



May 22, 2024

Speaker Carl E. Heastie
New York Assembly
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Albany, NY 12248
Speaker@nyassembly.gov

Majority Leader Crystal D. Peoples-Stokes
New York Assembly
LOB 926
Albany, NY 12248
PeopleC@nyassembly.gov

RE: ATA ACTION COMMENTS OPPOSING ASSEMBLY BILL 4983--C

Dear Speaker Heastie & Majority Leader Peoples-Stokes,

On behalf of ATA Action, I am writing to you to express our ongoing and unresolved concerns on Assembly Bill 4983--C, the New York Health Information Privacy Act, and to encourage the Assembly to work with stakeholders on what is a very complex issue and bill with possible unintended consequences if the current draft moves forward without important changes.

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 supports efforts to ensure telehealth practices meet standards for patient safety and data privacy, while advancing access to care and awareness of telehealth practices. In light of the advancement of privacy legislation in many states across the country directly or indirectly affecting telehealth practice, ATA Action has published its [Health Data Privacy Principles](#) (attached) to aid legislators in crafting legislation that supports both secure data practices and ensures patient access to care. ATA Action hopes these policy principles are helpful in crafting forward-thinking and thoughtful privacy legislation in New York.

ATA Action has several concerns that A4983 ("the Act") runs counter to sound data privacy policy and puts undue burdens on telehealth providers due to its complexity and undefined breadth. If the Assembly proceeds with a health-specific approach to data privacy – rather than a comprehensive approach that ATA Action prefers-- we make the following recommendations:

A4983--C is inconsistent with HIPAA despite the bill's stated intent: The stated justification of A4983--C notes that New York residents have the misimpression that HIPAA protects them anytime they share health information and that this legislation intends to afford privacy protections where HIPAA would not apply. ATA Action supports this intent and strongly agrees "state consumer privacy laws should be consistent with and not exceed HIPAA's standards to the greatest extent possible."

However, we echo the concerns other stakeholders have expressed that this Act imposes obligations and requirements that far 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

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represents both HIPAA and non-HIPAA covered entities, who nonetheless share a commitment to protect the confidentiality of patient’s personal information. Some of examples of how this legislation is inconsistent with and exceeds HIPAA include:

A4983--C prohibits marketing activities permitted under HIPAA: Under the proposed Act, 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 additional products or services to the consumer. However, a HIPAA-covered entity – and in some situations their contracted business associates – could engage in that same activity with the consumer’s HIPAA protected health information without any need for specific consent from the consumer under the HIPAA Privacy Rule.¹ This inconsistency not only undermines the stated intent of the Act, it would afford differing rights to New York 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 regulated health information may be used for purposes of treatment, payment, and health care operations.

Definition of regulated health information is overbroad: The bill’s broad definition of “regulated health information” far exceeds the HIPAA definition of “protected health information.” The bill captures not only an individual’s health-related data as the statute intends, but *any* data that *could* be used to create an inference around an individual’s health. ATA Action is concerned that providers and other online healthcare entities would be arbitrarily limited in their ability to communicate with current or potential New York residents – and potentially residents across the country if the entity has a New York presence -- about things such as reliable sexual health information, birth control options, 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. Future legislation should narrow the definition of “regulated health information” to track the definition of “protected health information” in the HIPAA Privacy Rule and to limit the reach to data of New York consumers. At a minimum, we strongly urge the Assembly to reconsider this definition and ensure it is narrowly tailored to achieve the legislation’s objectives and not unnecessarily restrict access to care.

A4983--C proposes a unique burden that consumers must wait 24 hours before providing authorization: Unlike HIPAA, Section 1102(2)(a)(ii) states that a request for a consumer’s valid authorization can only be made at least twenty-four hours after the consumer signs up for, or first uses the product or services. As an initial matter, increasing the steps in a sign-up process to a multi-day event will risk a significant drop off in consumer retention rates and increases the administrative burden on the regulated entity. But more importantly, this rule would also arbitrarily contravene the intent of A4983--C, which in part is meant to ensure consumers have adequate notice about a regulated entity’s data practices when the consumer begins to provide their personal health information to that entity, not 24-hours after. Consumers more-likely-than-not appreciate receiving this information at the beginning of a sign-up process (as they would at a physician office), not after they have already provided information to the regulated entity.

¹ *Marketing*, U.S. Dept. of Health and Human Servs. (July 26, 2013), <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/marketing/index.html>.



A4983--C has an unprecedented requirement that consumer authorization expires at 1 year:

The Act states that an authorization must have an expiration date and that it must be within a year of signing. ATA Action is unaware of any state or federal requirement that mandates a consumer's authorization expires after a year, even if the parties have agreed otherwise. For example, a HIPAA authorization remains valid until it expires or is revoked by the individual. We recommend the Act align with HIPAA and not prescribe limits on the authorization.

A4983--C informed consent requirements and restrictions to process health data are overly burdensome and impractical: A4983--C intends to ensure that regulated entities need "separate consent" to sell any health information to third parties and ATA Action agrees with that goal. Yet, this Act goes much further and requires authorization beyond sale to any processing for which there is not an exemption. ATA Action has concerns that requiring multiple authorizations—rather than a single consent—will lead to consumer consent fatigue and potentially lead to confusion and frustration for users who are simply trying to access a healthcare service or product. The ensuing confusion and frustration would significantly increase the probability that individuals who are seeking needed health care products and services will simply walk away from a digital health platform due to its difficulty of use.

A4983-C Should Include Exemption for Healthcare Data Already Protected Under New York's Existing Regulations: ATA Action supports that A4983-C currently exempts "protected health information under HIPAA" and HIPAA-Covered entities from the requirements of the Act. This is important to ensure entities already observing a complex system of regulations under both federal and state law do not have to apply those additional layers of compliance requirements to the same sets of health data. By this same logic, this data-level exemption should be extended for non-HIPAA covered entities and providers when regulated health information is collected, used, or disclosed in accordance with already existing New York health privacy frameworks and existing regulatory requirements applicable to health care providers. Without this additional exemption that currently appears in many state data privacy laws (CA, WA, CT to name a few), non-HIPAA covered entities will be subject to additional, duplicative, and potentially inconsistent regulation, which creates unnecessary and inappropriate burdens and costs. We therefore strongly recommend adding language for such a data level exemption in addition to protected health information (PHI) under HIPAA. We are requesting that the following language be added to the exemptions section of A4983-C:

"Patient information that is governed by state law, including but not limited to New York Public Health Law section 17, 18, 206(1)(j), 2782, 2805-m, 4410, Civil Rights Law section 79-I, New York State Education Law § 6530, and others governing patient information."

Please see the attached Privacy Principles for greater detail on ATA Action's data privacy policy positions and do not hesitate to let us know how we can be helpful to your efforts to advance common-sense telehealth policy. If you have any questions or would like to discuss the telehealth industry's perspectives further, please contact me at kzebley@ataaction.org.

Kind regards,

A handwritten signature in black ink, appearing to read "Kyle Zee", written over a light blue horizontal line.

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Kyle Zebley
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cc:

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