

March 20, 2020

Senate Majority Leader Mitch McConnell and Senators
United States Senate
Washington, DC 20510

House Speaker Nancy Pelosi and Members of the House of Representatives
United States House of Representatives
Washington, DC 20510

Via electronic delivery

Dear Majority Leader McConnell, Speaker Pelosi, and Members of Congress:

The proper use of personal data has the potential to have important benefits for public health as we face the COVID-19 crisis. However, allowing access to personal data, particularly health data, without guardrails could threaten fundamental rights and liberties and open the door to data exploitation that could violate civil rights and harm vulnerable populations. While some extraordinary necessary and proportionate measures may be taken during a time of crisis, those measures must be taken thoughtfully and fully withdrawn at the earliest moment after the emergency has passed. Under no circumstances should such extraordinary measures permit or be used for marketing or commercial efforts. Waiver of any privacy protection must be intended to exclusively serve public health.

Individuals must retain certain fundamental rights over the data collected from them during or as a result of the crisis, and whatever increased access to personal data is allowed to companies and the government during the emergency should be removed once the emergency has passed. In order to ensure this, it is not enough to expect that corporations will keep the promises they make in their unregulated terms of service. There must also be federal protections for new data collection, processing, and sharing, and real consequences for violations.

We the undersigned 15 groups strongly urge that forthcoming COVID-19 relief packages include privacy protections for data that is newly collected as a result of the crisis and pre-existing data that is used in new ways, whether that data was collected by government agencies or companies providing public health services. The data protections in the bill should comport with the principles below.

- **Necessity and Proportionality:** Collection and processing of personal data, including health and other data (for example, geolocation data) shall be necessary and proportionate in a democratic society for the protection of public health and pandemic response, and shall respect existing laws and the essence of fundamental rights established by the U.S. Constitution and international human rights conventions.
- **Time-limits:** All these measures shall be temporary in nature, limited in scope and adopted as a response to COVID-19 crisis.
- **Transparency:** Data collection and processing shall be transparent and individuals shall be provided with concise and reader-friendly information in clear and plain language regarding the purpose of collection and how long the data would be retained for.
- **Data Minimization:** Data collection and processing shall be limited to the minimum necessary amount of data for the purposes of implementing measures for pandemic

response and shall not be used or repurposed for marketing and advertisement purposes. Special protections will be afforded regarding the collection and use of the data of children.

- **Security and Confidentiality:** Any data processing or remote technology deployment should not minimize needed security protections in the context of pandemic response. Data shall be maintained in a secure environment and transmitted through secure methods.
- **Limited Retention:** Data retention shall be limited to period of pandemic response. Data collected for public health purposes related to COVID-19 shall be automatically deleted following the pandemic, and shall not be repurposed other than narrowly-defined medical research purposes and pandemic preparedness subject to informed and explicit consent of the individual.
- **Use restrictions:** There must be limits on processing newly-collected or acquired personal data for purposes unconnected to public health and service delivery. Those prohibitions must include limits on commercial and advertising activity, and should include heightened penalties for inappropriately targeting vulnerable populations while the health crisis is ongoing, and during any resulting economic slowdown. This includes closing loopholes that allow for marketing use of data outside of HIPAA.
- **Accountability and due process:** Any decision-making related to data collection and processing in the context of pandemic response shall be informed by guidance and directions of public health authorities and be documented. Individuals shall have access to their data and be granted due process rights. There shall be real, commensurate consequences for companies that fail to protect personal data or to abide by these privacy rules. The consequences for unjustified data collection and processing and data breaches shall be tough enough ensure that companies are accountable, data is held securely, and that the financial benefits of violating this law never exceed the consequences.

We look forward to working with you to ensure that public health and privacy protections go hand in hand during this time of crisis.

Sincerely,

Access Now
Amnesty International - USA
Campaign for a Commercial-Free Childhood
Center for Human Rights and Privacy
Center for Digital Democracy
Consumer Federation Of America
Common Sense Media
Free Press Action
Media Alliance
New America's Open Technology Institute
Oakland Privacy
Parent Coalition for Student Privacy
Public Citizen
Public Knowledge
U.S. PIRG

