burden on agencies to develop such agreements independently, thereby possibly reducing staff time invested in such activities. Such time savings are not expected to have any fiscal impact, as any related costs are currently absorbed within agencies' general administrative budgets.

The bill does not require any information technology investments to be made by the State or local entities. The OLS notes that a lot of publicly supported programs data, which would be useful in conducting the sort of cross-program analysis described by the supporters of the bill, is currently generated by, and housed in, antiquated information technology infrastructure. Investments in better data collection, storage, and organization would advance the aims of the

bill, but are not directly required by the bill. Any costs related to such upgrades would not be directly attributable to the bill.

Over time, research on the impacts of publicly supported programs that would be enabled by the iPHD Project may possibly allow for reforms in these programs that may improve performance or reduce costs. Any such potential effects are unknown and unquantifiable at this time, and would likely not manifest for five or more years after the bill's enactment.

If the iPHD Project is successful in establishing useful data sets for use by researchers, it is possible that it would allow researchers in the State to attract more research funding from private foundations and federal agencies. Such benefits are uncertain at this time, and are unlikely to become apparent for several years.

Section: Human Services

*Analyst: David Drescher
Senior Fiscal Analyst*

*Approved: Frank W. Haines III
Legislative Budget and Finance Officer*

This fiscal estimate has been prepared pursuant to P.L.1980, c.67 (C.52:13B-6 et seq.).

ASSEMBLY, No. 4790

STATE OF NEW JERSEY 216th LEGISLATURE

INTRODUCED NOVEMBER 16, 2015

Sponsored by:

Assemblyman LOUIS D. GREENWALD

District 6 (Burlington and Camden)

Assemblyman HERB CONAWAY, JR.

District 7 (Burlington)

Assemblywoman VALERIE VAINIERI HUTTLE

District 37 (Bergen)

Assemblywoman AMY H. HANDLIN

District 13 (Monmouth)

Assemblyman CARMELO G. GARCIA

District 33 (Hudson)

Co-Sponsored by:

Assemblywoman Pinkin

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, c.114
43 (C.30:4D-8.1 et seq.) requires the Rutgers Center for State Health
44 Policy to analyze patient data received from the Department of
45 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 7. The iPHD Governing Board and the Rutgers Center for State
37 Health Policy may apply for and receive funding in relation to the
38 iPHD from the following sources:

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

41 b. Federal grants;

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

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

ASSEMBLY HEALTH AND SENIOR SERVICES COMMITTEE

STATEMENT TO

ASSEMBLY, No. 4790

with committee amendments

STATE OF NEW JERSEY

DATED: DECEMBER 10, 2015

The Assembly Health and Senior Services Committee reports favorably and with committee amendments Assembly Bill No. 4790.

As amended, this bill establishes a secure, Statewide, integrated Population Health Data (iPHD) Project ("Project") containing certain data collected by New Jersey administrative departments and agencies, that includes data related to health and publicly supported programs that will facilitate approved, project-by-project analysis and research and the development of the most effective means for improving the health, safety, security, and well-being of New Jersey residents and the overall cost-efficiency of government programs.

Under the bill, the Rutgers Center for State Health Policy will be required to establish an operational iPHD Project capable of securely receiving, maintaining, and transmitting data. The project will be required to meet the requirements set forth in the bill, including ensuring individually identifiable information is secured in a form that prevents disclosure, and will also be required to meet applicable HIPAA privacy and security standards. The Rutgers Center for State Health Policy will be required to organize a consortium of researchers from New Jersey academic institutions and affiliated medical schools to facilitate actionable population health research to help improve health outcomes and promote New Jersey's research institutions. Departments and agencies receiving, maintaining, and transmitting data will be required to execute the necessary data sharing agreements, and data requests and transmissions will be subject to review by the Attorney General.

Oversight of the operations of the Project will be vested in the iPHD Project Governing Board, established under the bill. The bill requires that data may be received, maintained, and transmitted only with the approval of the Governing Board and the agency or department whose data is requested. Specifically, the Governing Board will be responsible for: (1) identifying publicly supported programs data that has been created, received, or maintained by agencies that may be appropriate for receipt, maintenance, and transmission by the Project; (2) reviewing and approving the appropriateness of receiving data, including consideration of whether

the transmitting department or agency has authority to collect the data, whether collection of the data is expected to further the purposes of the bill, and whether reasonable efforts have been made to ensure that the Project will receive only the appropriate data needed to accomplish the purposes of the bill; (3) reviewing and approving any necessary data use agreements or business associate agreements when data will include individually identifiable information; and (4) adopting and publishing policies and procedures for the efficient and transparent operation of the Project, including privacy and data security policies and procedures, data access policies and procedures that restrict access to appropriate entities, data retention policies identifying data that is to be returned to sponsoring agencies or destroyed when it is no longer needed by the Project, policies to require researchers to consult with subject matter experts in the datasets, and policies that establish processes to engage researchers and academic institutions across New Jersey to help set research priorities and promote the use of the Project.

The Governing Board will consist of 10 members, including: the Director of the Rutgers Center for State Health Policy, who will serve as a non-voting, ex-officio member; four public members with background expertise relevant to the Project, with one each appointed by the Speaker of the General Assembly and the President of the Senate and two appointed by the Governor; and five ex officio voting members, including the Commissioners of Health and Human Services, the State Treasurer, the Attorney General, and the Chief Information Officer for Rutgers, the State University of New Jersey, or their designees. The Commissioner of Health will serve as chair of the Board.

Public members will serve for a term of three years; of the public members first appointed to the Board, two will be appointed to terms of three years, one will be appointed to a term of two years, and one will be appointed to a term of one year. The Board will meet at least quarterly and at such other times as it determines to be necessary. The members will serve without compensation but may be reimbursed for necessary expenses incurred in the performance of their duties. The Board will be entitled to and avail itself of the assistance and services of the staff of the Department of Health and of the employees of any other State department, board, bureau, commission, or agency, as it may require and as may be available for its purposes. Members of the Board will not be liable in any civil action for actions or recommendations made in their capacity as Board members.

Members of the Board may not participate in deliberations or vote on any matter before the Board concerning an individual or entity with which the member has, or within the last 12 months has had, any substantial ownership, employment, medical staff, fiduciary, contractual, creditor, or consultative relationship. A member who has or who has had such a relationship with an individual or entity

involved in any matter before the Board will be required to make a written disclosure before any action is taken by the Board with respect to the matter, and will be required to make the relationship public in any meeting in which action on the matter is to be taken.

No later than 12 months following the receipt of data by the Project, and annually thereafter, the Rutgers Center for State Health Policy, in consultation with the Governing Board, will be required to publish a report that is to be made available and accessible to the public concerning the implementation of the Project, a list of data received and disclosures made, a list of publications and reports based on Project data, and a strategic plan for achieving the goals of the bill.

The Governing Board and the Rutgers Center for State Health Policy may apply for and receive funding from research and private entities, fees paid by persons and entities requesting access to Project data, and federal, State, and local grants.

COMMITTEE AMENDMENTS:

The committee amendments make several changes to the composition of the iPHD Project Governing Board: the Commissioner of Health is designated as the chair of the Board; two of the public members will be appointed by the President of the Senate and the Speaker of the General Assembly rather than by the Governor; the Secretary of State is removed from the Board; and the State Treasurer is added. In addition, the two public members appointed by the Governor will no longer require the advice and consent of the Senate.

The committee amendments provide that the Rutgers Center for State Health Policy will be required to organize a consortium of researchers from New Jersey academic institutions and from medical schools affiliated with New Jersey universities to facilitate actionable population health research to help improve health outcomes for New Jersey residents, as well as to promote New Jersey's research institutions as leaders in social science research.

The committee amendments require the Governing Board, in addition to its obligations under the original version of the bill, to develop various policies and procedures concerning data use, access, and retention and consultations and engagement with researchers and academic institutions which will further the purposes of the bill.

The committee amendments require that the Rutgers Center for State Health Policy is to publish annual public reports in consultation with the Governing Board; as introduced, the Governing Board alone was responsible for the reports.

The committee amendments clarify that departments or agencies holding data are required to approve the sharing of data that they collect, and are required to accept a data use, data sharing, or other similar agreement before being obligated to share data with the Project.

The committee amendments make several clarifying, technical, and stylistic changes, including replacing references to the “iPHD” with “iPHD Project,” and replacing references to “social services data” with “publicly supported programs data.”

LEGISLATIVE FISCAL ESTIMATE

[First Reprint]

ASSEMBLY, No. 4790

STATE OF NEW JERSEY 216th LEGISLATURE

DATED: DECEMBER 22, 2015

SUMMARY

- Synopsis:** Establishes a process to integrate certain health data and other data from publicly supported programs for population health research.
- Type of Impact:** No direct impact, but General Fund costs may be incurred to implement optional provisions of the bill.
- Agencies Affected:** Any agency of State or local government, within its own discretion.

Office of Legislative Services Estimate

Fiscal Impact	<u>Years 1-3</u>
State Cost	No direct impact; however, see comments below.
Local Cost	No direct impact; however, see comments below.

- Most of the mandatory costs of the bill, including administration of the integrated Population Health Data (iPHD) Project, staffing the Governing Board, and assembling a consortium of researchers from academic institutions and medical schools, can be accomplished at no cost to the State. The Director of the Rutgers Center for State Health Policy has testified that the Center can support these costs without a State appropriation, relying on private and federal grants.
- Costs borne by State and local agencies that may provide publicly supported programs data to the iPHD project would be optional, and the bill would have little effect on these agencies' current options and obligations. The Governing Board would perform some functions related to data sharing, including establishment of data sharing and use agreements and reviewing individual research project applications, which might allow agencies to reduce their own investments of staff time in such functions, allowing staff to spend time on other functions.
- The bill does not require any information technology investments to be made by the State or local entities. Investments in better data collection, storage, and organization would advance the aims of the bill, but are not directly required by the bill.

- Over time, research on the impacts of publicly supported programs that would be enabled by the iPHD Project may possibly allow for reforms in these programs that may improve performance or reduce costs. Any such potential effects are unknown and unquantifiable at this time.

BILL DESCRIPTION

Assembly Bill No. 4790 (1R) of 2014 establishes a secure, Statewide, iPHD Project containing certain data collected by New Jersey administrative departments and agencies, that includes data related to health and publicly supported programs that will facilitate approved, project-by-project analysis and research and the development of the most effective means for improving the health, safety, security, and well-being of New Jersey residents and the overall cost-efficiency of government programs.

Under the bill, the Rutgers Center for State Health Policy will be required to establish an operational iPHD Project capable of securely receiving, maintaining, and transmitting data. The project will be required to meet the requirements set forth in the bill, including ensuring individually identifiable information is secured in a form that prevents disclosure, and will also be required to meet applicable HIPAA privacy and security standards. The Rutgers Center for State Health Policy will be required to organize a consortium of researchers from New Jersey academic institutions and affiliated medical schools to facilitate actionable population health research to help improve health outcomes and promote New Jersey's research institutions. Departments and agencies receiving, maintaining, and transmitting data will be required to execute the necessary data sharing agreements, and data requests and transmissions will be subject to review by the Attorney General.

Oversight of the operations of the Project will be vested in the iPHD Project Governing Board, established under the bill. The bill requires that data may be received, maintained, and transmitted only with the approval of the Governing Board and the agency or department whose data is requested. Specifically, the Governing Board will be responsible for: (1) identifying publicly supported programs data that has been created, received, or maintained by agencies that may be appropriate for receipt, maintenance, and transmission by the Project; (2) reviewing and approving the appropriateness of receiving data, including consideration of whether the transmitting department or agency has authority to collect the data, whether collection of the data is expected to further the purposes of the bill, and whether reasonable efforts have been made to ensure that the Project will receive only the appropriate data needed to accomplish the purposes of the bill; (3) reviewing and approving any necessary data use agreements or business associate agreements when data will include individually identifiable information; and (4) adopting and publishing policies and procedures for the efficient and transparent operation of the Project, including privacy and data security policies and procedures, data access policies and procedures that restrict access to appropriate entities, data retention policies identifying data that is to be returned to sponsoring agencies or destroyed when it is no longer needed by the Project, policies to require researchers to consult with subject matter experts in the datasets, and policies that establish processes to engage researchers and academic institutions across New Jersey to help set research priorities and promote the use of the Project.

The Governing Board will consist of 10 appointed and ex-officio members. The Board will meet at least quarterly and at such other times as it determines to be necessary. The members will serve without compensation but may be reimbursed for necessary expenses incurred in the performance of their duties. The Board will be entitled to and avail itself of the assistance and services of the staff of the Department of Health and of the employees of any other State

department, board, bureau, commission, or agency, as it may require and as may be available for its purposes. Members of the Board will not be liable in any civil action for actions or recommendations made in their capacity as Board members.

No later than 12 months following the receipt of data by the Project, and annually thereafter, the Rutgers Center for State Health Policy, in consultation with the Governing Board, will be required to publish a report that is to be made available and accessible to the public concerning the implementation of the Project, a list of data received and disclosures made, a list of publications and reports based on Project data, and a strategic plan for achieving the goals of the bill.

The Governing Board and the Rutgers Center for State Health Policy may apply for and receive funding from research and private entities, fees paid by persons and entities requesting access to Project data, and federal, State, and local grants.

FISCAL ANALYSIS

EXECUTIVE BRANCH

None received.

OFFICE OF LEGISLATIVE SERVICES

Most of the mandatory costs of the bill, including administration of the iPHD Project, staffing the Governing Board, and assembling a consortium of researchers from academic institutions and medical schools, can be accomplished at no cost to the State. The Director of the Rutgers Center for State Health Policy has testified that the Center can support these costs without a State appropriation. Initially, the project could be supported through grant funding from private foundations and federal agencies. After several years, the Center expects that project fees for access to the data would fund most of its operational costs.

Costs borne by State and local agencies that may provide publicly supported programs data to the iPHD project would be optional, and the bill would have little effect on these agencies' current options and obligations. The bill requires agencies to share data with the iPHD only after execution of an enforceable data use, data sharing, or other similar agreement that is acceptable to the department or agency – in effect giving the agency an option not to participate in the Project if it desires not to do so. Current law permits public agencies to share data for research purposes with essentially the same limitations, but very often agencies fail to execute any such agreement or share data. The reasons may vary, but often agencies lack the staff time to appropriately review such agreements, or they lack internal capacity or staff to transform the data into a form that is in compliance with applicable data privacy and data security laws. The bill would require the iPHD Governing Board to establish various data access policies and procedures that may lessen the burden on agencies to develop such agreements independently, thereby possibly reducing staff time invested in such activities. Such time savings are not expected to have any fiscal impact, as any related costs are currently absorbed within agencies' general administrative budgets.

The bill does not require any information technology investments to be made by the State or local entities. The OLS notes that a lot of publicly supported programs data, which would be useful in conducting the sort of cross-program analysis described by the supporters of the bill, is currently generated by, and housed in, antiquated information technology infrastructure. Investments in better data collection, storage, and organization would advance the aims of the

bill, but are not directly required by the bill. Any costs related to such upgrades would not be directly attributable to the bill.

Over time, research on the impacts of publicly supported programs that would be enabled by the iPHD Project may possibly allow for reforms in these programs that may improve performance or reduce costs. Any such potential effects are unknown and unquantifiable at this time, and would likely not manifest for five or more years after the bill's enactment.

If the iPHD Project is successful in establishing useful data sets for use by researchers, it is possible that it would allow researchers in the State to attract more research funding from private foundations and federal agencies. Such benefits are uncertain at this time, and are unlikely to become apparent for several years.

Section: Human Services

*Analyst: David Drescher
Senior Fiscal Analyst*

*Approved: Frank W. Haines III
Legislative Budget and Finance Officer*

This fiscal estimate has been prepared pursuant to P.L.1980, c.67 (C.52:13B-6 et seq.).

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Trenton, NJ – Governor Chris Christie today took action on legislation, including a bill aimed at helping inmates who were victims of domestic violence and a second bill designed to help non-violent drug offenders reclaim their lives by streamlining the process for expungement of their criminal records.

The Governor suggested minor changes to strengthen Senate Bill No. 995, which seeks to help domestic violence victims who have been convicted of crimes against their abusers by establishing a community reentry program to assist victim-offenders assimilate into society upon release from custody and prevent further victimization.

Governor Christie conditionally vetoed the bill, proposing that the program be established solely in the Department of Corrections.

"The goal of this bill is commendable and I sincerely support its objective," Governor Christie said. "Domestic violence is tragic, and victims deserve support and counseling. However, the bill conflates the statutory and regulatory responsibilities of the Department of Corrections and the State Parole Board, combining the agencies' separate residential program functions. Accordingly, I suggest minor amendments, in accordance with the intent of the legislation to establish this program within the Department of Corrections, consistent with its existing reintegration programming and tailored to the specific needs of this limited inmate population."

The bill as written also called for an automatic early release program for this specific subset of inmates upon successful completion of the reentry program, an element of the bill that Governor Christie does not support.

"I cannot support the creation of early release programs because they would begin to chisel away at the long-standing function of the State Parole Board," Governor Christie said. "For decades, the State Parole Board has faithfully fulfilled its charge to carefully review and consider the underlying facts and circumstances of each applicant for parole. While I continue to encourage the Legislature to explore reforms that will create efficiencies in State government, I remain grounded in my belief that the review of parole applications is best accomplished through the reasoned, compassionate, experienced and individualized judgment of the State Parole Board and not through an automatic process based upon one factor."

Governor Christie similarly took action to strengthen the Assembly Committee Substitute for Assembly Bills Nos. 206, 471, 1663, 2879, 3060 and 3108, and urged quick approval from the Legislature.

The bill proposes to allow those who have successfully completed the Drug Court program to expunge the related criminal charges, and it further aims to make the expungement process more efficient.

Seeking to balance the needs of non-violent ex-offenders with public safety, Governor Christie conditionally vetoed the bill, retaining the current waiting period for expungements for indictable offenses, currently 10 years, or five years if a court determines that expungement is in the public's interest.

"While I support breaking down barriers to employment and education for non-violent ex-offenders, I cannot endorse a bill that compromises public safety," Governor Christie said. "As written, this bill would cut in half the presumptive waiting period to expunge indictable offenses, often felonies, from ten years to five years, and eliminate an important safeguard which allows a judge to consider whether granting an expungement is in the public's interest. The current public interest exception to the presumptive waiting period is an effective and efficient way to help ex-offenders combat the collateral consequences of their offense, while also ensuring that public safety is not compromised."

Governor Christie further suggested retaining the five-year waiting period for disorderly persons offenses, while adopting the bill's provision to lower this waiting period to three years, if a court determines that expungement is in the public interest.

The Governor also took the following action on other pending legislation:

BILL SIGNINGS:

S-475/A-3223 (Madden, Sweeney/Mosquera, Webber, Moriarty, Mukherji, Garcia, Munoz, Lampitt) - Requires certain information regarding Down syndrome be provided to certain parents and families

S-650 (Doherty, Beach/DiMaio, Andrzejczak, Peterson, DeAngelo) - Designates State Route 173 between Clinton and Phillipsburg as "173rd Airborne Brigade Highway"

S-835/A-1972 (Bateman/Garcia, Danielson) - Enhances penalties for false incrimination and making fictitious reports

S-939/A-2913 (Bateman, A.R. Bucco/Caride, Dancer, A.M. Bucco) - Designates Black Swallowtail butterfly as State Butterfly

S-1940/A-2893 (Oroho, Van Drew/Burzichelli, Space) - Exempts board of education and local government payments to entities under BPU jurisdiction from certain certification requirements

S-2145/A-631 (Van Drew, Madden/Moriarty, Burzichelli, Tucker, DeAngelo, Danielson, Mukherji) - Authorizes hiring preference for veterans in non-civil service jurisdictions

S-2301/A-3522 (Greenstein, Stack/Stender, Mukherji, Lagana, Diegnan) - Regulates pharmacy benefits managers and requires certain disclosures concerning multiple source generic drug pricing

S-2432/A-4720 (Madden/Moriarty, Mosquera) - Requires notification of member or retiree of State-administered retirement system under certain circumstances when member or retiree requests change in beneficiary for group life insurance

S-2453/A-3805 (Weinberg, Allen/Burzichelli, Singleton) - Requires earlier mandatory polling hours for school elections; requires discretionary additional polling hours be consistent with current primary and general elections

S-2523/A-3917 (Gill, Greenstein, Benson/DeAngelo, Johnson) - Permits municipalities and municipal parking authorities to create Senior Citizen Priority Parking Program

SCS for S-2586, 2587, A-3217, and 3218 (Stack, Cunningham, Mukherji, Pintor Marin, Garcia) - Requires certain sanitary and protective procedures for used mattresses

SCS for S-2668/A-4270 (Beach, Madden/Lampitt, Vainieri Huttle, Benson, Spencer, Wimberly, Mosquera) - Establishes "MVP Emergency Alert System" for missing persons with mental, intellectual, or developmental disabilities

SS for S-2770/AS for A-3956 (Sweeney, Addiego/Lampitt, Greenwald, Vainieri Huttle, Benson, Mazzeo) - Authorizes establishment of Achieving a Better Life Experience accounts for persons with certain disabilities

S-2940/A-4531 (Singer, Sweeney/Spencer, Benson, Casagrande, Muoio) - Creates new criminal offenses concerning endangering another person; repeals N.J.S.2C:12-2 and N.J.S.2C:24-7

S-2961/A-4188 (Codey, Vitale/Garcia, Lagana, Taliaferro, Vainieri Huttle, Danielsens, Holley, Benson, Jimenez) - Clarifies that Alzheimer's disease and related disorders may be listed as secondary cause of death on death certificate when appropriate

S-2978/A-4194 (Van Drew, Oroho/Burzichelli, Spencer, Rumana, Webber, Benson) - Authorizes mobile electronic waste destruction units to operate without DEP permit

S-3004/A-4685 (Cunningham, Van Drew/Andrzejczak, Johnson, Muoio, Wimberly) - Permits municipality with UEZ to participate in Downtown Business Improvements Zone Loan Fund

S-3076/A-4621 (Weinberg, Bateman/Johnson, Caride) - Increases maximum legal fee to represent victims from \$1,000 to \$3,000

S-3110/A-4617 (Scutari/Johnson, Webber) - Permits certain health clubs to offer swimming lessons and otherwise remain exempt from first aid personnel and lifeguarding requirements

S-3117/A-4781 (Gordon, Bateman, Sweeney, T. Kean/Vainieri Huttle, Eustace, Gusciora, Lampitt, Angelini, Moriarty) - Prohibits Division of Developmental Disabilities from compelling transfers of individuals with developmental disabilities from out-of-State to in-State facilities unless certain exceptions apply

S-3220/A-4790 (Sweeney, O'Toole, Vitale/Greenwald, Conaway, Vainieri Huttle, Handlin, Garcia) - Establishes a process to integrate certain health data and other data from publicly supported programs for population health research

S-3232/A-4834 (Sarlo, Oroho/Lagana, Burzichelli, Schaer, DeAngelo, Phoebus) - Allows businesses due to receive grant under Business Employment Incentive Program to receive tax credit instead of grant

S-3270/A-4705 (Gill, Bateman/Schaer, Coughlin, Lagana, S. Kean, Ciattarelli) - "Certificates of Insurance Act;" governs use of certificates of insurance; provides DOBI with enforcement authority

SJR-81/AJR-122 (Barnes/Vainieri Huttle, Schaer, Lampitt) - Condemns Boycott, Divestment, and Sanctions movement against Israel

A-308/S-2203 (Russo, Rumana/O'Toole, Smith) - Prohibits escrow agent evaluation services from charging escrow agents fees

A-1098/S-671 (Vainieri Huttle, Eustace, Diegnan, Giblin/Pou, Sarlo, Weinberg) - Requires DHS and DMVA to conduct or contract for follow-up studies of former residents transitioning to community from their facilities

A-1355/S-2963 (Stender, Lampitt, Holley, Moriarty/T. Kean, Vitale) - Requires DOH to provide information about crib safety on its Internet website

A-1783/S-2020 (McKeon, Rible, Sumter, Moriarty/Vitale, Cunningham) - "Art Therapist Licensing Act"

A-2023/S-2675 (Greenwald, Benson/Cruz-Perez) - Revises definition of "responsible charge" as it pertains to licensed professional engineers and licensed architects

A-2229 (Wisniewski, Diegnan) - Concerns contracts for asphalt work under the "Local Public Contracts Law"

A-2301/S-1481 (Andrzejczak/Van Drew) - Designates certain interchanges of Garden State Parkway in honor of Melvin M. Loftus and Christopher Meyer

A-3052/S-1090 (Mazzeo, Pinkin, Mukherji, Wimberly/A.R. Bucco, Whelan) - Concerns property taxes due and owing on real property damaged or destroyed during, or as the result of, a natural disaster when a state of emergency is declared by the Governor

A-3246/S-3069 (Dancer, Burzichelli, Vainieri Huttle/Oroho, Sarlo) - Requires timeframe of standardbred mare residing in New Jersey breeding farm be inclusive of foaling instead of between foal's conception and birth

A-3293/S-2146 (Mazzeo, Andrzejczak, Pinkin, Webber, Simon, Mukherji/Van Drew, Doherty) - Allows military personnel and veterans to present certain identifying documents in lieu of municipal beach tags to gain admission to certain beaches

A-3331/S-3111 (Benson, Rodriguez-Gregg, Coughlin/Gill, Beach) - Requires health benefits coverage for synchronization of prescribed medications under certain circumstances

A-3390/S-2309 (Coughlin, Pinkin, Webber, Diegnan/Vitale) - Permits transmittal of certain land use documents via email

A-3395/S-2294 (Wisniewski/Sacco) - Allows insurer to obtain certificates of ownership or salvage certificates of title for motor vehicles under certain circumstances

A-3499/S-2256 (Andrzejczak, Mazzeo, Johnson, Pinkin, DeAngelo/Van Drew) - Requires DMVA to encourage and facilitate returning service members' registration with VA

A-3507/S-2677 (Eustace, Webber, Munoz, Schepisi, Rumana/Gordon, Sarlo) - Amends law concerning county and municipal stream cleaning activities

A-3749/S-2568 (Lampitt, Mazzeo, Andrzejczak, Mukherji, Pinkin/Beach, Allen) - Establishes program to provide assistance to qualified veterans in in-patient and out-patient treatment programs to travel to medical counseling in State

A-3849/SCS for S-2466 (DeAngelo, Eustace, Mazzeo, Pintor Marin, Benson/Turner, Singer) - Requires BPU to provide links to pricing information to customers from electric and gas public utilities, and third-party electric power and gas suppliers

A-3950/S-2832 (Prieto, Jimenez, Quijano/Greenstein, Turner) - Permits correctional facilities to utilize body imaging scanning equipment

A-4079/S-2819 (Eustace, Andrzejczak, Taliaferro, Benson, Dancer/Van Drew, Beach) - Directs Department of Agriculture to publish on its website "New Jersey Gleaning Week" and "Farmers Against Hunger Day" page

A-4094/S-2884 (Conaway, Singleton, Wimberly, Lampitt, Benson/Whelan, Madden) - Permits administration of epinephrine auto-injector device by persons who complete approved educational program

A-4438/S-3202 (Mukherji, Burzichelli/Scutari, Madden) - Raises maximum workers' compensation fees for evaluating physicians

A-4518/S-3010 (Schaer, Eustace, Benson, Pintor Marin/Sarlo) - Modifies and clarifies provisions of certain economic incentive programs

AJR-57/SJR-42 (Space/Oroho) - Designates April of each year as "Sarcoidosis Awareness Month"

AJR-93/SJR-73 (Eustace, Andrzejczak, Taliaferro, Benson/Van Drew, Beach) - Designates third week of September as "New Jersey Gleaning Week"

AJR-94/SJR-74 (Eustace, Andrzejczak, Taliaferro, Benson/Van Drew, Beach) - Designates Wednesday of third week of September as "Farmers Against Hunger Day"

AJR-100/SJR-70 (Andrzejczak, Tucker, DeAngelo, Mazzeo/Van Drew, Whelan) - Designates first week in August of each year as "Coast Guard Week" and honors Cape May as U.S. Coast Guard's enlisted accession point and recruit training center

BILLS VETOED:

S-264/A-1347 (Greenstein, Cunningham/Stender, Egan, O'Donnell, Wimberly) – **ABSOLUTE** - "Thomas P. Canzanella Twenty First Century First Responders Protection Act"; concerns workers compensation for public safety workers

S-374/A-3403 (Scutari, Beck/Rible, DeAngelo, Mukherji) - **ABSOLUTE** - Concerns attorney fees for workers' compensation awards

SCS for S-779, 1952/ACS for A-2474 (Weinberg, Sarlo, Lesniak/Johnson, Garcia, Vainieri Huttie, Lagana, Mukherji, Moriarty) - **ABSOLUTE** - "Garden State Film and Digital Media Jobs Act" expands existing film and digital media production tax credit programs

S-995/A-1677 (Weinberg, Allen/Johnson, Vainieri Huttie, Lampitt, Mosquera) – **CONDITIONAL** - Establishes in DOC, supervised community reintegration program for certain victims of domestic abuse

S-1346/A-3837 (Rice/Coughlin, Garcia, Rodriguez-Gregg, Pintor Marin, Jasey) - **CONDITIONAL** - Concerns the recording of mortgages

S-2260/A-688 (Scutari, Cardinale/Schaer) - **CONDITIONAL** - Modifies certain fees charged by, and requirements imposed on, check casher licensees

S-2524/A-4067 (Gill, Allen/Lagana, Singleton, Moriarty) - **CONDITIONAL** - The "Municipal Volunteer Property Tax Reduction Act"; permits certain municipal property owners to perform volunteer services in return for property tax vouchers

S-2577/ACS for A-4139 (Stack, Schaer/Mazzeo, Andrzejczak, Mukherji, Quijano) - **CONDITIONAL** - Establishes temporary mortgage relief programs for certain owners of real property impacted by "Superstorm Sandy"

S-2867/A-4248 (Ruiz, Pou/Jasey, Sumter, Vainieri Huttie, Green, Holley, Wimberly) - **ABSOLUTE** - Permits municipal land banking in conjunction with online property database development

S-3024/A-4463 (Scutari/Giblin, Diegnan, Jimenez, Caputo, Vainieri Huttie) – **CONDITIONAL** - Revises laws concerning real estate licensees

S-3282/A-4850 (Rice, Cunningham/Wimberly, Mainor, Johnson) - **CONDITIONAL** - Expands Police Training Commission membership to include representative from Northern New Jersey and South Jersey Chapters of National Organization of Black Law Enforcement Executives

ACS for A-206, 471, 1663, 2879, 3060, and 3108/S-2663 (Green, Spencer, Gusciora, Johnson, McKeon, Giblin, Wimberly, Mainor, Quijano/Turner, Lesniak, Pou) - **CONDITIONAL** - Shortens waiting periods for expungement of criminal and other records and information; makes various changes to other expungement procedures and requirements

A-3257/S-2125 (Andrzejczak, Mazzeo, Burzichelli/Van Drew) - **CONDITIONAL** - Provides that determination by county agriculture development board or State Agriculture Development Committee as to what qualifies as farm-based recreational activity in pinelands protection area is binding on Pinelands Commission

A-4103/S-2840 (Mazzeo, Andrzejczak, Giblin/Allen, Whelan) - **ABSOLUTE** - Creates workforce training program for former casino workers

A-4233/S-2435 (Jasey, McKeon, Vainieri Huttie, Mukherji, Lampitt/Codey, Vitale) - **ABSOLUTE** - Provides Medicaid coverage for advance care planning

A-4275/S2831 (Prieto, Eustace, Lagana, Greewald, Quijano, Danielsen, Mukherji/Sweeney, Turner, Sarlo) – **CONDITIONAL** - "New Jersey Secure Choice Savings Program Act"; establishes retirement savings program for certain workers

A-4326/S-2942 (Schaer, Lagana, Eustace, Prieto/Gordon, Barnes) - **ABSOLUTE** - Reforms annual State revenue estimating and reporting, and executive State budget presentation and revenue certification processes

A-4386/S-3042 (Coughlin, Pinkin/Vitale, Singer) - **CONDITIONAL** - Permits candidates for school board to circulate petitions jointly and be bracketed together on ballot; permits short nonpolitical designation of principles on petitions and ballots; provides for study of impact of changes

A-4638/S-3118 (Vainieri Huttie, Singleton, Holley, Mosquera, Tucker, Benson/Sweeney, Madden) - **ABSOLUTE** - Requires DCPP to implement policies and procedures to ensure caseworker safety; "Leah's Law"

A-4703/S-3172 (Spencer, Tucker, Pintor Marin, Egan, Muoio, Gusciora/Rice, Smith) - **ABSOLUTE** - Increases tax credit cap by \$165 million for certain qualified residential projects under Economic Redevelopment and Growth Grant program and restricts increase to certain projects

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