## Consumer Federation of America

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The Honorable Kathy Hochul Governor of New York State

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## Sign the New York Health Information Privacy Act

The Consumer Federation of America (CFA) is an association of nonprofit consumer organizations that was established in 1968 to advance the consumer interest through research, advocacy, and education.

*CFA writes to urge the speedy signing of A2141/S929. Health* data is extraordinarily sensitive and has already been risked through purchase, sale, and more. <u>A 2023 Duke University study</u> illustrated how easy it is to buy individual's data from mental health apps, <u>a 2024 investigation by</u> <u>Senator Ron Wyden</u> illustrated how location history from people accessing reproductive health clinics was sold to an adversarial anti-abortion organization for purposes of targeting, and a 2023 FTC enforcement action against GoodRX exposed how they sold sensitive customer data for advertising. Several states allow <u>"bounty hunters"</u> to sue people that help others get reproductive healthcare, and allowing this data to be sold would enable this type of enforcement.

The bill restricts the sale of New Yorkers' electronic health data, including to out-of-state buyers, and requires affirmative consent for processing unless strictly necessary for specific purposes. It mandates that electronic health data be deleted after sixty days unless the individual requests otherwise and provides individuals with access and deletion rights.

Data that isn't held or collected cannot be stolen, bought, or leaked. This data can lead to life and death consequences -- restrictions on the collection and maintenance of the data is the right way to regulate extremely sensitive data.

The status quo allows location, transaction data, health app data, and more to be bought by anyone – advertisers, scammers, law enforcement from states with restrictive reproductive health laws, and more. Regardless of the political circumstances, health and other sensitive data must be regulated – but it's clear New Yorkers need this now.

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