



March 19, 2024

Hon. Jennifer Gong-Gershowitz
Chair, House Judiciary – Civil Committee
Representative, District 17
248-W Stratton Office Building
Springfield, IL 62706

RE: ATA ACTION COMMENTS IN OPPOSITION TO HOUSE BILL 4093 THE “PROTECT HEALTH DATA PRIVACY ACT”

Good afternoon Chair Gong-Gershowitz and members of the House Judiciary – Civil Committee,

On behalf of the ATA Action, I am submitting the following comments opposing House Bill 4093 – the Protect Health Data Privacy Act along with the following recommendations to improve the legislation.

ATA Action, the American Telemedicine Association’s affiliated trade association focused on advocacy, advances policy to ensure all individuals have permanent access to telehealth services across the care continuum. ATA Action recognizes that telehealth and virtual care have the potential to truly transform the health care delivery system – by improving patient outcomes, enhancing safety and effectiveness of care, addressing health disparities, and reducing costs – if only allowed to flourish.

Telehealth is and will remain an important way Americans access the healthcare they need. As more providers come online – figuratively and literally – ATA Action urges increased vigilance by the healthcare community to ensure these practices meet standards for patient safety, data privacy, and information security. Indeed, patient privacy and the protection of patient data are prerequisites for connected care and core principles for our organization. State and federal regulatory schemes should allow for innovation and support the advancement of technology-assisted care; however, telehealth and virtual care platforms, systems, and devices should be required to mitigate cybersecurity risks and provide for patient safety and confidentiality.

In light of the advancement of privacy legislation in many states across the country to address such concerns, the American Telemedicine Association has published [Health Data Privacy Principles](#) to aid legislators in crafting legislation that supports both secure data practices and patient access to care. ATA Action hopes these policy principles are helpful in crafting forward-thinking privacy legislation in Illinois.

ATA Action has several concerns that HB4093 (“the Act”) runs counter to sound data privacy policy and puts undue burdens on telehealth providers due to its complexity and undefined breadth. Specifically, ATA Action makes the following recommendations:

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Legislators should seek uniform privacy laws consistent across states and industries: As states adopt privacy laws across the nation, efforts to establish uniformity with existing federal and other state standards would reduce both complexity and costs regarding compliance, as well as confusion for consumers. Unfortunately, the Act at hand is both specific only to healthcare and creates uneven burdens on providers relative to federal laws (discussed below). Instead, ATA Action encourages legislators to take an approach that mirrors Virginia (see the Virginia Consumer Data Protection Act¹) and Connecticut (see the Connecticut Consumer Data Privacy and Online Monitoring Act²). As HB4093 continues to work through the legislative process, we hope this Committee and the Illinois legislature will strive for uniformity with these existing state regulatory frameworks and avoid burdensome requirements that would be specific only to Illinois.

Definition of health data is too broad and causes confusion: When read in tandem with the Act’s definition of personal information, the Act’s definition of “health data” includes, among other things, “efforts to research or obtain health services or supplies” related to past, present, or future physical or mental health (the Act’s scope, under Section 10, also applies to any consumer “seeking [or] researching” health services). This definition captures a wide range of data, including various search and browsing-related activities even when there is no personal health information being exchanged. ATA Action is concerned that providers and other online healthcare entities would be arbitrarily limited in their ability to communicate with current or potential Illinois consumers about reliable sexual health information, obtaining over the counter medication, or obtaining supplies. This is especially troubling for stigmatized conditions like sexual health, where online outreach and engagement might be the only way a patient would feel comfortable with treatment. To promote clarity and consistency, ATA Action requests that the definition of consumer health data track the definition of “protected health information” in the HIPAA Privacy Rule. At a minimum, we strongly urge the sponsors to reconsider this definition and ensure it is narrowly tailored to achieve the legislation’s objectives and does not unnecessarily restrict access to care.

Restrictions on collection and use of data are inconsistent with and exceed HIPAA, setting up an unequal framework for Illinois providers and consumers: ATA Action believes that state laws targeting health data privacy should be consistent with and not exceed HIPAA’s standards to the greatest extent possible, to ensure that patient protections are not contingent on whether the entity is HIPAA covered. Unfortunately, HB4093 imposes obligations and requirements that exceed HIPAA and other existing state and federal regulatory frameworks, creating significant uncertainty about compliance. The lack of clarity is particularly troubling as our organization represents both HIPAA and non-HIPAA covered entities, who nonetheless share a commitment to protect the confidentiality of patient’s personal information.

Under the HB 4093, for example, a regulated entity would need a specific consent to both collect and use a consumer’s data for any purpose other than to provide the product or service that the consumer requested. This would, for example, prohibit a regulated entity from sending communications about its own products or services to the consumer. However, a HIPAA-covered entity – and in some situations their contracted third-party business associates – could engage in that same activity with the consumer’s HIPAA protected health information without any need for consent from the consumer under the HIPAA

¹ Virginia Consumer Data Protection Act, VA Code Ann. § 59.1-575 *et seq.*, <https://law.lis.virginia.gov/vacodefull/title59.1/chapter53/>.

² Connecticut Consumer Data Privacy and Online Monitoring Act, Conn. Gen. Stat. § 42-515 *et seq.*, https://www.cga.ct.gov/current/pub/chap_743jj.htm.



Privacy Rule.³ This inconsistency not only undermines the stated intent of the Act, it would afford differing rights to Illinois consumers and unequal burdens on entities based solely on being subject to HIPAA. We suggest aligning the permitted uses and disclosures of the Act, at a minimum, with the HIPAA Privacy Rule, including that consumer health data may be used for purposes of treatment, payment, and health care operations.

State attorneys general should have sole enforcement authority when privacy laws are violated:

ATA Action believes that state attorneys general should have appropriate authority to investigate possible violations of privacy laws and determine when it is appropriate to pursue sanctions against bad actors. ATA Action also recommends that legislators avoid including private rights of action as a method of enforcing privacy laws, which are prone to a lack of clarity, result in frivolous lawsuits and result in out-of-court settlements that exacerbate legal uncertainty.

ATA Action hopes that the Committee will embrace these changes so as to simultaneously ensure patient data is effectively protected while not placing undue burdens on providers. We believe that this strikes a fair balance between these two significant public policy goals.

Thank you for your support of telehealth. We encourage you and your colleagues to consider amendments to HB4093 to ensure easy and efficient access to high-quality health care services in Illinois. Please do not hesitate to let us know how we can be helpful to your efforts to advance common-sense telemedicine policy. If you have any questions or would like to discuss the telemedicine industry's perspective further, please contact me at kzebley@ataaction.org.

Kind regards,

A handwritten signature in black ink, appearing to read "Kyle Zebley", written over a light grey circular stamp.

Kyle Zebley
Executive Director
ATA Action

³ Marketing, U.S. Dept. of Health and Human Servs. (July 26, 2013), <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/marketing/index.html>.