

# STATE OF NEW YORK

301

2021-2022 Regular Sessions

## IN SENATE

(Prefiled)

January 6, 2021

Introduced by Sen. THOMAS -- read twice and ordered printed, and when printed to be committed to the Committee on Health

AN ACT in relation to the collection of emergency health data and personal information and the use of technology to aid during COVID-19; and providing for the repeal of such provision upon the expiration thereof

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

- 1 Section 1. For the purposes of this act:
- 2 1. "Collect" means to buy, rent, gather, obtain, receive, or access
- 3 any personal information pertaining to an individual by any means,
- 4 online or offline, including but not limited to, receiving information
- 5 from the individual or from a third party, actively or passively, or
- 6 obtaining information by observing an individual's behavior.
- 7 2. "Covered entity" means any person, including a government entity:
- 8 (a) that collects, processes, or discloses emergency health data, as
- 9 defined in this act, electronically or through communication by wire or
- 10 radio; or
- 11 (b) that develops or operates a website, web application, mobile
- 12 application, mobile operating system feature, or smart device applica-
- 13 tion for the purpose of tracking, screening, monitoring, contact trac-
- 14 ing, or mitigation, or otherwise responding to the COVID-19 public
- 15 health emergency.
- 16 3. "De-identified information" means information that cannot reason-
- 17 ably identify, relate to, describe, be capable of being associated with,
- 18 or be linked, directly or indirectly, to a particular individual, house-
- 19 hold, or device. A covered entity that uses de-identified information:
- 20 (a) has implemented technical safeguards that prohibit re-identifica-
- 21 tion of the individual to whom the information may pertain;

EXPLANATION--Matter in italics (underscored) is new; matter in brackets [-] is old law to be omitted.

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1 (b) has implemented business processes that specifically prohibit  
2 re-identification of the information;

3 (c) has implemented business processes that prevent inadvertent  
4 release of de-identified information; and

5 (d) makes no attempt to re-identify the information.

6 4. "Disclose" means any action, set of actions, or omission in which a  
7 covered entity makes personal information available to another person,  
8 intentionally or unintentionally, including but not limited to, sharing,  
9 publishing, releasing, transferring, disseminating, making available,  
10 selling, leasing, providing access to, failing to restrict access to, or  
11 otherwise communicating orally, in writing, electronically, or by any  
12 other means.

13 5. "Emergency health data" means data linked or reasonably linkable to  
14 an individual, household, or device, including data inferred or derived  
15 about the individual, household, or device from other collected data  
16 provided such data is still linked or reasonably linkable to the indi-  
17 vidual, household, or device, that concerns the public COVID-19 health  
18 emergency. Such data includes:

19 (a) Information that reveals the past, present, or future physical or  
20 behavioral health or condition of, or provision of healthcare to, an  
21 individual including:

22 (i) data derived from the testing or examination;

23 (ii) whether or not an individual has contracted or been tested for,  
24 or an estimate of the likelihood that a particular individual may  
25 contract, such disease or disorder; and

26 (iii) genetic data, biological samples and biometrics; and

27 (b) Other data collected in conjunction with other emergency health  
28 data that can be used to infer health status, health history, location  
29 or associations, including:

30 (i) geolocation data, when such term means data capable of determining  
31 the past or present precise physical location of an individual at a  
32 specific point in time, taking account of population densities, includ-  
33 ing cell-site location information, triangulation data derived from  
34 nearby wireless or radio frequency networks and global positioning  
35 system data;

36 (ii) proximity data, when such term means information that identifies  
37 or estimates the past or present physical proximity of one individual or  
38 device to another, including information derived from Bluetooth, audio  
39 signatures, nearby wireless networks, and near field communications;

40 (iii) demographic data;

41 (iv) contact information for identifiable individuals or a history of  
42 the individual's contacts over a period of time, such as an address book  
43 or call log; and

44 (v) any other data collected from a personal device.

45 6. "Individual" means a natural person whom the covered entity knows  
46 or has reason to know is located in New York state.

47 7. "Personal information" means information that identifies, relates  
48 to, describes, is capable of being associated with, or could reasonably  
49 be linked, directly or indirectly, with a particular individual or  
50 household, or device.

51 8. "Process" means any operation or set of operations that are  
52 performed on personal data by either automated or not automated means.

53 9. "Public health authority" means the New York state department of  
54 health, a county health department or the New York city department of  
55 health and mental hygiene, or a person or entity acting under a grant of  
56 authority from or contract with such public agency, including the

1 employees or agents of such public agency or its contractors or persons  
2 to entities to whom it has granted authority, that is responsible for  
3 public health matters as part of its official mandate.

4 § 2. Individual rights.

5 1. The individual's right to opt-in. (a) A covered entity shall obtain  
6 freely given, specific, informed, and unambiguous opt-in consent from an  
7 individual to:

8 (i) process the individual's personal information or emergency health  
9 data; and

10 (ii) make any changes in the processing of the individual's personal  
11 information or emergency health data.

12 (b) It shall be unlawful for a covered entity to collect, process, or  
13 disclose emergency health data or personal information unless:

14 (i) the individual to whom the data pertains has freely given, specif-  
15 ic, informed, and unambiguous consent to such collection, processing, or  
16 disclosure; or

17 (ii) such collection, processing, or disclosure is necessary and for  
18 the sole purpose of:

19 (A) protecting against malicious, deceptive, fraudulent, or illegal  
20 activity; or

21 (B) detecting, responding to, or preventing security incidents or  
22 threats.

23 (c) To the extent that a covered entity must process internet protocol  
24 addresses, system configuration information, URLs of referring pages,  
25 locale and language preferences, keystrokes, and other personal informa-  
26 tion in order to obtain individuals' freely given, specific, informed,  
27 and unambiguous opt-in consent, the entity:

28 (i) shall only process the personal information necessary to request  
29 freely given, specific, informed, and unambiguous opt-in consent;

30 (ii) shall process the personal information solely to request freely  
31 given, specific, informed, and unambiguous opt-in consent; and

32 (iii) shall immediately delete the personal information if consent is  
33 withheld or withdrawn.

34 2. The individual's right to privacy. (a) All emergency health data  
35 and personal information shall be collected at a minimum level of iden-  
36 tifiability reasonably needed for the completion of the transaction  
37 disclosed to, affirmatively consented to, and requested by the individ-  
38 ual. For a covered entity using proximity tracing or exposure notifica-  
39 tion this includes changing temporary anonymous identifiers at least  
40 once in a 20 minute period.

41 (b) A covered entity shall not process personal information or emer-  
42 gency health data beyond what is adequate, relevant, and necessary for  
43 the completion of the transaction disclosed to, affirmatively consented  
44 to, and requested by the individual.

45 (c) A covered entity shall not process emergency health data or  
46 personal information for any purpose not authorized under this act,  
47 including:

48 (i) commercial advertising, recommendation for e-commerce, or the  
49 training of machine learning algorithms related to, or subsequently for  
50 use in, commercial advertising and e-commerce;

51 (ii) soliciting, offering, selling, leasing, licensing, renting,  
52 advertising, marketing, or otherwise commercially contracting for  
53 employment, finance, credit, insurance, housing, or education; or

54 (iii) segregating, discriminating in, or otherwise making unavailable  
55 the goods, services, facilities, privileges, advantages, or accommo-  
56 dations of any place of public accommodation (as such term is defined in

1 section 301 of the Americans with Disabilities Act of 1990), except as  
2 authorized by a state or federal government entity for a public health  
3 purpose; provided that a covered entity shall not process emergency  
4 health data or personal information to make categorical decisions about  
5 the allocation of care based on disability.

6 3. Covered entity privacy policy. (a) A covered entity shall provide  
7 to the individual a privacy policy, at a fourth grade reading level or  
8 below and in the language the entity regularly uses to communicate with  
9 the individual, prior to or at the point of collection of emergency  
10 health data or personal information:

11 (i) detailing how and for what purpose the covered entity collects,  
12 processes, and discloses emergency health data and personal information;

13 (ii) describing the covered entity's data retention and data security  
14 policies and practices for emergency health data and personal informa-  
15 tion; and

16 (iii) describing how an individual may exercise rights under this  
17 section.

18 (b) A covered entity shall create transparency reports, at least once  
19 every 90 days, that include:

20 (i) the number of individuals whose emergency health data or personal  
21 information the covered entity collected or processed;

22 (ii) the categories of emergency health data and personal information  
23 collected, processed, or disclosed;

24 (iii) the purposes for which each category of emergency health data or  
25 personal information was collected, processed, or disclosed;

26 (iv) the number of requests for individuals' emergency health data or  
27 personal information, including information on who the emergency health  
28 data or personal information was disclosed to; and

29 (v) the number of instances where emergency health data or personal  
30 information was produced, in whole or in part, without prior, explicit  
31 consents by the individuals specified in the request.

32 (c) The covered entity shall make each transparency report persistent-  
33 ly available and readily accessible on such entity's website.

34 4. Time limitation on retention. (a) Emergency health data and  
35 personal information shall be deleted when the initial purpose for  
36 collecting or obtaining such data has been satisfied or within 30 days,  
37 whichever occurs first, except that proximity tracing or exposure  
38 notification data which shall be automatically deleted every 14 days.

39 (b) This subdivision shall not apply to de-identified information.

40 5. Access rights. (a) Emergency health data and personal information  
41 shall be disclosed only as necessary to provide the service requested by  
42 an individual.

43 (b) A covered entity may share aggregate, de-identified data with  
44 public health authorities.

45 (c) A covered entity shall not disclose emergency health data or  
46 personal information to a third party unless that third party is  
47 contractually bound to the covered entity to meet the same privacy and  
48 security obligations as the covered entity.

49 (d) No covered entity in possession of emergency health data or  
50 personal information may disclose, redisclose, or otherwise disseminate  
51 an individual's emergency health data or personal information unless the  
52 subject of the emergency health data or personal information or the  
53 subject's legally authorized representative consents in writing to the  
54 disclosure or redisclosure.

55 (e) Without consent under subdivision one of this section, emergency  
56 health data, personal information, and any evidence derived therefrom

1 shall not be subject to or provided in response to any legal process or  
2 be admissible for any purpose in any judicial or administrative action  
3 or proceeding.

4 (f) Individuals shall have the right to access the emergency health  
5 data and personal information collected on them and correct any inaccuracies.  
6

7 (i) A covered entity must comply with an individual's request to  
8 correct emergency health data or personal information not later than 30  
9 days after receiving a verifiable request from the individual or, in the  
10 case of a minor, the individual's parent or guardian.

11 (ii) Where the covered entity has reasonable doubts or cannot verify  
12 the identity of the individual making a request under this paragraph,  
13 the covered entity may request additional information necessary for the  
14 specific purpose of confirming the identity of the individual. In such  
15 cases, the additional information shall not be processed for any purpose  
16 other than verifying the identity of the individual and must be deleted  
17 immediately upon verification or failure to verify the individual.

18 § 3. 1. A covered entity shall implement reasonable measures to ensure  
19 confidentiality, integrity, and availability of emergency health data  
20 and personal information.

21 2. A covered entity that collects an individual's emergency health  
22 data or personal information shall implement and maintain reasonable  
23 security procedures and practices, including administrative, physical,  
24 and technical safeguards, appropriate to the nature of the information  
25 and the purposes for which that information will be processed, to  
26 protect that information from unauthorized processing, disclosure,  
27 access, destruction, or modification.

28 3. A covered entity shall limit access to emergency health data and  
29 personal information to authorized essential personnel whose use of the  
30 data is reasonably necessary to operate the program and record who has  
31 accessed emergency health data or personal information, the date of  
32 access, and for what purposes.

33 § 4. 1. All covered entities shall be subject to annual data  
34 protection audits, conducted by a neutral third party auditor, evaluating  
35 the technology utilized and the development processes for statistical  
36 impacts on classes protected under section 296 of article 15 of  
37 the executive law, as well as for impacts on privacy and security, that  
38 includes at a minimum:

39 (a) a detailed description of the technology, its design, and its  
40 purpose;

41 (b) an assessment of the relative benefits and costs of the technology  
42 in light of its purpose, taking into account relevant factors including  
43 data minimization practices; the duration for which personal information  
44 and emergency health data and the results of the data analysis are  
45 stored; what information about the technology is available to the  
46 public; and the recipients of the results of the technology;

47 (c) an assessment of the risk of harm posed by the technology; the  
48 risk that the technology may result in or contribute to inaccurate,  
49 unfair, biased, or discriminatory decisions; the risk that the technology  
50 may dissuade New Yorkers from participating in contact tracing or  
51 obtaining medical testing or treatment; and the risk that personal  
52 information or emergency health data can be accessed by third parties,  
53 including, but not limited to law enforcement agencies and U.S. Immigration  
54 and Customs Enforcement; and

1 (d) the measures the covered entity will employ to minimize the risks  
2 described in paragraph (c) of this subdivision, including technological,  
3 legal and physical safeguards;

4 (e) an assessment of whether the covered entity has followed through  
5 on the promises made in its privacy notice regarding collection, access,  
6 sharing, retention, deletion and sunseting; and

7 (f) if the technology utilizes machine-learning systems, a description  
8 of the training data information.

9 2. The covered entity shall make the audit persistently available and  
10 readily accessible on such entity's website.

11 3. The cost of the audit shall be paid by the covered entity.

12 § 5. The attorney general may bring an action in the name of the  
13 state, or as parens patriae on behalf of persons residing in the state,  
14 to enforce the provisions of this act. In an action brought by the  
15 attorney general, the court may award injunctive relief, including  
16 preliminary injunctions, to prevent further violations of and compel  
17 compliance with this act; civil penalties up to twenty-five thousand  
18 dollars per violation or up to four percent of annual revenue; other  
19 appropriate relief, including restitution, to redress harms to individ-  
20 uals or to mitigate all substantial risk of harm; and any other relief  
21 the court determines.

22 § 6. Severability. If any clause, sentence, paragraph, subdivision,  
23 section or part of this act shall be adjudged by any court of competent  
24 jurisdiction to be invalid, such judgment shall not affect, impair, or  
25 invalidate the remainder thereof, but shall be confined in its operation  
26 to the clause, sentence, paragraph, subdivision, section or part thereof  
27 directly involved in the controversy in which such judgment shall have  
28 been rendered. It is hereby declared to be the intent of the legislature  
29 that this act would have been enacted even if such invalid provisions  
30 had not been included herein.

31 § 7. This act shall take effect on the thirtieth day after it shall  
32 have become a law and shall expire and be deemed repealed January 1,  
33 2024.