



MEMORANDUM IN SUPPORT OF THE PRIVACY OF EMERGENCY HEALTH DATA RELATED TO COVID-19, S. 8448C/A. 10583B

*An Act in relation to the collection of emergency health data and the use of technology-assisted contact tracing to aid during COVID-19; and providing for the repeal of such provision upon the expiration thereof
July 16, 2020*

STATEMENT OF SUPPORT: Access Now, Common Sense, Consumer Federation of America, Consumer Reports, Electronic Frontier Foundation, New York Civil Liberties Union, and New America’s Open Technology Institute support S. 8448C/A. 10583B to protect the privacy and security of data collected pursuant to the COVID-19 crisis, including health information, geolocation data and contact-tracing data. This bill puts important limits on the collection, use, and disclosure of this data, ensures that New Yorkers cannot be discriminated against on the basis of the data, and requires entities to protect the information from unauthorized access.

Now more than ever, New Yorkers need strong rules to ensure their privacy. Tech companies are working to create new tools to help counter the COVID-19 crisis, such as contact tracing apps and COVID-screening services, but people shouldn’t have to give up their right to privacy to protect their health.¹ A number of apps are in development to help public health agencies and individuals to engage in accelerated contact-tracing, based on Apple and Google’s proposed Bluetooth-based API.² There should be, at the very least, reasonable limits on companies’ data collection and sharing of individuals’ sensitive data pursuant to these services, limits that are backed up by law.³ Such limits will not only protect New Yorkers but also enhance their trust in any technologies rolled out to fight the pandemic. Currently, a majority of Americans don’t trust companies to protect their health data, which could pose a barrier to their use of contact-tracing technology.⁴

¹ Darius Tahir and Mohana Ravindranath, *How the Coronavirus is Upending Medical Privacy*, POLITICO (Apr. 28, 2020), <https://www.politico.com/news/2020/04/28/coronavirus-medical-privacy-217671>.

² Kaveh Waddell, *Tracking Everyone With Coronavirus Is a Huge Task. These Systems Could Help*, CONSUMER REPORTS (Apr. 24, 2020), <https://www.consumerreports.org/public-health/tracking-coronavirus-is-a-huge-task-these-systems-could-help/>.

³ Andrew Crocker, Kurt Opsahl, and Bennett Cyphers, *The Challenge of Proximity Apps For COVID-19 Contact Tracing*, ELECTRONIC FRONTIER FOUNDATION (Apr. 10, 2020) <https://www.eff.org/deeplinks/2020/04/challenge-proximity-apps-covid-19-contact-tracing>.

⁴ Craig Timberg, *Most Americans Are Not Willing or Able to Use an App Tracking Coronavirus Infections. That’s a Problem for Big Tech’s Plan to Slow the Pandemic*, WASH. POST (Apr. 29, 2020), <https://www.washingtonpost.com/technology/2020/04/29/most-americans-are-not-willing-or-able-use-an-app-tracking-coronavirus-infections-thats-problem-big-techs-plan-slow-pandemic/>.

Health information is often widely traded as a matter of course. A recent study found that 10 apps, including dating and period-tracking apps, together sent sensitive personal information on individuals (such as location data) to at least 135 companies involved in advertising and behavioral profiling.⁵ Because HIPAA typically does not cover these apps and services, personal health data lacks sufficient protections against unwanted disclosure. And without appropriate protections, companies will likely collect, use, share, and retain more data than they need. For example, Verily, a subsidiary of Alphabet, Google's parent company, has launched a service in California to help users determine whether or not coronavirus testing is appropriate, and requires them to login with their Google accounts.⁶ Since this information is not covered by HIPAA, the companies involved can do whatever they like with the data.⁷ Despite letters from Congress and privacy advocates calling on Verily to put limits on this data use, the company has thus far refused to make meaningful changes—and right now no law requires it to do so.⁸

This bill corrects that imbalance by establishing strong privacy protections over the data collected to address the COVID-19 crisis. Importantly, the bill requires covered entities to obtain the individual's consent before processing their data for these purposes, and limits processing to what is reasonably necessary to operate the service requested by the individual. And, the bill limits how long these entities can hold onto this sensitive data. In the absence of adequate federal privacy protections, New York must act now to secure these rights for its residents. While we urge legislators to also move forward with legislation that protects the privacy of all personal data, not just data related to COVID-19, this bill nevertheless constitutes an important step forward, and we urge your support.

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⁵ *Out of Control: How Consumers Are Exploited by the Online Advertising Industry*, NORWEGIAN CONSUMERS COUNCIL at 5-6 (Jan. 14, 2020), <https://fil.forbrukerradet.no/wp-content/uploads/2020/01/2020-01-14-out-of-control-final-version.pdf>.

⁶ Julia Carrie Wong, *Google's Coronavirus Testing Website Arrives – With Serious Privacy Concerns*, THE GUARDIAN (Mar. 16, 2020), <https://www.theguardian.com/us-news/2020/mar/16/coronavirus-testing-website-trump-promised-verily>.

⁷ Katie McInnis, *Privacy Concerns Raised by Verily's Baseline COVID-19 Pilot Program*, CONSUMER REPORTS (Mar. 23, 2020), <https://advocacy.consumerreports.org/wp-content/uploads/2020/03/Consumer-Reports-letter-to-Verily-Alphabet-3.23.20.pdf>.

⁸ Letter to Mr. Sundar Pichai from Senators Menendez, Brown, Blumenthal, & Harris regarding the COVID-19 Screening Portal (Mar. 18, 2020), <https://www.menendez.senate.gov/news-and-events/press/menendez-colleagues-warn-trump-admin-google-of-privacy-concerns-in-covid-19-screening-website>; Letter to Mr. Andrew Conrad from Senators Menendez, Brown, Blumenthal, & Harris regarding the COVID-19 Screening Portal (Mar. 31, 2020), <https://www.menendez.senate.gov/imo/media/doc/Letter%20to%20Verily%20on%20COVID-19%20website%20privacy.pdf>.