

Senate Bill 184

By: Senators Hufstetler of the 52nd, Unterman of the 45th, Beach of the 21st, Thompson of the 14th and Albers of the 56th

A BILL TO BE ENTITLED
AN ACT

1 To amend Article 4 of Chapter 12 of Title 45 of the Official Code of Georgia Annotated,
2 relating to the Office of Planning and Budget, so as to establish the Integrated Population
3 Health Data Project; to create a governing board and provide for its membership and terms;
4 to provide for oversight of the project; to provide for board responsibilities; to provide for
5 reporting; to provide for funding; to provide for data sharing; to provide for immunity; to
6 provide for open records and meetings; to provide for related matters; to repeal conflicting
7 laws; and for other purposes.

8 BE IT ENACTED BY THE GENERAL ASSEMBLY OF GEORGIA:

9 style="text-align:center">**SECTION 1.**

10 Article 4 of Chapter 12 of Title 45 of the Official Code of Georgia Annotated, relating to the
11 Office of Planning and Budget, is amended by revising Part 3, which is reserved, as follows:

12 style="text-align:center">"Part 3

13 45-12-150.

14 As used in this part, the term:

15 (1) 'Aggregated data' means information that has been combined into groups showing
16 averages or other summary statistics, and that is not individually identifiable information
17 as defined in this part.

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

22 (3) 'Governing board' or 'board' means the board charged with responsibility for
23 governing the Integrated Population Health Data Project established pursuant to Code
24 Section 45-12-151.

25 (4) 'Health data' means information that is created or received by a governmental
 26 department or agency that relates to the past, present, or future physical or mental health
 27 or condition of an individual or the past, present, or future payment for the provision of
 28 health care to an individual.

29 (5) 'HIPAA' means the Health Insurance Portability and Accountability Act of 1996,
 30 Pub. L.104-191, and any regulations promulgated thereunder by the Secretary of the
 31 United States Department of Health and Human Services.

32 (6) 'Individually identifiable information' means information that identifies an individual,
 33 or with respect to which there is a reasonable basis to believe the information can be used
 34 to identify an individual.

35 (7) 'iPHD Project' means the Integrated Population Health Data Project established
 36 pursuant to Code Section 45-12-52.

37 (8) 'IRB' means an institutional review board designated by the governing board and
 38 established pursuant to federal regulations (45 C.F.R. 46) with a federal-wide assurance
 39 for the protection of human subjects approved by the United States Department of Health
 40 and Human Services, Office for Human Research Protections, to review and monitor
 41 research involving human subjects to ensure that the subjects are protected from harm
 42 and that the rights of subjects are adequately protected.

43 (9) 'Protected health information' has the same meaning as defined under HIPAA.

44 (10) 'Publicly supported programs data' means information relating to an individual's
 45 receipt of services from or through public support programs administered by a federal,
 46 state, or local government or by a private entity, including, but not limited to, an
 47 individual's participation in or eligibility for Temporary Assistance for Needy Families
 48 (TANF), Supplemental Nutrition Assistance Program (SNAP), the medical assistance
 49 program under Article 7 of Chapter 4 of Title 49, the PeachCare for Kids Program under
 50 Article 13 of Chapter 5 of Title 49, or other similar programs.

51 (11) 'Research' means a systematic investigation, including research development,
 52 testing, and evaluation, which is designed to develop or contribute to generalizable
 53 knowledge as defined pursuant to 45 C.F.R. 46.102(d).

54 (12) 'Researcher' means a private entity or public entity that conducts research under the
 55 review and monitoring of an IRB and has received approval from the data steward for the
 56 purpose of requested data elements.

57 45-12-151.

58 (a) The iPHD governing board is established in the Office of Planning and Budget.

59 (b)(1) The governing board shall consist of ten members, as follows:

60 (A) One member shall be the Director of the Georgia Health Policy Center, who shall
61 serve as a nonvoting, ex-officio member;

62 (B) One member shall be a public member appointed by the President of the Senate,
63 representing an organization capable of advocating on behalf of persons whose data
64 may be received, maintained, or transmitted by the iPHD Project in accordance with
65 this part;

66 (C) One member shall be a public member appointed by the Speaker of the House of
67 Representatives, with experience in human subjects research who is affiliated with a
68 research university in Georgia; and

69 (D) Two members shall be public members appointed by the Governor, as follows:

70 (A) An individual with legal expertise in protecting the privacy and security of
71 individually identifiable information; and

72 (B) An individual with technical expertise in the creation and maintenance of large
73 data systems and data security.

74 (2) The five remaining members shall be voting, ex-officio members representing the
75 commissioner of public health, or his or her designee, who shall serve as chairperson of
76 the board; the commissioner of community health, or his or her designee; the director of
77 the Office of Planning and Budget, or his or her designee; the state auditor, or his or her
78 designee; and a chief information officer from a state university, or his or her designee.

79 (c) Of the public members first appointed to the governing board, two shall be appointed
80 to terms of three years, one shall be appointed to a term of two years, and one shall be
81 appointed to a term of one year. Following the expiration of the initial terms, public
82 members of the board shall be appointed for terms of three years. The voting, ex-officio
83 members of the board shall serve during their respective terms of office. Any vacancy
84 occurring in the membership of the board shall be filled in the same manner as the original
85 appointment, but for the unexpired term only. The board shall meet at least quarterly, and
86 at such other times as it determines, in its judgment, to be necessary. The appointed
87 members of the board shall serve without compensation but may be reimbursed for
88 necessary expenses incurred in the performance of their duties. In addition, the board shall
89 be entitled to and avail itself of the assistance and services of the staff of the Office of
90 Planning and Budget, and of the employees of any other state department, board, bureau,
91 commission, or agency, as it may require and as may be available for its purposes.

92 (d) A member of the governing board shall not, by reason of the member's performance
93 of any duty, function, or activity required of, or authorized to be undertaken by, the board,
94 be liable in an action for damages to any person for any action taken or recommendation
95 made by the member within the scope of the member's duty, function, or activity as a
96 member of the board, if the action or recommendation was taken or made without malice.

97 The members of the board shall be indemnified and their defense of any action provided
98 for in the same manner and to the same extent as employees of this state on the basis of acts
99 or omissions in the scope of their service.

100 (e) A member of the governing board shall not participate in deliberations or vote on any
101 matter before the board concerning an individual or entity with which the member has, or
102 within the last 12 months has had, any substantial ownership, employment, medical staff,
103 fiduciary, contractual, creditor, or consultative relationship. A member who has or who
104 has had such a relationship with an individual or entity involved in any matter before the
105 board shall make a written disclosure before any action is taken by the board with respect
106 to the matter, and shall make the relationship public in any meeting in which action on the
107 matter is to be taken.

108 (f) The governing board shall be a public body for the purposes of Chapter 14 of Title 50,
109 relating to open and public meetings, and shall conduct its business in accordance with the
110 provisions of said part. All proceedings of the governing board shall be subject to Article 4
111 of Chapter 18 of Title 50, relating to inspection of public records.

112 45-12-152.

113 (a) No later than July 1, 2018, the Office of Planning and Budget with the assistance of
114 Georgia Health Policy Center shall establish an operational iPHD Project capable of
115 securely receiving, maintaining, and transmitting data in accordance with this part and the
116 HIPAA privacy and security standards applicable to this part. The Office of Planning and
117 Budget may employ staff to assist with carrying out the functions associated with the
118 establishment and maintenance of the iPHD Project.

119 (b) Notwithstanding any provision of this part to the contrary, the iPHD Project shall seek
120 to receive, maintain, and transmit de-identified data wherever possible, and shall only
121 receive, maintain, and transmit individually identifiable information if permitted by this
122 Code section and other applicable law and if the information is in a form and format that
123 is secured to prevent disclosure of individually identifiable information.

124 (c) A consortium of researchers from Georgia academic institutions and from medical
125 schools affiliated with Georgia universities may be organized by the Georgia Health Policy
126 Center to facilitate actionable population health research to help improve health outcomes
127 for Georgia residents, as well as promote Georgia's research institutions as leaders in social
128 science research.

129 45-12-153.

130 Oversight of the operations of the iPHD Project, established pursuant to Code
131 Section 45-12-152, shall be vested in the governing board. The iPHD Project shall receive,

132 maintain, and transmit data only as permitted by this part and approved by the governing
133 board and agency or department whose data is requested. The governing board's
134 responsibilities shall include:

135 (1) Identification of publicly supported programs data that has been created, received,
136 or maintained by agencies that may be appropriate for receipt, maintenance, and
137 transmission by the iPHD Project in furtherance of the purposes of this part;

138 (2) Prior to the receipt of data by the iPHD Project, the review and approval of the
139 appropriateness of such receipt, including consideration of the following factors:

140 (A) Whether the transmitting department or agency has authority to collect the data
141 proposed to be received by the iPHD Project, particularly if the data includes
142 individually identifiable information;

143 (B) Whether collection of the data proposed to be received by the iPHD Project is
144 expected to further the purpose of this part, namely, the improvement of public health,
145 safety, security, and well-being of Georgia residents and the improvement of the overall
146 cost efficiency of government assistance programs; and

147 (C) Whether reasonable efforts have been made to ensure that the iPHD Project will
148 receive only the appropriate data needed to accomplish the purposes of this part;

149 (3) Prior to the receipt or transmission of data by the iPHD Project, the review and
150 approval of any necessary data use agreements or business associate agreements with any
151 person or entity from which or to which information is received or transmitted in
152 compliance with all applicable privacy and security standards, including, but not limited
153 to, HIPAA, when such data includes individually identifiable information that is
154 protected health information as defined under HIPAA; and

155 (4) Adopting and publishing policies and procedures for the efficient and transparent
156 operation of the iPHD Project, including, but not limited to, the following:

157 (A) Privacy and data security policies and procedures that comply with the applicable
158 federal and state privacy and security statutes and regulations, including HIPAA;

159 (B) Data access policies and procedures that allow access by a public entity or a private
160 entity, including a researcher, only when such access request meets the standards set
161 forth in the data access policies and procedures and has been approved by the governing
162 board and the appropriate agency or department. When data access is requested by any
163 public or private entity, including a researcher, for the purpose of conducting research,
164 the governing board shall only approve access to data after review and approval by an
165 IRB, and such access shall be limited to data identified in approved IRB research
166 protocols and only for the period of the approval. In no event shall the governing board
167 approve access to health data that identifies, or that may be used to identify, rates of
168 payment by a private entity for the provision of health care services to an individual

169 unless the party seeking access agrees to keep such information confidential and to
 170 prevent public disclosure of such data or the rates of payment derived from such data;
 171 (C) Data retention policies identifying that data shall be returned to sponsoring
 172 agencies or destroyed when it is no longer in the state's interest to promote analysis of
 173 the data and in accordance with applicable HIPAA regulations, data use agreements,
 174 and provisions of IRB approvals;
 175 (D) Policies to require researchers to consult with subject matter experts in the data sets
 176 being linked on a specific project. The purpose of such consultation shall be to help
 177 researchers understand and interpret the data being linked for a specific project; and
 178 (E) Policies that establish processes to engage researchers and academic institutions
 179 across Georgia to help set research priorities and promote the use of the iPHD Project
 180 to accelerate population health research in this state.

181 45-12-154.

182 No later than January 1, 2019, upon the receipt of data by the iPHD Project pursuant to this
 183 part, and on an annual basis thereafter, the Georgia Health Policy Center, in consultation
 184 with the board, shall publish a report that is made available and accessible to the public and
 185 that contains the following information:

- 186 (1) A description of the implementation of the iPHD Project, including identification of
 187 the sources and types of data received and maintained by the iPHD Project over the
 188 prior 12 months;
 189 (2) A list of all aggregated data maintained by the iPHD Project;
 190 (3) A description of each IRB-approved disclosure of data or data sets by the iPHD
 191 Project;
 192 (4) A list of publications and other reports based on iPHD Project data;
 193 (5) A strategic plan for achieving the purposes of this part during the successive 12
 194 month period; and
 195 (6) Any other information deemed appropriate by the governing board.

196 45-12-155.

197 The iPHD Project governing board and the Georgia Health Policy Center may apply for
 198 and receive funding in relation to the iPHD Project from the following sources:

- 199 (1) Grants from research or other private entities;
 200 (2) Fees paid by persons or entities requesting access to iPHD Project data or the
 201 performance of analyses by the iPHD Project, which fees have been approved by the
 202 governing board to support the cost of preparing data for access or the performance of
 203 analyses;

204 (3) Federal grants; and

205 (4) Grants or other financial assistance from state or local departments, agencies,
206 authorities, and organizations at the discretion of these entities, for specific projects of
207 interest to these entities.

208 45-12-156.

209 Any department or agency that creates, receives, or maintains publicly supported programs
210 data or health data shall, only after execution of an enforceable data use, data sharing, or
211 other similar agreement that is acceptable to the department or agency, transmit or allow
212 access to such data as is necessary and appropriate to further the goals of this part and shall
213 cooperate with iPHD Project requests for receipt of, or access to, such data.
214 Notwithstanding the foregoing, no department or agency shall be required to transmit data
215 it creates, receives, or maintains to the iPHD Project, or to allow access to such data, if the
216 Attorney General's review or the applicable department's or agency's review determines
217 that such transmission or access would violate state or federal law. The Attorney General's
218 review shall include consideration of an analysis from the department or agency whose data
219 is being requested. This Code section shall not prohibit the Georgia Health Policy Center
220 or any department or agency from creating, receiving, maintaining, or transmitting data in
221 data systems that are separate and distinct from the iPHD Project."

222 **SECTION 2.**

223 All laws and parts of laws in conflict with this Act are repealed.