

SENATE JUDICIARY COMMITTEE
Senator Thomas Umberg, Chair
2021-2022 Regular Session

SB 744 (Glazer)
Version: April 22, 2021
Hearing Date: April 27, 2021
Fiscal: Yes
Urgency: No
CK

SUBJECT

Communicable diseases: respiratory disease information

DIGEST

This bill requires that any report of a communicable respiratory disease by a health care provider to a local health officer and any electronic tool used by a local health officer for the purposes of reporting cases of a communicable respiratory disease include specified information about the patients. The bill provides for the expedited release of health care data to researchers at bona fide research institutions pursuant to memorandum of understanding executed with the California Department of Public Health (CDPH).

EXECUTIVE SUMMARY

In order to adequately respond to a health crisis, reliable and robust data is critical. This assists in understanding the origins of a disease, the path of the outbreak, and additional information that guides the response and the prevention of similar crises in the future. At the core of this information gathering and sharing is the trust of those involved that the information will be protected.

This bill provides for the expanded collection of health care data related to communicable respiratory diseases and the sharing of such data with public health officials. The bill requires CDPH to establish a program for the expedited release of health care data to qualified researchers at bona fide research institutions of higher education pursuant to specified agreements and subject to disclosure and use restrictions.

This bill is author-sponsored. It is supported by the California Teachers Association. It is opposed by the County Health Executives Association of California, the Health Officers Association of California, and a coalition of privacy and consumer groups. This bill passed out of the Senate Health Committee on a vote of 9 to 0.

PROPOSED CHANGES TO THE LAW

Existing law:

- 1) Requires CDPH to examine into the causes of communicable disease in human and domestic animals occurring or likely to occur in this state. (Health & Saf. Code § 120125.)
- 2) Requires CDPH to establish a list of reportable diseases and conditions. For each reportable disease and condition, CDPH must 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 pursuant to this section. The list of reportable diseases and conditions may include both communicable and noncommunicable diseases. (Health & Saf. Code § 120130.)
- 3) Provides, pursuant to state regulations, that it shall be the duty of every health care provider, knowing of or in attendance on a case or suspected case of any one of the dozens of diseases or conditions listed in the regulation to report to the local health officer for the jurisdiction where the patient resides as required in subsection (h) of this section. Where no health care provider is in attendance, any individual having knowledge of a person who is suspected to be suffering from one of the diseases or conditions listed in subsection (j) of this section may make such a report to the local health officer for the jurisdiction where the patient resides. (17 C.C.R. § 2500(b), (j).)
- 4) Requires the above report to include the following information:
 - a) 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, ethnicity, Social Security number, current gender identity, sex assigned at birth, sexual orientation, 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. (17 C.C.R. § 2500(d).)
- 5) Provides that the above information is acquired in confidence and shall not be disclosed by the local health officer except as authorized by these 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. (17 C.C.R. § 2500(f).)

- 6) Provides that each health officer knowing or having reason to believe that any case of the diseases made reportable by regulation of CDPH, or any other contagious, infectious or communicable disease exists, or has recently existed, within the territory under their jurisdiction, shall take measures as may be necessary to prevent the spread of the disease or occurrence of additional cases. (Health & Saf. Code § 120175.)
- 7) Provides, pursuant to the California Constitution, that all people have inalienable rights, including the right to pursue and obtain privacy. (Cal. Const., art. I, § 1.)
- 8) Establishes, pursuant to the federal Health Insurance Portability and Accountability Act (HIPAA), privacy protections for patients' protected health information and generally provides that a covered entity, as defined (health plan, health care provider, and health care clearing house), may not use or disclose protected health information except as specified or as authorized by the patient in writing. (45 C.F.R. § 164.500 et seq.)
- 9) Prohibits, under the State Confidentiality of Medical Information Act (CMIA), providers of health care, health care service plans, or contractors, as defined, from sharing medical information without the patient's written authorization, subject to certain exceptions. (Civ. Code § 56 et seq.)
- 10) Establishes the Information Practices Act of 1977 (IPA), which declares that the right to privacy is a personal and fundamental right and that all individuals have a right of privacy in information pertaining to them. It regulates the handling of personal information in the hands of state agencies. The IPA states the following legislative findings:
 - a) the right to privacy is being threatened by the indiscriminate collection, maintenance, and dissemination of personal information and the lack of effective laws and legal remedies;
 - b) the increasing use of computers and other sophisticated information technology has greatly magnified the potential risk to individual privacy that can occur from the maintenance of personal information; and
 - c) in order to protect the privacy of individuals, it is necessary that the maintenance and dissemination of personal information be subject to strict limits. (Civ. Code § 1798 et seq.)
- 11) Defines "independent institutions of higher education" as those nonpublic higher education institutions that grant undergraduate degrees, graduate degrees, or both, and that are formed as nonprofit corporations in this state and are accredited by an agency recognized by the United States Department of Education. (Ed. Code § 66010.)

This bill:

- 1) Requires an electronic tool used by a local health officer for the purpose of reporting cases of communicable respiratory disease to CDPH, as required, shall include the capacity to collect and report data relating to all of the following:
 - 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 a health care provider who knows of, or is in attendance on, a case or suspected case of specified communicable respiratory diseases or conditions to report to the local health officer for the jurisdiction where the patient resides, all of the following:
 - 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.
- 3) Requires CDPH to create a program to provide expedited release of health care data, including from Confidential Morbidity Reports and contact tracing reports, to researchers at a bona fide research institution of higher education.
- 4) Defines a “bona fide research institution of higher education” as a campus of the University of California or independent institutions of higher education, as defined in subdivision (b) of Section 66010 of the Education Code, that offer postgraduate degrees in public health.
- 5) Requires CDPH to make the data available promptly, and on an ongoing basis, to qualified researchers who sign a memorandum of understanding with the department agreeing to use the data only for public health research purposes, to not disclose it to any other party, and to keep all personal information confidential.

COMMENTS

1. Stated intent of the bill

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. Protections for medical information

HIPAA, enacted in 1996, guarantees privacy protection for individuals with regards to specific health information. (Pub.L. 104-191, 110 Stat. 1936.) Generally, protected health information is any information held by a covered entity which concerns health status, provision of healthcare, or payment for healthcare that can be connected to an individual. HIPAA privacy regulations require healthcare providers and organizations to develop and follow procedures that ensure the confidentiality and security of personal health information when it is transferred, received, handled, or shared. HIPAA further requires reasonable efforts when using, disclosing, or requesting protected health information, to limit disclosure of that information to the minimum amount necessary to accomplish the intended purpose.

The California Medical Information Act (CMIA) (Civ. Code § 56 et seq.) allows adult patients in California to keep personal health information confidential and decide whether and when to share that information. These provisions are guided to protect Californians' fundamental right to privacy. (Cal. Const., art. I, § 1.) CMIA provides a definition for what constitutes "medical information," and therefore what is protected under CMIA.

Providers of health care are subject to various requirements under CMIA. They are prohibited from sharing medical information without the patient's written authorization, subject to certain exceptions. (Civ. Code § 56.10.) A provider of health care who creates, maintains, preserves, stores, abandons, destroys, or disposes of medical information is required to do so in a manner that preserves the confidentiality of the information contained therein. Any provider of health care who negligently creates, maintains, preserves, stores, abandons, destroys, or disposes of medical information is subject to certain penalties. (Civ. Code § 56.101.) If a provider negligently creates, maintains, preserves, stores, abandons, destroys, or disposes of written or electronic medical records, they are subject to damages in a civil action or an administrative fine, as specified. (Civ. Code § 56.36.)

The Information Practices Act governs the collection, maintenance, and sharing of data by state agencies. (Civ. Code § 1798 et seq.) Agencies are required to "establish

appropriate and reasonable administrative, technical, and physical safeguards to ensure compliance with the provisions of this chapter, to ensure the security and confidentiality of records, and to protect against anticipated threats or hazards to their security or integrity which could result in any injury.” (Civ. Code § 1798.21.) Agencies are prohibited from disclosing any personal information in a manner that would allow for the information to be linked to the individual to whom it pertains, except as specifically provided. (Civ. Code § 1798.24.)

One exception is when the information is provided to the University of California or a nonprofit educational institution conducting scientific research. (Civ. Code § 1798.24(t).) However, the request for information must be approved by the Committee for the Protection of Human Subjects (CPHS) for the California Health and Human Services Agency (CHHSA) or an institutional review board, as provided. The approval process must ensure that a series of criteria have been satisfied. This criteria includes a plan, established by the researcher, that is determined to be sufficient to protect personal information from improper use and disclosures, including sufficient administrative, physical, and technical safeguards to protect personal information from reasonable anticipated threats to the security or confidentiality of the information. The researcher is also required to have a plan for destroying the personal information or to protect its confidentiality longer term if there is a demonstrated ongoing need. Written assurances that the information will not be reused or disclosed to another entity or other person must be provided.

3. Collecting and disseminating critical but sensitive health care information

This bill provides for the collection of additional health information in an effort to collect more data relevant to addressing the state’s response to managing and combating communicable diseases. This includes information about the housing where patients live and their occupations and workplaces. The electronic tools used by local health officers must be able to collect this new information. Health care providers that know of, or are in attendance on, a case or suspected case of specified communicable respiratory diseases or conditions are required to report such information to the local health officer.

The California Teachers Association explains their support for the bill: “Creating more transparency around the data will improve trust, establish a path to hold government accountable to the decisions they make, and prioritize safety.”

However, the County Health Executives Association of California and the Health Officers Association of California write in joint opposition:

California’s disease reporting system is governed by Section 2500 of Title 17 of the California Code of Regulations. Health officers rely on medical providers to report each case of the 88 diseases listed in section (j),

enabling us to monitor the spread of communicable disease in our state. We know that, despite our best efforts, not every health care provider remembers to report each case. Therefore, it is important that we eliminate any possible barriers by making the disease reporting process simple, easy, and confidential.

This bill would add four specific questions for the provider to ask and report for communicable respiratory diseases. This requirement would apply to 21 of the 88 diseases. Because it creates a new, significant step in the disease reporting process, we feel this requirement would decrease disease reporting among providers, leading to less public health information, not more.

Local public health officers rely on health providers to report timely disease case information in order to monitor the health of our local communities. Being required to provide additional data erodes the trust of both our medical community and the public we serve.

The bill also requires CDPH to establish a program providing for the expedited release of health care data, including from Confidential Morbidity Reports and contact tracing reports, to researchers at bona fide research institutions of higher education. CDPH is required to make the specified data available “promptly, and on an ongoing basis” to qualified researchers. The author argues the current system is too “slow and cumbersome” and that “[e]ffectively fighting a fast-moving virus requires good science, and good science relies most of all on good data.” The author asserts this provision would “allow the kind of rapid analysis by multiple scientists acting simultaneously to spot trends, pinpoint the source of spread and recommend policies to mitigate it.”

This language recently replaced a provision that would have allowed for the public release of individual record information. The previous provision raised considerable concerns from privacy and consumer groups, including the ACLU of California, the Electronic Frontier Foundation, and the Consumer Federation of America. They found the guardrails previously provided were “inadequate to protect the trove of sensitive individual information” that the bill would generate.

The author attempts to quell privacy concerns in the new provision by limiting the release of data to only qualified researchers and requiring those researchers to execute a memorandum of understanding with CDPH. Researchers are only authorized to use the data for bona fide public health research purposes and are restricted from disclosing the data to any other party. All personal information must be kept confidential.

Given the latest amendments were taken just days before the release of this analysis, these groups have not been able to thoroughly vet them. However, concerns have been raised that the guardrails still need to be tightened to adequately protect this

information. As the bill moves forward, the author may wish to narrowly specify what data can be shared and the specific conditions that must be abided by. Consideration might also be given to including an additional enforcement mechanism by which injured parties can hold institutions in violation accountable. In order to limit the exposure of this sensitive information, the author has agreed to an amendment that limits the availability of this expedited process to periods in which there is a declared public health emergency.

The author makes clear that “[t]his proposal would not alter in any way the stringent laws and policies already in place requiring academic researchers to safeguard confidential data with administrative, physical and electronic security protocols.” And it should be noted that the bill simply requires CDPH to expedite the release of the information and to make it available “promptly, and on an ongoing basis.” This amounts to a mandate on CDPH to make reasonable efforts to speed up the provision of this information as compared to existing processes. Currently, the CMIA allows a provider of health care to disclose medical information to public agencies, clinical investigators, including investigators conducting epidemiologic studies, health care research organizations, and accredited public or private nonprofit educational or health care institutions for bona fide research purposes. (Civ. Code § 56.10(c)(7).) However, the information cannot be further disclosed by the recipient in a way that would disclose the identity of a patient or violate this part. As discussed above, the Information Practices Act also allows for the release of personal information by state agencies to educational institutions for scientific research but only under strict conditions and after review. This bill does not relieve any of the parties from the commands of the applicable privacy laws; CDPH’s program will still need to work within the bounds of existing law while working to expedite the release of the specified data and the program will have to be built to ensure that.

SUPPORT

California Teachers Association

OPPOSITION

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

RELATED LEGISLATION

Pending Legislation:

AB 41 (Umberg, 2021) establishes the Genetic Information Privacy Act, providing additional protections for genetic data by regulating the collection, use, maintenance, and disclosure of such data. This bill is currently in the Senate Appropriations Committee.

AB 1252 (Chau, 2021) revises the Confidentiality of Medical Information Act (CMIA) to define personal health record (PHR) and personal health record information (PHRI), and deem a business that offers PHR software or hardware to a consumer, as specified, for purposes of allowing the individual to manage their information, or for the diagnosis, treatment, or management of a medical condition of the individual, to be a “health care provider” subject to the requirements of the CMIA. This bill is currently in the Assembly Appropriations Committee.

Prior Legislation: AB 1782 (Chau, 2020) would have established the Technology-Assisted Contact Tracing Public Accountability and Consent Terms (TACT-PACT) Act, which would have regulated business and public entity engagement in TACT, which is defined as the use of a digital application or other electronic or digital platform that is capable of independently transmitting information and is offered to individuals for the purpose of identifying and monitoring individuals, through data collection and analysis, who may have had contact with an infectious person as a means of controlling the spread of a communicable disease. This bill died in the Senate Appropriations Committee.

PRIOR VOTES:

Senate Health Committee (Ayes 9, Noes 0)
