SENATE COMMITTEE ON HEALTH
Senator Dr. Richard Pan, Chair

BILL NO: SB 744
AUTHOR: Glazer
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HEARING DATE: April 21, 2021
CONSULTANT: Melanie Moreno

SUBJECT: Communicable diseases: respiratory disease information

SUMMARY: Requires any electronic tool used by local health officers for the purpose of reporting cases of communicable respiratory disease to the California Department of Public Health (CDPH) to include data related to housing, occupation and workplace, and recent travel of the patient. Requires CDPH to collect and make specified information publicly available in cases of communicable respiratory disease.

Existing law:

1) Requires CDPH to examine the causes of communicable disease in man and domestic animals occurring or likely to occur in this state. [HSC §120125]

2) Requires CDPH to establish a list of reportable diseases and conditions to be properly reported as required to CDPH by local health officers (LHOs). Requires CDPH to specify the timeliness requirements related to the reporting of each disease and condition, and the mechanisms required for, and the content to be included in, reports made. Permits the list to include both communicable and non-communicable diseases. Permits the list to be modified at any time by CDPH, after consultation with the California Conference of Local Health Officers. [HSC §120130]

3) Requires, through regulation, every health care provider, knowing of or in attendance on a case or suspected case of any reportable diseases or conditions, to report to the LHO for the jurisdiction where the patient resides. Permits any individual having knowledge of a person who is suspected to be suffering from one of the diseases to make such a report to the LHO for the jurisdiction where the patient resides when there is no health care provider in attendance. Defines "health care provider" as a physician and surgeon, a veterinarian, a podiatrist, a nurse practitioner, a physician assistant, a registered nurse, a nurse midwife, a school nurse, an infection control practitioner, a medical examiner, a coroner, or a dentist. [17 CCR §2500]

4) Requires, through regulation, each report made pursuant in 3) above to include all of the following information if known: [17 CCR §2500(d)]

    a) The name of the disease or condition being reported;
    b) The date of onset;
    c) The date of diagnosis;
    d) The name, address, telephone number, occupation, race/ethnic group, Social Security number, gender, pregnancy status, age, and date of birth for the case or suspected case;
    e) The date of death if death has occurred; and,
    f) The name, address and telephone number of the person making the report.

5) Prohibits, through regulation, information reported pursuant to the communicable disease reporting requirements from being disclosed by the LHO except as authorized by regulations, as required by state or federal law, or with the written consent of the individual to whom the information pertains or the legal representative of the individual. Permits an LHO, for purposes of his or her investigation, to disclose any information, including personal information, contained in an individual case report as may be necessary to prevent the spread of disease or occurrence of additional cases. [17 CCR §2502(f)]

6) Requires, through regulation, an administrator of each health facility, clinic, or other setting where more than one health care provider may know of a case, a suspected case or an outbreak of disease within the facility, to establish and be responsible for administrative procedures to assure that reports are made to the LHO. [17 CCR §2500(c)]

7) Requires, through regulation, each clinical laboratory director, or the laboratory director's designee, an approved public health laboratory, or a veterinary laboratory, to report findings of specified communicable diseases and conditions to the LHO of the local health jurisdiction (LHJ) where the health care provider who first submitted the specimen is located. Requires the laboratory, if the patient residence is unknown, to notify the LHO of the jurisdiction in which the health care provider is located. [17 CCR §2505]

8) Requires LHOs to immediately report to CDPH every discovered or known case or suspect case of a designated disease. Requires LHOs to make reports that CDPH requires within 24 hours after investigation. [HSC §120190]

This bill:

1) Requires any electronic tool used by LHOs for the purpose of reporting cases of communicable disease to CDPH to include:

    a) The type of housing where the patient resides;
    b) The number of people in the household where the patient resides;
    c) The occupation and workplace of the patient; and,
    d) The cities that the patient has traveled to in the previous 14 days.

2) Requires health care providers who know of, or are in attendance on, a case or suspected case of any of reportable communicable respiratory diseases or conditions to report the information in 1) above to the LHO for the jurisdiction where the patient resides.

3) Requires CDPH to collect and make publicly available, in machine-readable form, information collected in cases of communicable respiratory disease.

4) Requires CDPH, during a declared public health emergency, to make publicly available, in the same form, a weekly summary of the information, by county, in cases of communicable respiratory disease.

5) Requires CDPH to remove from the reports all of the information listed in the Safe Harbor provisions of the federal Health Insurance Portability and Accountability Act (HIPAA).

FISCAL EFFECT: This bill has not been analyzed by a fiscal committee.

COMMENTS:

1) *Author's statement.* According to the author, more than a year after the start of the COVID-19 Pandemic, we still don't know how and where the virus is most likely to spread and which measures are most effective in stopping it. This is because we lack the data necessary to support sound scientific research. Without that science, policymakers and the public are flying blind, and our essential workers and vulnerable populations are put at even more risk. Much of the data we need is already collected by the state. We should make that information available to researchers and the public after removing identifying information to protect the privacy of individuals. We also need more data. The state asks basic questions about the housing, and work status of people who test positive. But without more detail, that data is of little help. We need to ask smart questions to get answers that can drive smart policy.

2) *COVID-19 public health emergency.* On March 11, 2020, the novel Coronavirus (SARS-CoV-2), which causes the infection known as COVID-19, was declared a global pandemic and set in motion public health emergency declarations across the U.S. The COVID-19 outbreak was declared a nationwide public health emergency on January 31, 2020 (retroactive to January 27, 2020), and a national emergency on March 13, 2020. On March 4, 2020, Governor Newsom declared a state of emergency to make additional resources available, formalize emergency actions already underway across multiple state agencies, and help the state prepare for broader spread of COVID-19. The U.S. Department of Health and Human Services has indicated the federal public health emergency is likely to remain in place for the entirety of 2021. As of April 15, 2021, COVID19.CA.GOV reports 3,608,898 positive cases of COVID-19 and 59,508 deaths in California, with a disproportionate impact on communities of color. The data indicates that white people represent 20% of cases and 31% of deaths compared to non-white people who represent 70% of cases and 67% of deaths. Latino people represent 56% of cases and 47% of deaths, Black people represent 4% of cases and 6% of deaths, and Asian people represent 7% of cases and 12% of deaths.

3) *Existing reporting mechanisms.* According to CDPH, its Division of Communicable Disease Control (DCDC) works to promptly identify, prevent, and control infectious diseases that pose a threat to public health. CDPH works with LHJs to implement infectious disease control at the local level through the 61 LHJs in California, one in each of the 58 counties and three in Berkeley, Long Beach, and Pasadena. DCDC identifies, monitors, prevents and controls communicable diseases that pose a threat to public health, including emerging and re-emerging infectious diseases, vaccine-preventable diseases, tuberculosis, sexually-transmitted diseases, and diseases caused by toxins, bioterrorism, and pandemics. DCDC works with LHJs on 90 reportable diseases, including recently added COVID-19. These reportable diseases and conditions are reported by health care providers and laboratories to LHJs and the statewide electronic disease reporting system, called the California Reportable Disease Information Exchange (CalREDIE). LHJ staff also enter case information into CalREDIE or report via other mechanisms to CDPH.

4) *CalREDIE*. CalREDIE is CDPH's electronic disease reporting and surveillance system. According to CDPH, CalREDIE allows for 24/7/365 reporting and receipt of notifiable conditions. LHJs and CDPH have access to disease and laboratory reports in near real-time for disease surveillance, public health investigation, and case management activities. Coordinated by the California Disease Emergency Response Program within DCDC, the CalREDIE system is widely utilized by LHJs and healthcare providers. Additionally, over 3200 facilities (including clinical and commercial labs, skilled nursing facilities, and schools) electronically submit reportable lab results to public health through CalREDIE Electronic

Laboratory Reporting. All 61 of California's LHJs use CalREDIE in some capacity, and 58 LHJs use the system for surveillance of all notifiable communicable diseases. According to CDPH, although Los Angeles and San Diego Counties do not use CalREDIE for reporting their COVID-19 cases, CDPH captures this data through other mechanisms. CDPH states that 61% of COVID-19 cases are reported in CalREDIE. In August 2020, the Newsom Administration announced that it would establish a separate data reporting system for COVID-19 cases following issues with CalREDIE that resulted in a backlog and delay in reporting. CDPH entered into a six-month, $15.3 million agreement with OptumInsight, Inc. (using federal funding) to handle the surge in reportable disease cases resulting from the pandemic. The Optuminsight contract was renewed for an additional 12 months, and they continue processing all electronic lab results sent to CalREDIE.

5) *HIPAA Privacy Rule and "safe harbor" deidentification*. The HIPAA Privacy Rule establishes national standards to protect individuals' medical records and other personal health information, and applies to health insurance plans, health care clearinghouses (which are organizations that process health information and convert data into types that conform to HIPAA standards), and health care providers such as hospitals, doctors and pharmacies that transmit health information electronically (collectively, these are called "covered entities"), as well as business associates of covered entities. Under HIPAA, health information that "does not identify an individual and with respect to which there is no reasonable basis to believe that the information can be used to identify an individual" is not individually identifiable health information. HIPAA permits a covered entity to determine that health information is not individually identifiable only if one of the following two deidentification methods are used:

   a) *Expert determination*. Under this method, a person with appropriate knowledge of and experience with generally accepted statistical principles and methods for rendering information not individually identifiable, applying such principles and methods, determines that the risk is very small that the information could be used, alone or in combination with other reasonably available information, by an anticipated recipient to identify an individual who is a subject of the information. The expert is required to document the methods and results of the analysis that justify such a determination; or,

   b) *Safe harbor*. Under this method, a long list of identifiers of the individual or of relatives, employers, or household members of the individual, are removed, including: all geographic subdivisions smaller than a State except for the initial three digits of a zip code; all elements of dates directly related to an individual, including admission or discharge date or dates of birth; device identifiers and serial numbers; health plan beneficiary numbers; and so on.

   HIPAA also provides for a mechanism for reidentification by permitting a covered entity to assign a code or other means of record identification to allow information deidentified to be reidentified by the covered entity, provided that the code or other means of record identification is not derived from or related to information about the individual, and the covered entity does not use or disclose the code or other means of record identification for any other purpose and does not disclose the mechanism for reidentification.

6) *Double referral*. This bill has been double referred. Should it pass out of this Committee, it will be referred to the Committee on Judiciary.

7) *Prior legislation.* SB 932 (Weiner, Chapter 183, Statutes of 2020) requires any electronic tool used by LHOs for the purpose of reporting cases of communicable disease to CDPH to include the capacity to collect and report data relating to the sexual orientation and gender identity of individuals who are diagnosed with a reportable disease, and requires health care providers who are in attendance on a case of a reportable disease to report the patient's sexual orientation and gender identity, if known.

   AB 262 (Gloria and Gonzalez, Chapter 798, Statutes of 2019) requires LHOs, during an outbreak of a communicable disease, or upon the imminent and proximate threat of a communicable disease outbreak or epidemic that threatens the public's health, to notify and update governmental entities within the LHO's jurisdiction, as specified, and make relevant information available to governmental entities, as specified.

8) *Support*. Several individual researchers wrote in support, stating that CDPH should update the data it collects for respiratory disease and routinely make those data available to the general public, researchers and public health specialists including the communication of regular summary statistics. These individuals state that the lack of currently available comprehensive and timely data has greatly hampered our efforts to control effectively the current COVID-19 pandemic in California resulting in the unnecessary loss of life and livelihood. The California Teachers Association writes that creating more transparency around the data will improve trust, establish a path to hold government accountable to the decisions they make, and prioritize safety.

9) *Opposition*. The County Health Executives Association of California and the Health Officers Association of California write that publishing individual data points, even with the removal of some identifying information, could reasonably lead to the identification of an individual – a violation of their privacy. LHOs rely on health providers to report timely disease case information in order to monitor the health of our local communities, and being required to provide additional data erodes the trust of both the medical community and the public. Consumer privacy organizations write that the HIPAA Safe Harbor is inadequate to protect the trove of sensitive individual information that this bill will generate, and researchers have borne out that concern time and time again. Making personal information anonymous by removing data identifiers—things like names, SSN, and other data that obviously identifies a person — seems easy in theory. In practice, though, it is often not only possible but relatively easy to reidentify the data by cross-referencing the supposedly anonymized data to other databases that contain identifiers but no sensitive information. Consumer privacy organizations state that even "HIPAA-compliant" deidentified datasets have been demonstrated to be reidentifiable. Of particular concern to researchers was location information, which was found to significantly increase the risk of re-identification. Under this bill, the individual household information, workplace information and 14-day travel record is comparable to location information and could be similarly revealing.

SUPPORT AND OPPOSITION:

Support: California Teachers Association
Seven Individuals

Oppose: ACLU of California
Consumer Federation of America
County Health Executives Association of California
Electronic Frontier Foundation

Health Officers Association of California
Media Alliance
Oakland Privacy
Privacy Rights Clearinghouse

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