

March 13, 2025

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

RE: Request to Amend the New York Health Information Privacy Act (S929)

Dear Governor Hochul,

On behalf of the Network Advertising Initiative (NAI), I'm writing to encourage tailored amendments to the New York Health Information Privacy Act (S929). The NAI and our members support the goals of this legislation to create strong protections for sensitive health information, but we are concerned that the bill as passed by the legislature would have the unintended consequence of limiting valuable services to New York residents and subject New York businesses to a competitive disadvantage nationwide.

Founded in 2000, the NAI is the leading non-profit, self-regulatory trade association for advertising technology companies.¹ For over 20 years, the NAI has promoted strong consumer privacy protections, a free and open Internet, and enabled small businesses to thrive by promoting the highest voluntary industry standards for the responsible collection and use of consumer data.

The NAI shares New York's goal of protecting consumers' sensitive information. In June 2022, the NAI published an industry-leading set of Voluntary Enhanced Standards for Precise Location Information to promote heightened protections around consumer location data associated with sensitive points of interest, such as reproductive and mental health facilities, among others, where consumer precise location data creates higher risks and deserves stronger protections around processing and sharing.² These standards also restrict participating companies from using, selling, or sharing any U.S. consumer precise location information for law enforcement or national security purposes, except when needed to comply with a valid legal obligation.³

While S929 maintains similar objectives, the legislation is likely to inadvertently restrict valuable, and often vital, products and services that benefit consumers and society. Consumers benefit from knowing which medical treatments or medications may provide them relief from their health conditions.⁴ Further, data-driven health advertising critically improves participation in, and the resulting viability of, clinical trials organized to develop targeted, effective treatments that improve health equity in New

¹ See *History of the NAI*, The Network Advertising Initiative, <https://thenai.org/about-the-nai-2/history-of-the-nai/>.

² See *NAI Precise Location Information Solution Provider Voluntary Enhanced Standards*, The Network Advertising Initiative (June 22, 2022), <https://thenai.org/wp-content/uploads/2022/06/Precise-Location-Information-Solution-Provider-Voluntary-Enhanced-Standards.pdf> (hereinafter "Voluntary Enhanced Standards").

³ See Voluntary Enhanced Standards at 3 ("Participating members shall not use, allow the use of, sell, or share Precise Location Information for law enforcement, national security, or bounty-hunting purposes, except as necessary to comply with a valid legal obligation.").

⁴ See generally *Bates v. State Bar of Arizona* 433 U.S. 350, 364 (1977) ("[C]ommercial speech serves to inform the public of the availability, nature, and prices of products and services, and thus performs an indispensable role in the allocation of resources in a free enterprise system.")

York.⁵ Additionally, location-data based services are regularly used for beneficial purposes such as: helping to promote vaccine availability campaigns by serving ads to mobile phones in the close vicinity to vaccination providers; and informing shoppers during the COVID-19 pandemic to prevent overcrowding and spread foot traffic at essential businesses.⁶ These examples are among many services that provide substantial benefits to the health and general awareness of New York residents that would no longer be available if S929 is enacted in its current form.

Therefore, the NAI recommends the following amendments to S929 to ensure New Yorkers' regulated health information is protected without unnecessarily restricting valuable health services or punishing New York businesses:

- Amend the definition of “regulated health information” to limit its application only to *personal data* that is *used* to make sensitive health-related inferences.
- Define “Individual” as a natural person who is a resident of New York to support the policy goal of empowering New York residents to reclaim and retain control of their healthcare information.
- Amend the definition of “regulated entity” to remove “is located in New York” as it is unnecessary to meet the objectives of this law and will subject businesses that have chosen to establish offices in New York to a competitive disadvantage.
- Classify the destruction and deidentification of regulated health information as a strictly necessary form of processing that does not require valid authorization to properly meet the policy goal of minimizing the private sector’s collection and maintenance of New Yorkers’ regulated health information.
- Include “research and development, or providing products or services to third parties” as a permissible purpose to enable ongoing research and development to improve consumers’ health outcomes, including how derivatives of such research and development are then transferred to third parties to deliver such outcomes.
- Exempt health care-related information that is de-identified in accordance with the requirements for de-identification pursuant to HIPAA, as there are beneficial secondary uses of this information that have been protected and encouraged at the federal level.
- Provide for an authorization process that is effective yet more practical, such as (1) requiring this only for sales of covered data; (2) enabling streamlined authorization; and (3) providing for a timelier offering of choice than the current 24-hour delayed process.
- Consolidate enforcement authority under the Attorney General to limit the opportunity for this legislation to generate spurious class action litigation where there is no reasonable risk of harm to consumers.

⁵ See *Social Media Marketing and its Vital Role in Improving Clinical Trial Recruitment*, the Association of Clinical Research Professionals (Dec. 13, 2024) (“Lack of targeted outreach can hinder studies from recruiting and retaining diverse patient populations, potentially resulting in biased outcomes and limited generalizability.”), <https://acrpnet.org/2024/12/13/social-media-marketing-and-its-vital-role-in-improving-clinical-trial-recruitment>.

⁶ E.g. *Using Location Data to Help Shoppers Stay Safe During COVID-19*, Foursquare Blog (Mar. 2, 2021), <https://location.foursquare.com/resources/blog/about-our-data/using-location-data-to-help-shoppers-stay-safe-during-covid-19/>; see also Travis Sanchez & Amaryllis Mavragani, *Using Location Intelligence to Evaluate the COVID-19 Vaccination Campaign in the United States: Spatiotemporal Big Data Analysis*, the National Library of Medicine (Feb. 16, 2023) (Concluding that location intelligence and mobile phone–based monitoring platforms can be effective in measuring impact of large-scale vaccination campaigns in near real time), <https://pmc.ncbi.nlm.nih.gov/articles/PMC9937108/>.

Thank you in advance for your consideration of this request. We would welcome the opportunity to work with you to provide minor amendments to this legislation to achieve the desired protections, while also allowing valuable uses of this data that do not pose a significant risk to consumers.

Sincerely,

A handwritten signature in black ink, appearing to read "Leigh Freund", enclosed within a thin black rectangular border.

Leigh Freund
President & CEO