

Eastern Region Office PO Box 60173 Philadelphia, PA 19102 215-592-1513 T 215-592-1343 F

Central Region Office PO Box 11761 Harrisburg, PA 17108 717-238-2258 T 717-236-6895 F

Western Region Office PO Box 23058 Pittsburgh, PA 15222 412-681-7736 T 412-681-8707 F

TO: The Pennsylvania Senate

Pennsylvania FROM: Elizabeth Randol, Legislative Director, ACLU of Pennsylvania

DATE: April 27, 2020

RE: OPPOSITION TO SENATE BILL 1110 P.N. 1651 (K. WARD)

Senate Bill 1110 P.N. 1651 proposes a fundamental change in both content and scope to Pennsylvania's Disease Prevention and Control Law of 1955. 35 P.S. § 521.15 prohibits state and local health authorities from disclosing reports of diseases or records pertaining to diseases to anyone outside those agencies, "except where necessary to carry out the purposes of this act." SB 1110 largely keeps the current statute intact, but creates a new provision that regulates the disclosure of private health information related to a communicable disease that is the subject of a disaster declaration that:

- Requires (rather than limits) disclosure of "individually identifiable health information" within 24 hours of a confirmed case:
- Broadly defines the content of the health information to be collected/maintained;
- Expands the agencies with whom this personal health information is shared (beyond state and local health authorities) to include 911 centers, law enforcement officers, fire department personnel, emergency medical services personnel; and
- Discloses this data to each of those entities in every county in the commonwealth.

While SB 1110 aims to assist first responders by sharing identifying information of everyone who tests positive for a communicable disease declared as a disaster emergency, its provisions are needlessly invasive, capture more data than is reasonably warranted, and risk breaches by requiring health data to be shared so broadly.

The Pennsylvania Constitution places a high value on individual privacy, including medical privacy.¹ But the right to privacy, like all constitutional rights, is not absolute. When an individual's right to privacy is implicated, courts will use a balancing test to determine whether the invasion of privacy is outweighed by a compelling state interest.² There is no doubt that significant state interests are at stake here, given the grave public health risk posed by COVID-19. But even in the midst of extraordinary circumstances, fundamental rights can – and must – be protected against unnecessary government intrusion.

On behalf of over 100,000 members and supporters of the ACLU of Pennsylvania, I respectfully urge you to oppose Senate Bill 1110 for the following reasons:

SB 1110 will apply to all communicable diseases, not just COVID-19

SB 1110 would require disclosure of information for **all** infectious diseases, not just COVID-19, that become the subject of a disaster emergency. SB 1110's provisions are cabined such that the governor must first declare an emergency based on a communicable disease, but disclosure of health data would then be required, even if the nature of the disease does not lend itself to first responders benefitting from such information.

¹ Article 1, Section 1 of the Pennsylvania Constitution provides even "more rigorous and explicit protection for a person's right to privacy" than the federal constitution. In re B, 394 A.2d 419, 425 (Pa. 1978). The right to privacy, for Pennsylvanians, is considered "as much property of the individual as the land to which he holds title and the clothing he wears on his back." Pa. State Educ. Ass'n v. Commonwealth, Dep't of Comm. & Econ. Dev., 148 A.3d 142, 151 (Pa. 2016) (quoting Commonwealth v. Murray, 223 A.2d 102, 109 (Pa. 1966)). In In re B, 394 A.2d 419 (Pa. 1978), the Pennsylvania Supreme Court found that a mother's psychiatric records could not be subpoenaed in connection with a dependency placement for her son. The Court found that while the information might be "useful," the "right of privacy ... must prevail." 394 A.2d at 426. In 2019, the Court reiterated that while protected medical information could be constitutionally disclosed in some instances, it "admonished that it should not be subject to wholesale release." In re Fortieth Statewide Investigating Grand Jury, 220 A.3d 558, 570 (Pa. 2019); see also Stenger v. Lehigh Valley Hosp. Ctr., 609 A.2d 796, 800-801 (Pa. 1992) (finding privacy interest not to be offended by disclosure of HIV status because disclosure of information was anonymous). ² An individual's right to privacy is weighed against a countervailing state interest. Denoncourt v. Commonwealth, State Ethics Comm'n, 470 A.2d 945, 948 (Pa. 1983). An intrusion into a person's private affairs is only justifiable "when the government's interests are significant and there is no alternate reasonable method of lesser intrusiveness to accomplish the government's purpose." Id. at 949. "Whether there is a significant state interest will depend, in part, on whether the state's intrusion will affect its purpose; for if the intrusion does not affect the state's purpose, it is a gratuitous intrusion, not a purposeful one." Id.

SB 1110 captures and maintains private health information far exceeding COVID-19 status

SB 1110 would collect "individually identifiable health information" defined as "*information, whether oral, written, electronic, visual, pictorial, physical or in any other form that relates to an individual's past, present or future physical health status, condition, treatment, service, products purchased or provision of care.*" This data **must** reveal the identity of the person who is the subject of the record OR serve as a reasonable basis upon which to identify that person. In other words, these records <u>cannot be anonymous</u>.

Furthermore, SB 1110 mandates disclosure of records far beyond what first responders may need when responding to a call. For instance, do first responders need to know what products someone has purchased when responding to a call? Their past COVID status if they are now testing negative? What treatment (including experimental) they may have received? It strains credulity to imagine that this much information is necessary before first responders can safely respond to a call.

SB 1110 requires disclosure to an alarmingly broad audience

SB 1110 requires that *all* personal information be disclosed to *all* 911 centers, law enforcement officers, fire department personnel, and EMS personnel in *every* county. There are approximately 4,700 entities across the commonwealth that could receive individually identifiable health information, including volunteer departments. This puts the onus on each agency to abide by complex state and federal privacy laws, but it is unclear if or how many personnel receive adequate privacy law compliance training. Simply stated, SB 1110 puts personal health information in more hands than is necessary and hopes that employees do not violate someone's privacy. This is a dangerous gamble, especially considering how much personal information is collected and required to be disclosed.

SB 1110 proposes overly-broad and ill-suited measures to protect first responders

When balancing public health and privacy interests, the ACLU relies on medical expertise to identify and assess the health interests at hand. Protecting the health of first responders is clearly an important priority for the state. However, <u>public health experts</u>³ have noted that disclosing names and addresses of those testing positive for COVID-19 does not ensure a first responder would be safe from exposure. There are people in Pennsylvania with COVID-19 who are not known to public health officials and there are certainly some people who are infected but unaware they have COVID-19. Many cases of COVID-19 are <u>asymptomatic</u>,⁴ present mild symptoms, or are undiagnosed due to <u>limited availability of tests</u>⁵ throughout the United States.

It is also important to recognize the critical role confidentiality plays in protecting the public health. Sharing individually identifying medical information of those who test positive could deter some people from getting tested. There is a long history of social stigma⁶ attached to communicable diseases; vulnerable populations such as unhoused or undocumented individuals, or people living in marginalized and over-policed communities may not be willing to get tested if they know their information will end up in the hands of government authorities other than those responsible for public health. Confidentiality laws are neither insignificant nor mere administrative burdens; in fact, they are integral to successful public health management.

SB 1110's mandated disclosure of individually identifiable health information is far from the least intrusive way to achieve the state's goal of protecting first responders. At an absolute minimum, collecting less information and disclosing it to fewer entities might begin to better balance these two critical interests.

For these reasons, we urge you to oppose Senate Bill 1110.

 ³ Greenwald, Robert. (2020 March 23). Applying Lessons Learned from the AIDS Epidemic to the Fight Against COVID-19. Harvard Center for Health Law and Policy Innovation. <u>chlpi.org/applying-lessons-learned-from-the-aids-epidemic-to-the-fight-against-covid-19</u>
⁴ The Centers for Disease Control, How COVID-19 Spreads. <u>https://www.cdc.gov/coronavirus/2019-ncov/prepare/transmission.html</u>

⁵ U.S. FDA (2020, February 29). COVID-19 Update: FDA Issues New Policy to Help Expedite Availability of Diagnostics.

fda.gov/news-events/press-announcements/coronavirus-covid-19-update-fda-issues-new-policy-help-expedite-availability-diagnostics ⁶ Williams, J. L. (2011). Infectious diseases and social stigma. Applied Technologies and Innovations, 4(1), 58–70. academicpublishingplatforms.com/downloads/pdfs/ati/volume4/201105020547 07 ATI V4 JoanWilliams et al Social Stigma.pdf