

STATE OF NEW YORK

5927

2021-2022 Regular Sessions

IN SENATE

March 23, 2021

Introduced by Sens. HOYLMAN, RIVERA, BIAGGI, BRISPORT, BROUK, COMRIE, COONEY, HARCKHAM, HINCHEY, JACKSON, LIU, MANNION, MAY, MAYER, MYRIE, PERSAUD, RAMOS, REICHLIN-MELNICK, SALAZAR, SANDERS, STAVISKY -- read twice and ordered printed, and when printed to be committed to the Committee on Health

AN ACT to amend the public health law, in relation to enacting the New York State COVID-19 Health Registry Act

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

1 Section 1. Article 21 of the public health law is amended by adding a
2 new title 9 to read as follows:

3 TITLE 9

4 New York State COVID-19 Health Registry

5 Section 2185. Legislative findings and purpose.

6 2185-a. Definitions.

7 2185-b. New York state COVID-19 health registry.

8 2185-c. Enrollment and eligibility.

9 2185-d. Confidentiality.

10 2185-e. Annual report.

11 § 2185. Legislative findings and purpose. 1. The legislature hereby
12 finds, determines and declares that COVID-19 has had a devastating
13 impact on the state of New York. Since the first recorded death of a
14 New York resident from the virus on March fourteenth, two thousand twenty,
15 tens of thousands of New Yorkers have lost their lives to COVID-19,
16 and over one and a half million confirmed cases have been diagnosed as
17 of the effective date of this article. The sudden emergence and rapid
18 spread of COVID-19 around the world has led to an evolving understanding
19 of the transmissibility, virulence, and symptoms of the virus by scien-
20 tists and public health experts that continues to this day. Questions
21 remain as to why approximately eighty percent of those infected with
22 COVID-19 experience mild to no symptoms, while the remainder experience

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

LBD09897-01-1

1 a more severe response that can result in hospitalization or death, and
2 weeks-long recoveries for those who survive. There is also growing
3 awareness and concern about post-acute COVID-19 syndrome, sometimes
4 referred to as "long COVID," in which a small but significant percentage
5 of patients experience persistent symptoms weeks or months after recov-
6 ering from their initial infection.

7 It is vital that the state of New York commit to monitoring and track-
8 ing the long-term health impacts of COVID-19, even as effective vaccines
9 become more widely available. The establishment of a voluntary registry
10 of New Yorkers who survived COVID-19 infection holds the promise of
11 providing public health experts with a database of information that may
12 lead to a better understanding of trends in long-term illness and recov-
13 ery, and the needs of survivors, particularly those suffering from post-
14 acute COVID-19 syndrome.

15 § 2185-a. Definitions. As used in this title:

16 1. "COVID-19" means infection with or the disease caused by the severe
17 acute respiratory syndrome coronavirus 2 (SARS-CoV-2);

18 2. "Registry" means the COVID-19 health registry established by this
19 title.

20 § 2185-b. New York state COVID-19 health registry. The department is
21 hereby authorized and directed to establish a voluntary statewide
22 COVID-19 health registry for the purpose of monitoring the long-term
23 health impacts of the virus. The registry shall serve, and shall be
24 administered consistent with, the following public health purposes:

25 1. Monitoring the long-term physical and mental health impacts of
26 COVID-19 infections, including, but not limited to, post-acute COVID-19
27 syndrome;

28 2. Periodically surveying registry enrollees to gather relevant infor-
29 mation for the purposes of monitoring the long-term physical and mental
30 health impacts of COVID-19 infections;

31 3. Sharing, subject to the confidentiality requirements of section
32 twenty-one hundred eighty-five-d of this title and any other applicable
33 state or federal laws or regulations, de-identified survey data or other
34 registry information with researchers for the purpose of medical, public
35 health or other scientific research. As a condition of sharing such data
36 or information, any subsequently published studies, reports or findings
37 that used such data or information shall be made available at no charge
38 to the public on the department's website; and

39 4. Providing enrollees with information about COVID-19-related health
40 studies, programs, benefits, and other relevant information.

41 § 2185-c. Enrollment and eligibility. 1. The initial enrollment period
42 for the registry shall begin ninety days after the effective date of
43 this section. The commissioner may set a date upon which the initial
44 enrollment period ends, but such date shall not be prior to one year
45 after the initial enrollment period begins.

46 2. The commissioner may, at his or her discretion, order additional
47 enrollment periods subsequent to the initial enrollment period, of such
48 lengths as he or she determines.

49 3. The commissioner shall promulgate regulations to establish eligi-
50 bility for enrollment in the registry. Eligible participants shall, at a
51 minimum, include New York residents who receive a diagnosis of post-a-
52 cute COVID-19 syndrome made by an individual licensed to provide health
53 care services within the state of New York.

54 § 2185-d. Confidentiality. 1. All registry information shall be kept
55 confidential by the department and may not be disclosed except for a
56 permitted purpose.

1 2. The commissioner shall promulgate regulations establishing permit-
2 ted purposes and uses of registry information.

3 (a) All such regulations shall maintain the anonymity of individuals
4 enrolled in the registry and govern access to information maintained by
5 the registry.

6 (b) It shall not be a permitted purpose for the department or any
7 authorized user of the registry to provide information contained in the
8 registry with immigration authorities.

9 3. The registry shall comply with all state and federal laws and regu-
10 lations related to maintaining the privacy and confidentiality of
11 records contained with the registry.

12 § 2185-e. Annual report. The commissioner shall submit on or before
13 December first, an annual report to the governor and the legislature
14 concerning the operation of the registry. The first such report required
15 under this section shall be published on December first of the calendar
16 year following the commencement of the initial enrollment period for the
17 registry, and shall include strategies for implementation of the regis-
18 try and for promoting the registry to the general public, with a partic-
19 ular focus on eligible enrollees belonging to racial or ethnic groups
20 that have been disproportionately impacted by the COVID-19 pandemic.
21 Subsequent annual reports shall include the findings of any surveys
22 conducted by the department of registry enrollees, the findings of any
23 scientific studies, papers, or reports produced using data or informa-
24 tion collected in the registry, and recommendations for state action to
25 address health issues or trends identified by the department.

26 § 2. This act shall take effect on the ninetieth day after it shall
27 have become a law.