

Procedures for Release by a State Agency of Statistical Information for Research Purposes

This Act establishes a procedure for the release by a state agency of statistical information for research purposes. Under this Act, a requestor of such information shall sign a data use agreement specifying certain limitations for the use of the information.

Submitted as:

New Hampshire

[Chapter 292, 2003](#)

Status: Enacted into law in 2003.

Suggested State Legislation

(Title, enacting clause, etc.)

1 Section 1. [*Short Title.*] This Act may be cited as the "Act Establishing a Procedure for
2 Release by a State Agency of Statistical Information for Research Purposes."

3

4 Section 2. [*Statement of Purpose.*]

5 I. The [legislature] recognizes that:

6 (a) Preserving the confidentiality of individually identifiable information in the
7 possession of the state is of great importance to our citizens;

8 (b) Openness in the conduct of public business is essential to a democratic
9 society;

10 (c) Information and data collected or maintained with public funds is held for the
11 collective benefit of the citizenry;

12 (d) Public policy can be improved and program administration can be made more
13 efficient and effective through analysis of information and data; and

14 (e) The collection and maintenance of reliable and comprehensive health care data
15 is necessary to promote informed decision-making, increase accountability in the health care
16 system, and improve health care planning.

17 II. Therefore, the [legislature] hereby determines that there is a need to collect encrypted
18 insurance claims data and to clarify the conditions under which limited data sets and health care
19 data and information that may relate to individual citizens may be released.

20

21 Section 3. [*Release of Statistical Tables and Limited Data Sets for Research:
22 Definitions.*]

23 I. As used in this Act:

24 (a) "Agency" means each state board, commission, department, institution, officer
25 or other state official or group.

26 (b) "Agency Head" means the head of any governmental agency which is
27 responsible for the collection and use of any data on persons or summary data.

28 (c) "Cell Size" means the count of individuals that share a set of characteristics
29 contained in a statistical table.

30 (d) "Data Set" means a collection of personal information on one or more
31 individuals, whether in electronic or manual files.

32 (e) "Direct Identifiers" means:

- 33 (1) Names.
 34 (2) Postal address information other than town or city, state, and zip code.
 35 (3) Telephone and fax numbers.
 36 (4) Electronic mail addresses.
 37 (5) Social security numbers.
 38 (6) Certificate and license numbers.
 39 (7) Vehicle identifiers and serial numbers, including license plate
 40 numbers.
 41 (8) Personal Internet IP addresses and URLs.
 42 (9) Biometric identifiers, including finger and voiceprints.
 43 (10) Personal photographic images.
- 44 (f) "Individual" means a human being, alive or dead, who is the subject of
 45 personal information and includes the individual's legal or other authorized representative.
- 46 (g) "Limited Data Set" means a data set from which all direct identifiers have
 47 been removed or blanked.
- 48 (h) "Personal Information" means information relating to an individual that is
 49 reported to the state or is derived from any interaction between the state and an individual and
 50 which:
- 51 (1) Contains direct identifiers.
 52 (2) Is under the control of the state.
- 53 (i) "Provided By Law" means use and disclosure as permitted or required by state
 54 law governing programs or activities undertaken by the state or its agencies, or required by
 55 federal law.
- 56 (j) "Public Record" means records available to any person without restriction.
- 57 (k) "State" means this state and its agencies or instrumentalities.
- 58 (l) "Statistical Table" means single or multivariate counts based on the personal
 59 information contained in a data set and which does not include any direct identifiers.

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 61 Section 4. [*Application and Data Use Agreement Procedures.*]

62 I. Except as otherwise provided by law, upon request an agency shall release limited data
 63 sets and statistical tables with any cell size more than 0 and less than 5 contained in agency files
 64 to requestors for the purposes of research under the following conditions:

- 65 (a) The requestor submits a written application that contains:
- 66 (1) The following information about the principal investigator in charge of
 67 the research:
- 68 (A) Name, address, and phone number;
 69 (B) Organizational affiliation;
 70 (C) Professional qualification; and
 71 (D) Name and phone number of principal investigator's contact
 72 person, if any.
- 73 (2) The names and qualifications of additional research staff, if any, who
 74 will have access to the data.
- 75 (3) A research protocol which shall contain:
- 76 (A) A summary of background, purposes, and origin of the
 77 research;
 78 (B) A statement of the general problem or issue to be addressed by
 79 the research;
 80 (C) The research design and methodology including either the
 81 topics of exploratory research or the specific research hypotheses to be tested;

82 (D) The procedures that will be followed to maintain the
83 confidentiality of any data or copies of records provided to the investigator; and

84 (E) The intended research completion date.
85 (4) The following information about the data or statistical tables being
86 requested:

87 (A) General types of information;
88 (B) Time period of the data or statistical tables;
89 (C) Specific data items or fields of information required, if
90 applicable;
91 (D) Medium in which the data or statistical tables are to be
92 supplied; and
93 (E) Any special format or layout of data requested by the principal
94 investigator.

95 (b) The requestor signs a "Data Use Agreement" signed by the principal
96 investigator that contains the following:

97 (1) Agreement not to use or further disclose the information to any person
98 or organization other than as described in the application and as permitted by the Data Use
99 Agreement without the written consent of the agency.

100 (2) Agreement not to use or further disclose the information as otherwise
101 required by law.

102 (3) Agreement not to seek to ascertain the identity of individuals revealed
103 in the limited data set and/or statistical tables.

104 (4) Agreement not to publish or make public the content of cells in
105 statistical tables in which the cell size is more than 0 and less than 5 unless:

106 (A) Otherwise provided by law; or
107 (B) The information is a public record.

108 (5) Agreement to report to the agency any use or disclosure of the
109 information contrary to the agreement of which the principal investigator becomes aware.

110 (6) A date on which the data set and/or statistical tables will be returned to
111 the agency and/or all copies in the possession of the requestor will be destroyed.

112
113 Section 5. [*Stipulations for Data Release.*]

114 I. The agency head shall release limited data sets and statistical tables and sign the Data
115 Use Agreement on behalf of the state when:

116 (a) The application submitted is complete.

117 (b) Adequate measures to ensure the confidentiality of any person are
118 documented.

119 (c) The investigator and research staff are qualified as indicated by:

120 (1) Documentation of training and previous research, including prior
121 publications; and

122 (2) Affiliation with a university, private research organization, medical
123 center, state agency, or other institution that will provide sufficient research resources.

124 (d) There is no other state law, federal law, or federal regulation prohibiting
125 release of the requested information.

126
127 Section 6. [*Agency Response; Denial.*] Within 10 days of a receipt of written application,
128 the agency head, or designee, shall respond to the request. Whenever the agency head denies
129 release of requested information, the agency head shall send the requestor a letter identifying the
130 specific criteria which are the basis of the denial. Should release be denied due to other law, the

131 letter shall identify the specific state law, federal law, or federal regulation prohibiting the
132 release. Otherwise the agency head shall provide the requested data or set a date on which the
133 data shall be provided.

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135 Section 7. [*Violations.*] Any person violating any provision of a signed Data Use
136 Agreement shall be guilty of a violation.

137

138 Section 8. [*Fees.*] Nothing in this Act shall exempt any requestor from paying fees
139 otherwise established by law for obtaining copies of limited data sets or statistical tables. Such
140 fees shall be based on the cost of providing the copy in the format requested. The agency head
141 shall provide the requestor with a written description of the basis for the fee.

142

143 Section 9. [*Severability.*] [Insert severability clause.]

144

145 Section 10. [*Repealer.*] [Insert repealer clause.]

146

147 Section 11. [*Effective Date.*] [Insert effective date.]