

United States Senate

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U.S. SENATE CLIMATE CHANGE TASK FORCE

April 9, 2020

The Honorable Donald J. Trump
President of the United States
The White House
1600 Pennsylvania Avenue, NW
Washington, DC 20500

Dear President Trump:

I write regarding reports that your Administration is pursuing the creation of a national coronavirus surveillance system, one that relies on highly sensitive information about Americans. Although the federal government should utilize technology and data to respond to the ongoing coronavirus crisis, I strongly urge you to reject any action that may lead to harmful invasions of privacy.

Publicly reported details about this project remain limited, but the components revealed to date point to deeply troubling privacy risks. Close advisers of yours are purportedly discussing with health technology companies the construction of a “national coronavirus surveillance system,” which would use health information and other data — for example, metrics on the flow of patients into specific emergency rooms — to inform federal resource-allocation decision-making.¹ It would also permit federal officials, based on individuals’ health records, to extrapolate insights into hospital capacity and medical equipment use.²

Personally identifiable health information is a highly sensitive class of data, widely recognized as deserving stringent protection against unauthorized disclosure.³ Misuse of or inappropriate access to personal health information can cause significant harm to individuals, including discrimination based on a medical condition. Congress acknowledged these concerns by enacting the Health Insurance Portability and Accountability Act (HIPAA), which safeguards the privacy of personal health information, and imposes civil and criminal penalties for its violation.

¹ Adam Cancryn, *Kushner’s team seeks national coronavirus surveillance system*, Politico (Apr. 7, 2020), <https://www.politico.com/news/2020/04/07/kushner-coronavirus-surveillance-174165>.

² *Id.*

³ Electronic Privacy Information Center, *Medical Record Privacy*, <https://epic.org/privacy/medical/> (last visited Apr. 8, 2020).

Although community-level public health data are an integral component of any response to a public health crisis, use of *individualized* health information raises significant concerns. According to reports, the surveillance system under consideration would rely on de-identified information.⁴ But computer scientists have shown that anonymized information can be re-identified, “such that the sensitive information may be linked back to an individual.”⁵

The privacy implications of the surveillance system that your Administration is reportedly considering are highly concerning. I therefore request responses to the following questions by April 16, 2020:

1. Please describe any plans that your Administration is considering to establish a national coronavirus surveillance network or database, including the project’s scope and duration, and the identities of any private entities with which your Administration has communicated about it.
2. Please identify the types and sources of data that would populate this network or database, including:
 - a. the format of the data;
 - b. whether it will be maintained in an aggregated and anonymized form;
 - c. the federal or private entities that would be responsible for maintaining it;
 - d. the identities of those who would have access to it and any limits on access;
 - e. how the data will be safely maintained during the project and how it will be safely disposed of upon its conclusion.
3. Please explain how this project would be a more effective tool for medical-resource-allocation efforts than building on existing information sets and communications systems with local entities that have access to real-time, on-the-ground information about the needs of patients and health care providers.
4. Will you commit to providing Congress with regular, comprehensive reports on the nature and effectiveness of any coronavirus surveillance network or database?
5. Will you commit to submitting for external review any dataset this project may utilize, in order to allow experts to identify and address privacy pitfalls, including risks of data re-identification?
6. Will you ensure that the federal government stops collecting health data for the proposed surveillance system and disposes of any collected data once the coronavirus pandemic is over? If so, please describe your plans for this data disposal in detail. If not, why not?
7. How would this project specifically protect against unique threats that health privacy invasions pose for racial minorities, LGBTQ individuals, people with disabilities, and low-income individuals?

⁴ Adam Cancryn, *Kushner’s team seeks national coronavirus surveillance system*, Politico (Apr. 7, 2020), <https://www.politico.com/news/2020/04/07/kushner-coronavirus-surveillance-174165>.

⁵ Electronic Privacy Information Center, *Re-identification*, <https://epic.org/privacy/reidentification/#process> (last visited Apr. 8, 2020).

I welcome your Administration's efforts to make more transparent a resource-allocation process thus far plagued by political concerns and a lack of clear criteria.⁶ And I fully support efforts to identify and implement inventive solutions to the public health crisis facing our country. But the contours of the proposal under consideration appear to represent a significant threat to Americans' right to privacy.

Thank you in advance for your attention to these requests. If you have any questions, please contact my office at 202-224-2742.

Sincerely,



Edward J. Markey
United States Senator

⁶ Nik DeCosta-Klipa, *Why Massachusetts has only gotten a fraction of the emergency stockpile supplies it requested*, Boston.com (Mar. 31, 2020) <https://www.boston.com/news/politics/2020/03/31/massachusetts-stockpile-requests>.