ata ACTION
Telehealth Policy to Transform Healthcare

January 24, 2025

The Honorable Kathy Hochul
Governor of New York State
NYS State Capitol Building
Albany, NY 12224

RE: ATA ACTION COMMENTS SEEKING AMENDMENTS TO SENATE BILL 929/ASSEMBLY BILL 2141

Dear Governor Hochul**,**

On behalf of ATA Action, I am writing to you to express our concerns regarding Senate Bill 929/Assembly Bill 2141, the New York Health Information Privacy Act. We urge you to work with stakeholders and the Legislature on critical amendments on what is a very complex bill with possible unintended consequences if the current legislation becomes law 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 S929/A2141 ("the Act") runs counter to sound data privacy policy and puts undue burdens on telehealth providers due to its complexity and undefined breadth. As one legal commentator noted, the Act is "so onerous in fact, that in many cases it simply cannot scale and will, in effect, serve as a ban on common and beneficial data practices."[1] If New York proceeds with a health-specific approach to data privacy – rather than a comprehensive approach that ATA Action prefers-- we highlight the follow issues and our recommendations:

The Act is inconsistent with HIPAA despite the bill's stated intent: The stated justification of the Act 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

[1] **New York Legislature Passes Extraordinarily Restrictive Health Data Privacy Bill**, Jan 22, 2025 (citing May 29, 2024 summary)

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. Some examples of how this legislation is inconsistent with and exceeds HIPAA include:

The Act requires onerous authorization for beneficial uses that are permitted under HIPAA: Under the proposed Act, a regulated entity would need a signed authorization to both collect and use a consumer's data for any purpose other than what is "strictly necessary" to provide the product or service that the consumer requested, absent few narrow exceptions. For example, an entity would need to go through the Act's onerous authorization process for a number of common and beneficial uses of data: researching consumer data to understand how patients book appointments on the website, directly sending a customer a coupon for future health products, using customer data to improve websites experience, informing their patients of new clinical services they might be offering, and 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 these same activities with the consumer's HIPAA protected health information without any need for specific authorization from the consumer under the HIPAA Privacy Rule.[2] 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.

The Act 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 the Act, 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 twenty-four 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. We urge the Governor to get rid of the twenty-four-hour requirement, which is operationally impossible to implement and creates a barrier for patients and consumers.

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

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

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 Governor to reconsider this definition and ensure it is narrowly tailored to achieve the legislation's objectives and not unnecessarily restrict access to care.

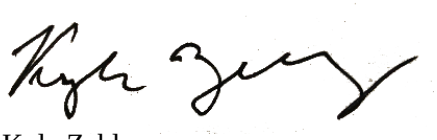
The Act has an unprecedented requirement that consumer authorization expires at 1 year: The Act states that an authorization must have an expiration date and that it must be within a year of signing. ATA Action is unaware of any state or federal requirement that mandates a consumer's authorization expires 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.

The Act's definition of regulated health entities is extremely broad: The Act intends to apply to not only entities controlling the processing of data of New Yorkers, but also entities serving an individual that happens to be in New York when data is collected and entities located in New York that collect health care information *even when their consumers are not in New York or they do not offer services in New York.* This extraordinary breadth will require entities to perhaps process more geolocation data than they otherwise would collect to determine whether the Act's provisions apply and may require entities to pause services for patients or consumers when they are in the state. Further, mandating that New York based health entities apply the Act's framework on a nationwide basis will lead to operational challenges, conflicts with other laws, and disrupt the patient experience. We are concerned that this requirement could lead to an exodus of digital health companies from being located, moving to, or being founded in the state, particularly for those that frequently deliver services out of state and will have already developed compliance frameworks to align with the privacy requirements of the state where the patient is located. We recommend amendments to the scope of this legislation, consistent with laws across the country, to the regulated health information of New York consumers.

The Act Should Include Exemption for Healthcare Data Already Protected Under New York's Existing Regulations: ATA Action supports that the Act 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.

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,



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