

House Bill 197

By: Representatives Dempsey of the 13th, Houston of the 170th, Gardner of the 57th, England of the 116th, and Powell of the 171st

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 provide for the establishment of the
3 Strategic Integrated Data System; to provide for definitions; to establish a governing board
4 and provide for its membership and terms; to provide for oversight of the operation of the
5 project by the governing board; to provide for data submission from state agencies and
6 departments; to provide for reporting; to provide for funding; to provide for related matters;
7 to repeal conflicting laws; and for other purposes.

8 BE IT ENACTED BY THE GENERAL ASSEMBLY OF GEORGIA:

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

21 (3) 'Governing board' or 'board' means the board established pursuant to Code Section
22 45-12-152 charged with oversight of the operation of the Strategic Integrated Data
23 System established pursuant to this part.

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

28 (5) 'HIPAA' means the federal Health Insurance Portability and Accountability Act of
29 1996, P.L. 104-191, and any regulations promulgated thereunder by the United States
30 secretary of health and human services.

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

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

40 (8) 'Protected health information' has the same meaning as provided for under HIPAA
41 in effect as of July 1, 2019.

42 (9) 'Research' means a systematic investigation, including research development, testing,
43 and evaluation, which is designed to develop or contribute to generalizable knowledge
44 as defined pursuant to 45 C.F.R. Section 46.102(d).

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

48 (11) 'SIDS Project' means the Strategic Integrated Data System established pursuant to
49 this part. Reserved.

50 45-12-151.

51 (a) No later than September 1, 2019, the Office of Planning and Budget shall establish an
52 operational Strategic Integrated Data System capable of securely receiving, maintaining,
53 and transmitting data in accordance with this part and with the HIPAA privacy and security
54 standards applicable to this part. The Office of Planning and Budget may employ staff to
55 assist with carrying out the functions associated with the establishment and maintenance
56 of the SIDS Project.

57 (b) The Office of Planning and Budget shall ensure the procurement of hardware,
58 software, and a data base system capable of performing analytics at scale and capable of
59 evaluating all data to the extent required to carry out the purposes of the SIDS Project

60 pursuant to this part. Further, the Office of Planning and Budget shall procure sufficient
61 management services to develop and maintain the system.

62 (c) Notwithstanding any provision of this part to the contrary, the SIDS Project shall seek
63 to receive, maintain, and transmit de-identified data wherever possible and shall only
64 receive, maintain, and transmit individually identifiable information if permitted by this
65 Code section and other applicable law and if the information is in a form and format that
66 are secured to prevent disclosure of individually identifiable information.

67 45-12-152.

68 (a) The Strategic Integrated Data System governing board is established in the Office of
69 Planning and Budget.

70 (b) The governing board shall consist of nine members as follows:

71 (A) One member shall be the director of the SIDS Project who shall serve as a
72 nonvoting, ex officio member;

73 (B) One member of the Senate appointed by the President of the Senate;

74 (C) One member of the House of Representatives appointed by the Speaker of the
75 House of Representatives;

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

77 (i) An individual with legal expertise in protecting the privacy and security of
78 individually identifiable information; and

79 (ii) An individual with technical expertise in the creation and maintenance of large
80 data systems and data security; and

81 (E) Four members shall be voting, ex officio members consisting of the commissioner
82 of public health or his or her designee, who shall serve as chairperson of the board; the
83 commissioner of community health or his or her designee; the director of the Office of
84 Planning and Budget or his or her designee; and the state auditor or his or her designee.

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

96 department, board, bureau, commission, or agency, as it may require and as may be
 97 available for its purposes.

98 (d) A member of the governing board shall not, by reason of the member's performance
 99 of any duty, function, or activity required of or authorized to be undertaken by the board,
 100 be liable in an action for damages to any person for any action taken or recommendation
 101 made by the member within the scope of the member's duty, function, or activity as a
 102 member of the board, if the action or recommendation was taken or made without malice.
 103 The members of the board shall be indemnified, and their defense of any action shall be
 104 provided for in the same manner and to the same extent as employees of this state on the
 105 basis of acts or omissions in the scope of their service.

106 (e) A member of the governing board shall not participate in deliberations or vote on any
 107 matter before the board concerning an individual with whom or entity with which the
 108 member has, or within the previous 12 months has had, any substantial ownership,
 109 employment, medical staff, fiduciary, contractual, creditor, or consultative relationship.
 110 A member who has or who has had such a relationship with an individual or entity
 111 involved in any matter before the board shall make a written disclosure before any action
 112 is taken by the board with respect to the matter and shall make the relationship known
 113 publicly at any meeting in which action on the matter is to be taken.

114 (f) The governing board shall be a public body for the purposes of Chapter 14 of Title 50,
 115 relating to open and public meetings, and shall conduct its business in accordance with the
 116 provisions of such chapter. All proceedings of the governing board shall be subject to
 117 Article 4 of Chapter 18 of Title 50, relating to inspection of public records.

118 45-12-153.

119 Oversight of the operation of the SIDS Project established pursuant to this part shall be
 120 vested in the governing board. The SIDS Project shall receive, maintain, and transmit data
 121 only as permitted by this part and as approved by the governing board and the state agency
 122 or department whose data are requested. The governing board's responsibilities shall
 123 include:

124 (1) Identification of data that have been created, received, or maintained by state
 125 agencies or departments that may be appropriate for receipt, maintenance, and
 126 transmission by the SIDS Project in furtherance of the purposes of this part;

127 (2) Prior to the receipt of data by the SIDS Project, review and approval of the
 128 appropriateness of such receipt, including consideration of the following factors:

129 (A) Whether the transmitting agency or department has authority to collect the data
 130 proposed to be received by the SIDS Project, particularly if the data include
 131 individually identifiable information;

132 (B) Whether collection of the data proposed to be received by the SIDS Project is
133 expected to further the purposes of this part, namely, the improvement of public health
134 and the safety, security, and well-being of Georgia residents; and
135 (C) Whether reasonable efforts have been made to ensure that the SIDS Project will
136 receive only the appropriate data needed to accomplish the purposes of this part;
137 (3) Prior to the receipt or transmission of data by the SIDS Project, review and approval
138 of any necessary data use agreements or business associate agreements with any person
139 or entity from which or to which information is received or transmitted in compliance
140 with all applicable privacy and security standards, including, but not limited to, HIPAA,
141 when such data include individually identifiable information that is protected health
142 information;
143 (4) Adopting and publishing policies and procedures for the efficient and transparent
144 operation of the SIDS Project, including, but not limited to, the following:
145 (A) Privacy and data security policies and procedures that comply with the applicable
146 federal and state privacy and security statutes and regulations, including HIPAA;
147 (B) Data access policies and procedures that allow access by a public or private entity,
148 including a researcher, only when such access request meets the standards set forth in
149 the data access policies and procedures and has been approved by the governing board
150 and the appropriate state agency or department. When data access is requested by any
151 public or private entity, including a researcher, for the purpose of conducting research,
152 the governing board shall only approve access to data after review and approval by an
153 IRB, and such access shall be limited to data identified in approved IRB research
154 protocols and only for the period of the approval. In no event shall the governing board
155 approve access to health data that identifies, or that may be used to identify, rates of
156 payment by a private entity for the provision of health care services to an individual
157 unless the entity seeking access agrees to keep such information confidential and to
158 prevent public disclosure of such data or the rates of payment derived from such data;
159 (C) Data retention policies requiring that data be returned to transmitting state agencies
160 or departments or destroyed when it is no longer in the state's interest to promote
161 analysis of such data and in accordance with applicable HIPAA regulations, data use
162 agreements, and provisions of IRB approvals;
163 (D) Policies to require researchers to consult with subject matter experts in the data sets
164 being linked on a specific project. The purpose of such consultation shall be to help
165 researchers understand and interpret the data being linked to a specific project; and
166 (E) Policies that establish processes to engage researchers and academic institutions
167 across Georgia to help set research priorities and promote the use of the SIDS Project
168 to accelerate population health research in this state;

169 (5) Communicating to all state agencies and departments that each state agency or
 170 department shall, upon request of the board, make available to the board through the
 171 SIDS Project all data housed within its respective office pursuant to policies established
 172 pursuant to this Code section;

173 (6)(A) Establishing the process by which each state agency or department is required,
 174 in consultation with the board, to identify and submit to the board a minimum of two
 175 distinct policy concerns that may be studied in an integrated information environment
 176 in order to identify evidence based solutions to such policy concerns; and

177 (B) Establishing procedures for ranking the submission and selection of such policy
 178 concerns considered by the board to be of greatest concern to the health, safety,
 179 security, and well-being of Georgia's citizens; and

180 (7) Establishing a process to set research priorities that utilize the SIDS Project to
 181 provide effective and efficient policy management for the state.

182 45-12-154.

183 (a) Any state agency or department that creates, receives, or maintains publicly supported
 184 program data or health data shall, only after execution of an enforceable data use, data
 185 sharing, or other similar agreement that is acceptable to the state agency or department,
 186 transmit or allow access to such data as is necessary and appropriate to further the purposes
 187 of this part and shall cooperate with SIDS Project requests for receipt of or access to such
 188 data. Notwithstanding the foregoing, any state agency or department shall not be required
 189 to transmit data which it creates, receives, or maintains to the SIDS Project or to allow
 190 access to such data if the Attorney General's review or the applicable state agency's or
 191 department's review determines that such transmission or access would violate state or
 192 federal law. The Attorney General's review shall include consideration of an analysis from
 193 the state agency or department whose data are being requested.

194 (b) This Code section shall not prohibit the Office of Planning and Budget or any agency
 195 or department from creating, receiving, maintaining, or transmitting data in data systems
 196 that are separate and distinct from the SIDS Project.

197 45-12-155.

198 No later than July 1, 2020, upon the receipt of data by the SIDS Project pursuant to this
 199 part, and on an annual basis thereafter, the Office of Planning and Budget, in consultation
 200 with the board, shall publish a report that is made available and accessible to the General
 201 Assembly consisting of:

- 202 (1) A description of the implementation of the SIDS Project, including identification of
 203 the sources and types of data received and maintained by the SIDS Project over the prior
 204 12 months;
 205 (2) A list of all aggregated data maintained by the SIDS Project;
 206 (3) A description of each IRB approved disclosure of data or data sets by the SIDS
 207 Project;
 208 (4) A list of publications and other reports based on SIDS Project data;
 209 (5) A strategic plan for achieving the purposes of this part during the successive 12
 210 month period; and
 211 (6) Any other information deemed appropriate by the governing board.

212 45-12-156.

- 213 (a) The governing board and the Office of Planning and Budget may apply for and receive
 214 funding in relation to the SIDS Project from the following sources:
 215 (1) Grants from research or other private entities;
 216 (2) Fees paid by persons or entities requesting access to SIDS Project data or the
 217 performance of analyses by the SIDS Project, which fees have been approved by the
 218 governing board to support the cost of preparing data for access or performing analyses;
 219 (3) Federal grants;
 220 (4) Grants or other financial assistance from state or local departments, agencies,
 221 authorities, and organizations at the discretion of such entities, for specific projects of
 222 interest to such entities; and
 223 (5) Appropriations made to the SIDS Project pursuant to the General Appropriations Act
 224 or a supplementary appropriations Act.
 225 (b) The governing board shall submit its budget to and through the Office of Planning and
 226 Budget."

227 **SECTION 2.**

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